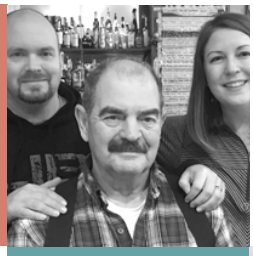
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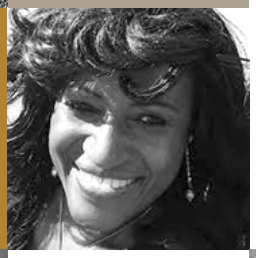
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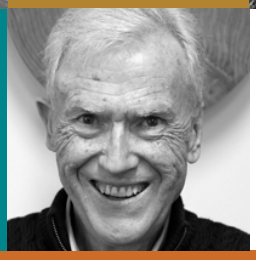
Information and insight from people living with dementia, care partners, and leading dementia specialists












Developed by:

Dementia Action Alliance

Creating a better society in which to live with dementia

We are thankful to the following for their grant and donation support for the Manual.





DISCLAIMER

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PATHWAYS TO WELL-BEING WITH DEMENTIA
2ND EDITION

BY:

Barbara White, Second Edition Project Manager/Editor (2025)

More Than 60 Contributors--People Living With Dementia, Care Partners, and Leading Dementia Specialists

And First Edition Writers/Editors: Beth Baker and Karen Love

 2025

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For citation purposes:

Dementia Action Alliance, et.al., 2025. *Pathways to Well-Being with Dementia, 2nd Edition.*

ACKNOWLEDGEMENTS

The development of a comprehensive Manual of this kind would not have been possible without the passion, knowledge, and generosity of time of many people. The saying, "It takes a village," is especially befitting of the dementia community, and this belief was foundational to the development of *Pathways* in 2022, and this 2025 second edition. A person's support network becomes their village and includes care partners, family, friends, service providers, healthcare professionals, allied health professionals, community-based services and supports, faith-based organizations, researchers, policymakers, advocates, academics, and many others.

Pathways has been written by many contributors who reflect the broad diversity of the dementia community. The decision to use the Creative Commons copyright was purposeful to recognize and celebrate the broad authorship.

We especially acknowledge and thank the 2025 Manual Steering Committee members, listed in the *Introduction*, and the Dementia Action Alliance Advisory Board members, listed here, who helped guide and shape the development of the Manual:

Monica Downer; Jack George; Craig Hanke; Julie Moore; Deborah Lloyd; Pauline Scanlon; Laurie Scherrer; Steve Taylor; and Mark Timmons

Additionally, we thank the following who are not formally recognized in the *Introduction* section but whose knowledge, expertise, and experience contributed meaningfully to *Pathways* in 2022:

Vicky Aberilla, Bonnie Burman, PhD; Richard Fenker, PhD; Magda Kaczmarska, MFA; Carmelita Karhoff, MSHA; Rick Kral, DNP, LNHA; Kim McRae; Colin Milner; Jackie Pinkowitz, MEd; Patty Sherin; and David Troxel, MPH.

We are proud to recognize the following Manual Partners

Age-u-cate

AgingMe, Maine's Geriatrics Workforce Enhancement Program (GWEP) at the University of New England

Akron-Summit County Public Library

Alter Dementia

Alzheimer's Speaks

The Association for Frontotemporal Degeneration

Brigade Health

DanceStream Projects

Debra Tann, Ed.D., Reminiscent, CEO

Dementia Engagement, Education, and Research (DEER), School of Public Health, University of Nevada, Reno

Dementia Friendly America

Dementia Friendly Indiana

Dementia Friendly Nevada

Dementia Friendly Pennsylvania

Dementia Together

The Eden Alternative

Homewatch CareGivers

Indiana University School of Medicine

Jewish Family and Children's Service of Greater Boston

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McCarthy Fiduciary Services

Memory Care Support

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Ohio Council for Cognitive Health

Perspective Coaching

Scripps Gerontology Center

Silverbright Circle

Simplified Eldercare

Soundscaping Source

Susan Wehry, MD, Geriatric Psychiatrist, Advocate, Educator

TheKey

Total Brain Health

University of Utah College of Nursing

2ND EDITION

PATHWAYS TO WELL-BEING WITH DEMENTIA

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Introduction

I.1 About This Guide

Welcome to the second edition of *Pathways to Well-Being with Dementia*. This edition builds on the foundation of the original guide by incorporating valuable feedback and expanding content to better support the diverse and evolving needs of individuals living with dementia.[1] The content is up to date as of printing.

Central to this updated guide is the unwavering belief in the importance of purpose, empowerment, and accessibility. At every stage of the dementia journey, having a voice, being heard, and exercising agency are non-negotiable. This guide not only provides practical resources but also encourages readers to explore the full breadth of support offered by Dementia Action Alliance (*www.daanow.org*), including DAA's numerous publications and podcasts on topics aligned with those included here.

The highlights of the second edition include:

- **Section Introductions:** Each section now begins with a concise introduction, providing an outline of its contents to help guide your journey through the Manual.
- **Highlight Boxes:** With quick, accessible, practical information.
- **Expanded and Updated Content:**
  - *Eat/Drink Healthy*: Tips to maintain proper nutrition and hydration.
  - *Dementia-Friendly Initiatives*: Community efforts to create more inclusive spaces.

[1] This Manual is intended primarily for individuals experiencing cognitive changes, those diagnosed with mild cognitive impairment, or those diagnosed with any form of dementia. To simplify terminology throughout the Manual, we use the term "dementia" as an inclusive reference to encompass all types of cognitive changes.

- *Memory Cafes*: A deeper look at these vital social connection resources.
- *Functional Health*: Strategies for maintaining independence and mobility.
- *Medication*: Updated guidance on managing medications effectively.
- *Financial and Legal Matters*: Clear advice to help navigate these essential topics.
- *Medical Affairs*: Practical tips for partnering with healthcare providers, and important information and perspectives on end-of-life considerations.
- *Technology Supports*: Leveraging technology for enhanced daily living.

- **New Content Areas:**
  - *Anosognosia*: Understanding and managing lack of awareness of one's condition.
  - *Expanded Community Experiences and Supports*: Insights into the experiences of underrepresented communities, including individuals with intellectual and developmental disabilities (IDD), Latino, Asian, and rural populations.

Why This Guide Matters

If you search Amazon for "books on dementia," thousands of results appear, yet most are written for care partners. While care partners are a crucial part of the lives of individuals living with dementia, this guide is different—it's written primarily for you, the person navigating life living with dementia.

Access to earlier diagnosis means people are learning they have dementia while still living with mild symptoms. This guide empowers you to live proactively, with strategies for self-care, resilience, and adaptation. While those around you can play a critical role in supporting you, this guide emphasizes your ability to take charge of your journey, build coping mechanisms, and find purpose and joy in everyday life.

Collaboration At Its Core

This Manual is a collaborative effort, enriched by experiences of people living with dementia and their care partners, alongside contributions from dementia specialists and other experts. Individuals with lived experience serve as your guides, offering inspiration and practical wisdom to empower you every step of the way. A special thank you to Katie Silvester, PhD, Associate Professor of English at Indiana University, Bloomington, and the dedicated students who generously contributed their time and energy to this project.

The Davis Phinney Foundation's excellent book, *Every Victory Counts*, for people living with Parkinson's Disease continues to be an inspiration in the creation of the second edition of this Manual.

A Resource For All

While written primarily for individuals living with dementia, this guide also serves care partners, family members, friends, neighbors, advocates, healthcare providers, policymakers, and anyone seeking to foster dementia-inclusive communities.

Transformation Through Action

When living well becomes a priority, transformation follows. Apathy turns to determination. Disempowerment shifts to enablement. Hope becomes tangible. You are not alone—together, we are part of a larger community supporting and empowering one another.

This second edition reaffirms our commitment to providing a resource that uplifts, informs, and inspires. Let this guide be your companion as you navigate the journey ahead. There is still so much life to live—and you have the power to shape it.

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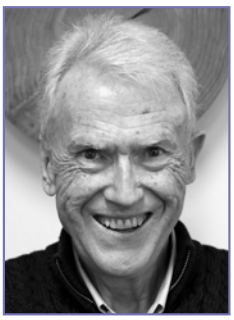
Jack George

Jim Mann

Anneliese Perry, MS, NHA

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I.2 Welcome



Jim Mann, Manual Guide

Life has a habit of throwing curve balls—and I want you to know Dementia Action Alliance is here for you. Whether you are a person living with dementia, a family or friend care partner, or a medical or healthcare professional, we welcome you to the Dementia Action Alliance's *Pathways to Well-Being with Dementia*.

Over the years since my own Alzheimer's disease diagnosis (in 2007, at the age of 58), I have heard people speak of the shock, or the punch in the gut, when they hear their doctor say, "You have dementia." They were clearly not prepared for this diagnosis!

With that in mind, Dementia Action Alliance has produced this Manual for you, your family, friends, care partners, or anyone else seeking insight into living with dementia.

The Manual is not intended to be read all at once, but rather to be used as a resource as needed. Pick it up when you have a question. The pages are filled with valuable insights and information. Reading directly from people living with dementia is an invaluable tool, and it will help you realize you are not alone and move forward with greater confidence.

You will read the important message that life does not end the day you receive the doctor's diagnosis and message. You will also read stories from other people living with dementia about their experiences and life lessons. I think you will find **purpose**, the need for **purpose**, the fulfilment from **purpose**, and the benefits of **purpose**, weaved throughout their contributions in this *Manual*. I encourage you to read their words and reflect on how they can apply in your own life.

Speaking of hearing directly, the daughter of a person living with dementia posted these words on Twitter (X). She wrote, in part:

A person with dementia is a person first and foremost, very much alive and deserving of our respectful appreciation, compassion, and support. Like everyone else, they have unique personalities, needs, and preferences.

There is widespread misunderstanding around dementia, and there is certainly stigma around the condition. I have been touched by what Jonathan Evans, MD, a geriatrician, said in a video produced by the Dementia Action Alliance:

Even though dementia is something that affects the brain, dementia does not equal or result in a loss of intelligence. On the contrary, people use their intelligence to overcome some of the impairments that dementia causes…Dementia doesn't rob you of your ability to experience joy or to be happy.

When you need us, Dementia Action Alliance is here for you; we have your back. All the best!

I.3 You are Not Alone on this Journey



Rev. Dr. Cynthia Huling Hummel, Manual Guide

Many years ago, I was traveling abroad and ended up stranded at JFK International Airport because of bad weather in Rochester, NY. The delay made me miss my international flight. Aargh. I wasn't alone! Nearly all of my fellow passengers who were traveling on that flight missed their connections as well. It was a dark and stormy night both inside and outside the airport. We had gotten in so late that all the kiosks were closed up tight for the night. All the airport hotels were full and the rental car folks had already gone home. So there we all were — weary travelers, strangers with our plans disrupted and trips ruined in a place we didn't want to be. Many of us felt angry, lost, and alone.

We may have been strangers to each other, but not for long. Something wonderful began to happen. Folks started helping one another by sharing what they knew and what they had. Passengers offered their cell phones so that fellow travelers could make calls to loved ones and to book new flights. A maintenance worker brought out cases of water and distributed snacks to us. A flight attendant appeared with a box of blankets and folks helped to pass them out with comforting and encouraging words. Passengers helped one another to arrange chairs to make beds for the children. Strangers offered to hold babies to give parents a break. A man handed out flattened boxes that would become our beds for the night. And as the lights were dimmed, and as we said good night to one another, I think we all realized that we were not alone on this journey — that we were in it together, that there were folks who cared and folks who, despite their own difficult situations, wanted to help.

Some who are living with a dementia diagnosis may find themselves (ourselves!) identifying with the poor travelers who were suddenly stranded in the airport terminal. Perhaps, like the frustrated travelers, you are thinking, "This was NOT in my plans" or "Why me? This is not where I want to be." For those reading who are care partners, you may be wondering what lies ahead, and how a dementia diagnosis will change your life and the life of your loved one. Some readers may be waiting for results of tests or waiting for a diagnosis for themselves or for someone they love. It's hard to wait in uncertainty, unsure of what do next — and what "next" will even look like.

Whoever you are. Wherever you are. Stop. Take a deep breath because YOU are not alone on this journey. The Dementia Action Alliance (DAA) is here to help. DAA created this Manual, this guide of resources that have been written by THE experts: people living with dementia, care partners, physicians, social workers, clergy, and others to help you on this dementia journey. So take a deep breath. You might just be surprised to find unexpected joy in this journey of friendships made, resources shared, and people you can lean on and count on when you are weary. We are here to help guide you, encourage you, and offer our support. Remember, you are NOT alone. — Blessings, Cynthia

I.4 Words Matter

When advocate John-Richard Pagan was invited to participate at a forum at the National Academy of Sciences, he was pleased to be there. But one incident marred the day. "I didn't like that someone from the National Institute on Aging used the word *demented* in describing people living with dementia. I spoke up. 'How dare you use that word? I am not demented. I am living with dementia. It's a condition that affects my life but I'm still living.'"

John-Richard is one of the Guides in this Manual whose experiences and wisdom you will hear throughout. They care deeply about being seen as individuals striving to live as fully as possible, even though they have been diagnosed with dementia. One recurring theme is that the words our culture uses to talk about dementia can greatly contribute to people's fears, sorrows, and despair. For John-Richard, the sting of being called "demented" is still with him. Words matter!

The Dementia Action Alliance has taken this to heart. As you will see, we use the term "living with dementia" to stress that a diagnosis is not a death sentence, and that individuals indeed are still living. We also recognize that your diagnosis does not define you. Advocates in the field of dementia have taken lessons from those living with developmental disabilities who reject labels and use "people-first" language. So, for example, "people with an intellectual disability" rather than "the retarded" became the norm. (In fact, President Obama in 2010 signed "Rosa's Law" that replaced the term "mental retardation" with the term "intellectual disability" in federal documents.)

Another term we use is "care partner" rather than "caregiver." Individuals living with dementia are agents of their own lives for as long as possible. They are not mere recipients of care. They need support, not pity or control. They also continue to give to others. Relationships are reciprocal even as they change over time.

In contrast to language that conveys hope and dignity, our culture, including the media and some advocacy organizations, has adopted the "tragedy narrative" to define living with dementia. The British organization DEEP (The Dementia Engagement and Empowerment Project), in its guide on language [*www.innovationsindementia.org.uk/wp-content/uploads/2018/03/DEEP-Guide-Language-4.pdf*] urges people to avoid "curl up and die" words, specifically:

- words that make people physically flinch when they hear or read them
- words that send out the message that a life with dementia is not worth living, that people are helpless and have nothing to contribute
- words that are negatively attached to the person rather than the condition of dementia
- words that create stereotypes

Examples are referring to people living with dementia as "sufferers," "zombies," "erased," or "shells." Or dementia viewed as a tragedy or tsunami of misery. This is not to downplay the challenges and pain that dementia can cause, but rather to recognize that after the dementia diagnosis, people typically live many years having fun, learning new things, volunteering, participating in life. Being hit over the head repeatedly with grim words and images of vacant people slumped in wheelchairs is not helpful.

We encourage everyone to join us in pushing back against the tragedy narrative, embracing language of dignity, hope, and possibility. Words do matter.

I.5 Meet Your Manual Guides

The following people are your Guides throughout the Manual. They are people who have many years of experience living with dementia, as well as a few care partners. You will hear their stories and viewpoints, and learn from their experiences and insights. We are deeply grateful for their honesty and openness, and for their willingness to share with you their stories.

Rushern Baker and Christa 'Cis' Beverly



Christa Beverly was a force to be reckoned with. She was a lawyer for the underdog, including those on death row. "If anyone was done wrong, she'd elevate it to her cause," says her husband, Rushern Baker III. "She would not let injustice go by."

Christa, known to friends and family as Cis, was a steadfast wife and mother to their three children. She was also her husband's chief political advisor, speechwriter, and campaigner.

The couple met at Howard University in Washington, D.C., and even then, her peers recall, she was dressed professionally and mentored other students. She was interested in public policy, but not the business of politics. "I was always running for something," her husband says. "I wanted to go into politics. She tolerated the idea, hoping I'd grow out of it." He went on to win two terms as County Executive of Prince George's County, the second most populous county in Maryland.

Meanwhile, Cis was beginning to change. At first it was little things, but steadily it grew worse. The day she got lost on her way to pick up their daughter from high school was

a wake-up call. She went to physician after physician, including four neurologists. She had such a deep well of intelligence and organizational skills that she kept passing the cognitive tests, according to her husband. After four years, though, she was diagnosed with younger onset Alzheimer's disease.

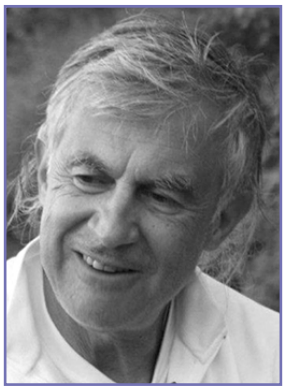
Rushern sought to shield her from the public spotlight. He even hid it from their two daughters, telling only their son, the oldest child. Rather than show up for expected public appearances, she stayed at home, gardening, cooking, and taking care of their youngest child. The family stopped going to church, a huge part of Cis's life. Hiding her disease, Rushern now realizes, was a mistake. Part of his concern was the stigma, especially in African-American communities. "I didn't want people judging or feeling sorry for us," he says. "We were not unhappy. We had challenges."

Eventually, though, the family decided to go public, appearing on a local television news show. The response was overwhelmingly positive. Appreciative people shared their own stories of family members living with dementia. "Once we went public the world opened up," he says. "Her line [sorority] sisters who were concerned about her kicked into hyper gear." He was able to continue his career as a prominent elected official with the help of friends, family, and paid care partners. The family also became outspoken supporters of those living with dementia.

And instead of being isolated at home, whenever possible Cis was at her husband's side. The final ten years of her life, when she lived with the disease, was in many ways the best, Rushern says. "It forced me to really listen, to pay attention," he says. "I had to focus completely on her."

Cis died in September, 2021, at the age of 61. Announcing her death, Rushern Baker said, "Today I lost the love of my life, my best friend, and the source of all my strength. She was our rock — the absolutely best mother to my kids and wife to me. She spent her life fighting injustice, inequities and, for the last decade, illness with grace and grit."

Dave Baldridge



Dave Baldridge of Albuquerque, New Mexico, has worked on behalf of Native elders for more than 25 years. After leading the National Indian Council on Aging, he co-founded the International Association for Indigenous Aging (IA2) in 2003, an organization that he still directs. In recent years, IA2 began to focus on dementia, an area that historically had received scant attention. "There is a lot of denial and a great lack of education [about dementia] in Indian Country," he says.

As he was leading the effort to raise dementia awareness, in 2020, at the age of 73, Dave got a call that left him feeling "overwhelmed by the irony." (See *Staying Positive with an Unexpected Diagnosis*, Section 2.4, page 164.) He was diagnosed with progressive supranuclear palsy (PSP), a rare neurological disease, sometimes confused with Parkinson's. Hallmarks of the disease include loss of executive function and balance, and depression is common. "Dealing with that diagnosis is extremely challenging," he says.

Since sharing the news with his staff, he has been gratified by how understanding and supportive they have been. "They're not asking me to do detailed budgeting, but they're still making room for me to contribute. In the end, that's all that any of us can do. I try to keep up the highest level of professional performance, but the challenges grow incrementally and imperceptibly."

His balance is severely compromised now, so he has had to make accommodations that can be especially challenging for someone like him who lives alone. So too is managing his depression. "It's very difficult to deal with decline when you're used to being a performer," he says. "Keeping that depression at bay is an effort towards not ruminating, staying in the moment, not being carried away by the negatives or the potential of it. Being as present as we can."

He is buoyed by a network of supportive friends and colleagues, as well as his daughter, who lives across the country in New York. He also has two dogs who are a source of companionship and care. "The two passions in my life are Indian elders and search-and-rescue dogs," he says. He has been on dozens of missions with his dogs, looking for missing people, many of whom had dementia.

One lesson he has learned through his experience: "People with dementia are still people who can contribute a great deal in their life and in our lives. It doesn't make them less of a person. It is an aspect of [our] behavior, and it doesn't diminish anything that we can contribute."

The Carson-Arand Family



In Memoriam: Ray Arand (1945–2024)

We honor the memory of Ray Arand, who dedicated 40 years to law enforcement and was a beloved father and grandfather. He lived courageously with dementia, never allowing it to define him, and faced life's challenges with unwavering bravery until his passing in December 2024. His legacy of service,

strength, and love continues to inspire all who knew him. When interviewed for this Manual, Ray Arand was 77.

Ray Arand dedicated his life to law enforcement, first as a Deputy Sheriff and later as a Correctional Sergeant before retiring in Port Angeles, Washington, a rural community on the Olympic Peninsula. Reflecting on his extensive career, he stated, "I was in law enforcement for 40 years." Ray's late brother was also in law enforcement, and continuing the family tradition, his son, Dave Arand, followed the same path.

Dave and his wife, Katie, chose to live near both sets of parents in Port Angeles, fostering a close-knit family environment with their two sons, Tom, a 17-year-old high school senior, and Ray, 19, who serves in the United States Marine Corps. Also integral to the family is Ray's daughter, Jennifer Carson, PhD, a dementia researcher and specialist at the University of Nevada, Reno.

Jennifer first became aware of her father's cognitive challenges in 2016 when her mother expressed concerns about Ray's difficulty managing their finances. His driving had also become a little erratic. Jennifer encouraged him to get a comprehensive cognitive assessment. Reluctantly, he agreed, but then the family faced a terrible shock. "I lost my mom," Jennifer says. Her mother died suddenly of a heart attack.

Compounding Ray's grief and cognitive concerns was a serious diabetes-related foot infection that led to a month-long hospital and short-term rehabilitation stay later in 2016.

Upon his discharge, Ray underwent a cognitive assessment and was diagnosed with vascular dementia and early Alzheimer's disease. His children supported his wish to live independently for as long as possible.

Over time, Jennifer observed symptoms that resembled Lewy body dementia more than Alzheimer's. She encouraged another comprehensive cognitive assessment to ensure an accurate diagnosis. Sure enough, in 2019, doctors confirmed a new diagnosis of Lewy body and vascular dementia.

For some time, Ray continued to live independently with frequent family visits and four hours of home care on weekdays. That was all he could afford out of pocket, but it wasn't enough. As his needs increased, this arrangement became unsustainable. Dave's family found themselves stopping by Ray's house more frequently—often after long workdays—to ensure his well-being. Even though they lived just five minutes away, the constant back-and-forth became stressful.

After receiving dementia training from their Aunt Jennifer, grandsons Tom and Ray, along with a few of their buddies, took turns staying overnight at Ray's house in case he needed help. But the situation remained challenging, so Jennifer encouraged her dad and brother to partner with her in creating a sustainable plan.

Ray was adamant that he never wanted to move into a care facility. Having witnessed his wife's experiences as a nursing home nurse, he did not feel confident in the long-term care system. Instead, the family found a creative solution: Dave and his wife would sell their home and buy Ray's, bringing three generations under the same roof. With the proceeds from the sale, Ray could afford additional home care while Dave's family continued working and attending school.

"It's been great," Ray said. "I was by myself for several years. Now, I have the satisfaction of being safe."

Ray takes an active role in interviewing and hiring his home care aides. "I now have home care eight hours a day," he says. "They come in at 8:00, make sure I'm up and still breathing, and then they fix my breakfast. If I have a doctor's appointment, they take me to it. They even go in with me and take notes. I'm very fortunate, I got two right now that are lovely people."

Ray's care partners also take him on scenic drives, to a paved waterfront trail for walks, and grocery shopping. They also prepare lunch. Ray often eats supper with Dave's family — if he likes what's on the menu. When dining out, the family finds restaurants that are accessible, quiet, and calm for Ray.

The living arrangement is working well, according to Dave, in part because they have always had a family culture of being open and direct. "We grew up having family meetings," Jennifer explains. Continuing this tradition, they've navigated difficult decisions together around such things as driving, gun ownership, and advance directives.

"Dad may think we're overzealous in wanting to help," says Jennifer. (Ray agrees.) "But I'm grateful to Dad for appreciating that these decisions help us all sleep better at night, knowing everything is safe and taken care of. I appreciate Dad's respect for shared decision-making. Any decision one of us makes affects the others."

Ray Edward Cole



Raymond Edward Cole was born in Toledo, Ohio, Oct. 25, 1971, to Frank and Terry Cole. The third of their three sons, he was diagnosed with Down syndrome at birth. Doctors suggested he be institutionalized, but his parents insisted he be raised with love as a part of their family.

With the support network of family, friends, other parents of children with developmental disabilities, and what is now the Lucas County Board of Developmental Disabilities, Ray was able to live a fulfilling life.

Ray initially attended Larc Lane School for students with developmental disabilities, but after his mother became a teacher's aide with Washington Local Schools, Ray became a part of the district's special education program, eventually graduating with a diploma from Whitmer High School.

Ray was also raised in the Catholic faith and received his First Holy Communion in the chapel of St. Francis de Sales High School in the early 1980s.

After graduating from high school, Ray got a job as a busser at a local restaurant. He was well liked by employees and diners alike but eventually found work closer to home at The Andersons general store in Toledo, where he worked in the deli and bakery for nearly 25 years – being named Employee of the Month more than once.

Ray had major open-heart surgery when he was just nine years old to repair a number of congenital heart conditions, but he has otherwise led a healthy life until being diagnosed with dementia in 2023.

Ray began attending an adult day center in the summer of 2024 and now attends almost daily. He very much enjoys the activities and camaraderie – especially after getting his daily cup of coffee.

Ray also enjoys summer weekends at the family lake house on Round Lake in Michigan and cheering on the University of Toledo Rocket football and basketball teams.

Pictured: Ray (right) with his brothers Jeff (left) and Peter, celebrating their mother's 90th birthday in 2023.

Jack George



Jack is a native of northern Michigan and is on his second tour of Ohio, where, in 1989, he met his wife, and (now) care partner, Susan. For 37 years, Jack held a variety of management positions in various manufacturing industries, and was fortunate to travel multiple times to 10 different countries during his career. He left work on disability in 2017 after receiving an Alzheimer's diagnosis.

Jack started having symptoms of brain change in 2004 when he was just 48 years old. But it wasn't until 2016 that Susan, a Special Education teacher, noticed a significant issue with Jack's thought processes and behaviors. This began a journey taking four years, eight different diagnoses, several out-of-state road trips, and nine different specialists to finally hear the words "behavioral variant Frontal Temporal Degeneration", or (bv)FTD.

In 2021, Jack's bvFTD diagnosis was "confirmed" when he was genetically tested and found to be carrying a rare hereditary gene mutation (C9orf72) that causes FTD and Amyotrophic Lateral Sclerosis (ALS).

Today, Jack is an ambitious participant in FTD research, contributing to finding a cure and prevention for all future generations. Applying his leadership skills, he also advocates for public awareness of living well with dementia, and to promote brain donation efforts. Within DAA, Jack participates in several programs to help others living with dementia/MCI to live purposeful, fulfilled lives.

Rev. Dr. Cynthia Huling Hummel



Rev. Dr. Cynthia Huling Hummel grew up in New Jersey, the oldest of six children. Always an achiever, she was in the first class of women at Rutgers College. After a stint in the Peace Corps in Jamaica, she was hired by Dun and Bradstreet, where she worked for 15 years in technical support. Married with two children, the family became active in their church. Her life changed when her pastor urged her to explore a call to ministry.

Cynthia went on to complete her seminary studies, earned her MDiv, and became the 15th Pastor of the First Presbyterian Church in Lyons, New York. "Life was good," she says. She was leading a very busy church, working on her DMin, and raising two teenagers. In the midst of all that, she began to have memory problems. She forgot people's names and faces. "I forgot what people had shared with me," she recalls, a serious problem when you are expected to hold congregants' confidences and be praying for them.

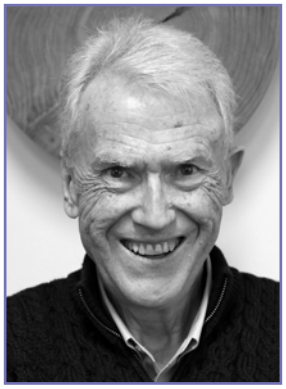
Because she was only 49 and highly functional, her diagnosis was a long time coming. Doctors blamed her symptoms on stress, menopause, depression, and a previous head injury. After eight years, she was finally diagnosed with amnestic mild cognitive impairment due to Alzheimer's disease. Because others in her family had had Alzheimer's, she says, "It wasn't a surprise, but it was a sadness."

Unable to continue as a full-time pastor, she moved to Elmira, a place she had never lived. Her marriage had ended, and she felt alone. "Who was I, if I wasn't Pastor Cynthia?" she wondered. But brick by brick, she began to build a new life. She enrolled in a large-scale study, the Alzheimer's Disease Neuroimaging Initiative, to do her part in fighting the disease. Passionate about research, she has served on prestigious national boards, including the National Advisory Council on Aging and committees of the National Academy of Sciences and the National Alzheimer's Project Act. Contributing to scientific research "is part of my new ministry," she says.

A lifelong learner, Cynthia has audited 40 classes — and counting — at Elmira College. She also is spiritually nourished by artistic pursuits, including mask-making and music. Ten of her masks of living with dementia were displayed at the National Gallery of Art in Stockholm, Sweden. She is retired from ministry but continues to fill in at the Lyons church and other churches in her area, and sometimes recycles sermons that she preached in the past, refreshing them to reflect current events.

Cynthia feels the disease progressing, and she continues to develop new strategies to compensate for new losses. When asked how she feels, she answers, "Blessed! It took me a while to accept and reframe these changes. Look at all I've found — I've had so many amazing opportunities, I've met so many wonderful people, and I have a new purpose, a new ministry that God's given me. Yes, it's been a huge blessing in a strange sort of way."

Jim Mann



Jim Mann, who lives in Vancouver, Canada, is a researcher and advocate who was diagnosed with young onset Alzheimer's disease in 2007. Since that time, he has focused on the stigma of living with dementia, issues of consent and unconscious bias in research and in the wider community, and technology.

As a care partner to his mother who also lived with Alzheimer's, he saw the stigma of the disease that she dealt with and experienced with his own diagnosis. Jim soon recognized that by putting his business experience together with her lived experiences and his own, he would be able to contribute to the reduction of stigma efforts at the same time as advocating and educating. He has since become a leading

advocate in Canada and beyond, educating the public and policymakers about the full life that many with cognitive challenges continue to enjoy.

Recognizing this work, he was awarded an honorary Doctor of Laws degree from the University of British Columbia. The University noted, "He has been acknowledged as the single-most influential person in Canada for countering negative stereotypes and promoting an inclusive society in which persons with dementia can make an active and meaningful contribution."

Jim has authored/co-authored many peer-reviewed papers and continues to mentor early career researchers and students providing an important perspective to their learnings. He is the "Jim" in the City of Vancouver's YouTube video, *www.youtube.com/watch?v=Lzd2aYpuKdk&feature=youtu.be .*

Jim volunteers his time with many organizations such as the World Health Organization's (WHO) Global Dementia Observatory (GDO) Knowledge Exchange Platform. He was also a member of an Advisory Board that developed Canada's national dementia strategy entitled *A Dementia Strategy for Canada ~ Together We Aspire.*

Chuck McClatchey



Chuck McClatchey grew up in rural Paradise, California. He recalls the beauty of the forests there, and said it was heartbreaking to see the terrible wildfires that have swept through in recent years.

He went from the quiet of the forests to a career of adventure, beginning with 21 years in the Air Force as a flight engineer on C-41 transport aircraft. He traveled to 56 countries, including doing "an air drop on the South Pole on the 4th of July. That was an experience, I tell you."

After retiring from the military, he spent 16 years working for the Arizona Department of Transportation as a traffic signal technician, before landing his dream job in Dallas, as superintendent of maintenance for a construction group with the Texas Department of Transportation. That was when he noticed something was amiss.

First it was not remembering how to program equipment and other operations that he used to teach others how to do. He only lasted at his new job for six weeks and ended up working in the plumbing and electrical department at a Lowe's. "People would come in and describe what they were doing, and I was giving them the wrong parts," he says. The last straw was when his wife, Bobbie, brought home a little red desk that needed a simple assembly, a task that would normally have taken him 30 minutes. He couldn't figure it out and grew

increasingly frustrated. She sat him down and told him that something wasn't right, and he needed to see a doctor. After considerable testing, he was told he had Alzheimer's disease. "It was a 100 percent nightmare," he says. "My darkest point was when I thought I was totally alone." He was 61.

After intense anxiety attacks and fear of what the future might hold, Bobbie gave him the shove he needed when she said, "This is not who you are." He began seeing a therapist and joined a support group where he met people who had been living with dementia for many years. He soon became a national advocate, initially for the Alzheimer's Association, and then on the DAA Advisory Board.

Eight years later, he co-leads Dementia Conversations, a weekly support group, with Jennifer Carson, through Dementia Friendly Nevada, and hosts a DAA podcast, *This Dementia Life.* "It opens your eyes, to see the joy you can get in being around people who understand what you are going through," he says. "To me, humor is essential to get through this."

Terrie Montgomery



Terrie Montgomery took a few detours along the way, but her strong work ethic and quick mind led her to a full and varied professional life. Her mother had fervently hoped that Terrie would be the first in the family to graduate from college. But at 18 Terrie married her high school sweetheart and had a baby. Having learned administrative skills at the vocational high school she attended in Chicago, she soon landed a job at a downtown insurance company.

She learned how to do billing and general accounting and went on to work in a hospital. Her father, who saw she was good in math, encouraged her to take a tax course, and she went on to become a tax consultant. By then, she and her husband had divorced and she had three daughters. She sold insurance as a way to supplement her income, allowing her to raise her family in a thriving community. In her 40s and remarried, she eventually found her way to college, taking an accelerated adult program and receiving a bachelor's degree.

Drawn to being with elders, she volunteered to visit people in the hospital who were terminally ill. She also became a family caregiver when both her mother and her husband had cancer at the same time. Those experiences led her to become a social worker. "I landed the best job, to help those who were low income to become independent. I didn't make much money, but I loved what I did," she says.

But over time, she noticed she was forgetting her clients' names. Then she lost her wallet and her passport. Always a very neat person, she became a packrat and her apartment

filled with purchases she didn't need. In 2015, at 58, she was diagnosed with Alzheimer's disease. She soon became an advocate, initially with the Alzheimer's Association, for legislation to help people living with dementia. She was thrilled to discover the Dementia Action Alliance, with people like her in leadership. She joined the Advisory Board and stays busy as an advocate. "The opportunity of being here with DAA gives us hope, it keeps us busy, where you say 'let me check my calendar.' Of course we may have a moment — 'where IS my calendar?'"

Even after having to be treated for breast cancer, Terrie maintains a positive attitude and a determination to make a difference. "I speak up for those in the African-American community, because there are not enough of us who share what's going on with us."

Barney Nelson



Barney Nelson, from Portland, OR, spent two decades working for a global technology company, then became an entrepreneur and ran a very successful business. In 2018 he noticed he was beginning to feel overwhelmed. It was more difficult to multitask and keep up with the pace of his business.

He also started to experience tremors and hallucinations, leading to a Lewy body dementia diagnosis in early 2019. He is now a Dementia Advocate and serves on the Dementia Action Alliance Board of Directors, Advisory Board, and Speakers Bureau, and is a PAC Core Team Member with Teepa Snow's Positive Approach To Care Organization.

John-Richard Pagan



John-Richard Pagan spent many years on a spiritual quest before becoming a contemplative Christian, based in the Episcopal Church. He has found a home with the Community of the Gospel, who are dedicated to spiritual growth and nurturing love and compassion. "I've gone in and out of faiths and struggled with acceptance for a very long time," he says. "The Episcopal Church became a haven for acceptance for who I am."

John-Richard is also a busy advocate, leading several support groups, helping to establish dementia-friendly airports, and working with a dementia and sobriety group to help people like him who live with dementia and are in recovery.

Before being diagnosed with Lewy body dementia, he lived in Southern California, working in the travel industry, then as a network administrator, followed by four years as a coffee shop owner, and finally a marriage and family therapist. He also served in the military and was working on his Ph.D. when he began to experience cognitive problems, including speech and balance issues. He went through many doctors before finding the right one, who diagnosed him with Lewy body dementia.

As his abilities changed, he decided to return to his parents' home in Virginia. John-Richard, who is gay, notes that gay people are less likely to be married with children and may have a harder time finding care partners. His parents, in their late 70s, have their own cognitive challenges. "There are times we can laugh about it," he says. "Other times we get frustrated with ourselves or with each other."

As part of his Lewy body symptoms, John-Richard has vivid hallucinations, which he knows are not real even as they are occurring. "I still drive locally," he says. "I know if I see, which I have, a six-foot tall beaver waving at me, it's time to pull over and call my dad." Many times, hallucinations aren't scary, he adds. "My friend lives with a purple rooster and she's happy as can be."

He finds joy in new pursuits. He is gardening for the first time and loves spending time in the backyard. He is pursuing a second bachelor's degree, one course at a time, in religious studies. "I have dreams that I used to put off for when I retire. Now I look at how soon can I get them in." One was to go to Disney World, and he treated his mom to four days at the theme park. "We had a blast," he says.

Kim and Robert Reid



Kim and Robert Reid grew up in Hopkinsville in southwestern Kentucky, where they met in seventh grade and became sweethearts. Two years later, Robert's mother died, and he moved to Georgia to live with his father. After Kim graduated from Western Kentucky University, she joined him there.

Meanwhile, Robert's own education had been interrupted when he became a care partner to his grandmother. He eventually got a degree in Architectural Drawing, and he and Kim were married in 1989. They now live in Hampton, Georgia, and have two children in their 20s, who live with them.

Kim worked in logistics for many years, tracking freight shipments from around the nation. At first, when she noticed something wasn't quite right, she assumed it was stress from

her job. She was having trouble keeping up with the multi-tasking that was required. "I knew something was wrong, but I couldn't say what," she says.

Robert had not yet noticed anything was amiss. Kim's primary care physician assured her it was probably just menopause. But the problems persisted. Eventually, Robert went with her to an appointment, and he asked the doctor to investigate Kim's concerns. After she was referred to a neurologist and a neuropsychologist, "That's when we got on the road for the diagnosis of early onset Alzheimer's," says Robert. Although getting the diagnosis was difficult, "in some ways it was a relief. I did want to know what the heck was going on," says Kim. "I thought my brain was going crazy."

They received little guidance from their healthcare providers. "It really wasn't until we got involved ourselves in different organizations that we started getting more support and understanding," says Robert.

They also receive help from family and friends. "Everybody in the family has been pretty helpful," says Kim. "They know I've got some issues going on. We have really good kids, they're on up in age, they can help. Everything's working out pretty good."

Their faith has also been foundational for them. "Our faith has given us hope that we can live through this, that we can make it, that it's going to be alright," Kim says.

Robert, who is a deacon at Live Oak Baptist Church, says he is proud of Kim's decision to be open about sharing her diagnosis with their church family. "She has been an advocate and not ashamed to speak about it, even from the original diagnosis," he says. "The ladies of the church made a special effort to pick her up and take her out to lunch. There has been support all around."

Laurie Scherrer



Laurie Scherrer had worked her way up the career ladder and enjoyed the challenges of the business world. Her positions included Training Supervisor, Marketing Supervisor, Human Resources Manager, Vice President of Phone & Web Center at a bank, and Sales and Sales Trainer. "I was a workaholic because I really enjoyed my career."

But then things changed. She found she could no longer add and subtract. And although always a "bubbly motivational" person who thrived on social interaction, she found that being around people often agitated her. She became irritated by little things and extremely frustrated in traffic.

In 2013, at age 55, Laurie was diagnosed with Frontotemporal dementia (FTD). As with most people newly diagnosed, she went through emotions of anger, depression, fear, and disbelief. But her natural positivity soon emerged, and she became an advocate for others living with dementia. She turned the damaging emotions into a passion to change the stigma and fear around dementia. She promised God that she would do her best to make a positive impact on someone every day that she could.

Now, Laurie focuses most of her cognitive abilities towards working with Dementia Action Alliance and other dementia organizations. At DAA, she serves on the Executive Board of Directors and is the Program Director. Her core concentration is helping people living with dementia to live a purpose-filled life and educating care professionals and communities on how to help accomplish this goal.

Laurie also mentors people living the dementia journey, helping them find strategies to cope with the challenges and overcome the obstacles of dementia symptoms. She is an international speaker and has been interviewed often including by AARP, the *New York Times*, PBS, and the *South Africa Times*.

"You need to have a reason to get out of bed and make you smile," she says, "If there is no reason – why bother?" "The Dementia Action Alliance has become a huge part of my purpose to keep pushing. I feel useful again!"

She comes from a close-knit family with five siblings who often buoy her spirits. Laurie, who also writes a blog (dementiadaze.com), believes laughter and purpose is key to her well-being, along with a devoted husband and their companion pet, Lil Dawg, and support from her family. Since her diagnosis, she and her husband have been scuba diving, skydiving, hiking, kayaking, and parasailing in South Africa. They have also vacationed in 32 states in their motorhome. They recently moved to Alabama from Pennsylvania to live in a warmer climate, due to her husband's health.

"I'm blessed that God has given me a purpose," she says. "I'm so thankful that I'm able to touch people's lives."

Stephen and Susan Taylor



Steve grew up in Fort Wayne, Indiana, and began public speaking at an early age, which became one of the cornerstones of his life. At the age of thirty-eight, Steve decided to rematriculate to Indiana University's home campus in Bloomington to obtain a degree in Children's Television Production. Here he met Susan, who became his wife in 2004, best friend, and now additionally, care partner after Steve was diagnosed with Mild Cognitive Impairment (MCI), Vascular Dementia, and Early Onset Alzheimer's Disease.

Susan was born in Bloomington, Indiana, and attended Indiana University and Indiana Wesleyan University graduating Suma cum Laude, with a career including Computer Technology, Accounting/Finance, Human Resources, and Healthcare Management.

Together, they have a daughter, Megan Malone Davis, who Steve adopted. She is married to Kevin Davis, and they reside in Ellettsville, Indiana.

Susan and Steve enjoy traveling and have been blessed with opportunities to visit three countries, 21 U.S. states and Puerto Rico, including their favorite trip, Yellowstone National Park. They also enjoy gardening, and volunteering, including Singles Ministry and Children's Ministry, which included performing at events as clowns and multiple other characters.

Due to dementia, in 2017, it became necessary for Steve to retire early on disability from his career in Banking.

Since learning his diagnosis, Steve has focused his time educating the public about what dementia and Alzheimer's disease ARE and ARE NOT. He has spoken at live engagements both locally and around the country, on radio, and on Zoom. Steve is honored to serve on the Advisory Board for Dementia Action Alliance (*daanow.org*), help with global efforts, as well as serve on multiple other Dementia Support Organizations from their home in Bloomington. Susan hopes by sharing their story, encouraging others, fostering education, and offering helpful tips it will inspire others in this journey to seek out the positive things and thrive in living well with dementia.

Steve has discovered that he can still live a rich and full life, pursuing the passions of his life with the love of his life – happily, successfully, and with meaning.

Mark Timmons



Working for Ernst and Young in Arizona, Mark Timmons maintained 4,000 trust accounts for a bank client, including preparing all the tax forms. "I was good at what I did," he says.

But in one year he went from being one of the top consultants in his office to being one of the worst. His attention to detail, his accounting skills, his ability to learn changes to tax law – it all seemed to have vanished. He noticed he had post-it notes stuck everywhere, reminding him of details he used to commit to memory. Clients would ask him routine questions, and he'd put off answering them. Eventually, he was diagnosed with younger onset Alzheimer's disease. He was 48 years old.

With that news, he packed up his little red pick-up truck, and he and his dog headed east, camping at National Parks along the way. In three weeks, he was back in his native New England. He bought a house "in the middle of nowhere" in Downeast Maine, about a 20 minute drive to the coastal Canadian border. He enjoyed the remote lifestyle. But when his symptoms impacted his ability to drive, and he voluntarily gave up his driver's license, rural living was impossible. "I needed to get back to civilization," he says.

He now lives in Massachusetts near the city he grew up in. He has reconnected with several old friends. Although living alone has its challenges, "My friends are very supportive, and when needed they are protective of me as well," he says. He has faced a lot of loss in his life, including the deaths of his biological parents, two siblings, and the death of his youngest son at the age of 26, as well as becoming widowed twice. Still, he tries to live "with well-being, and purpose."

Mark is determined to reduce the stigma and stereotypes people have about dementia. "I don't let dementia define who I am," he says. "It is slowing me down somewhat. There are things I can't do that I used to, but it's all about adapting to whatever symptoms are getting in my way on any particular day. Today I may seem fine to you, but you might see me tomorrow and see a different me. Symptoms often change."

He has found new purpose as a photographer, advocate (for dementia, mental health, and homelessness), and writer. "Dementia has severely compromised the analytical side of my brain, but the creative side of me is thriving," he says. He has a website for his photographs, has an annual gallery show, combines original poetry with his photography, and wants to someday publish his works.

When he discovered DAA, he soon became an advocate, leading discussion groups and co-administering the Memory Warriors Facebook page, a group exclusively for people living with dementia. He serves on the speaker's bureau, the DAA Advisory Board, and

the Board of Directors, which benefits from Mark's experience managing nonprofits. "DAA gives me purpose by embracing the parts of my life I enjoy and using these interests to make a positive impact in the lives of other people living with brain change and their care partners," he says. His love of music led to his co-hosting DAA's bi-weekly "Music Beat and Trivia" virtual program with Laurie Scherrer. His love of writing and art led him to co-hosting "Literature and Art," with fellow Advisory Board member Deborah Lloyd.

Mark continues to lead a life full of mental engagement and exercise, "a key part of slowing the procession of my (his) dementia."

I.6 Contributors



Sherrie All, PhD, is an international keynote speaker, writer, licensed clinical neuro-rehabilitation psychologist, brain health expert, and the owner and director of the Centers for Cognitive Wellness. She is passionate about empowering people to use their brains to live better, lead better, and love better. She is the author of *The Neuroscience of Memory: Seven Skills to Optimize Your Brain Power, Improve Memory, and Stay Sharp at Any Age*.

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Elise Baker is an English graduate student at Indiana University Bloomington, researching the accessibility and disclosure of knowledge and identity through politics and media. As a student in Dr. Katherine Silvester's Mobilities Studies seminar, Elise's work has focused on the negotiation and shaping of disability and accessibility in our modern world.



Anne Basting, PhD, is Professor of English at the University of Wisconsin-Milwaukee, where she is Director of the Center for 21st Century Studies. She is author/editor of multiple books, including her latest, *Creative Care: A Revolutionary Approach to Dementia and Elder Care,* as well as *The Penelope Project*, and *Forget Memory*. She is founder of and a Creative Strategist for the award-winning non-profit TimeSlips Creative Storytelling, an alliance of artists and care partners bringing meaning and joy to late life through creative engagement. In 2016 she became a MacArthur Fellow (known as the MacArthur Genius Award).

www.anne-basting.com/about



P.K. Beville founded Second Wind Dreams® (*www.secondwind.org*), an internationally acclaimed nonprofit created to change the perception of aging through fulfilling elders' dreams and offering educational programs to help caregivers understand challenges facing those living with dementia, in 1997.

Beville created the Virtual Dementia Tour® (VDT®), an evidence-based training method designed to build sensitivity and awareness in individuals caring for those living with dementia, and developed additional programs to meet the needs of those living with dementia including Dementia Aware Competency Evaluation®, Family VDT, Inclusive VDT and Hospital VDT. Most recently, Beville has developed a training program to address end-of-life care for people living with dementia and their families. Beville and the VDT have been featured in many news outlets and Beville is frequently a guest on podcasts.

Beville holds a B.S. Degree in Psychology, a master's degree in clinical psychology and PhD in gerontology. She is a Certified Eldercare Mediator and End of Life Doula.

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Dr. Jill Bjerke, BS, DC, Certified Aging in Place Specialist, has 40 years' experience as a healthcare executive. She is passionate about creating a safe home environment for seniors. In 2005 she founded her business, Home Transition Solutions Group LLC. She is the creator of the first aging-in-place, senior safety home check mobile app, Silver Spaces, first released in 2015 and being re-released in 2022 as a highly expanded and detailed home assessment tool. She is a physician, international author, and aging-in-place keynote speaker and consultant.

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Salli Bollin, MSW, has experience working in non-profit and healthcare organizations serving older adults, individuals living with dementia, and their care partners. She is President & CEO of the Ohio Council for Cognitive Health (*https://ocfch.org*) and MemoryLane Care Services (*https://memorylanecareservices.org*) and holds a master's degree in social work from the University of Michigan. She is grateful for the opportunities in which she has learned from individuals with dementia, those with intellectual and developmental disabilities and dementia, their families, and care partners. One of Salli's most recent rewarding experiences and learning moments was as a caregiver for her parents, Rose and Glen. In her free time, she enjoys spending time with her family, traveling, and perfecting traditional family recipes.

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Stacie L. Bonenberger, MOT, OTR/L, is a program manager at the Jewish Healthcare Foundation (JHF) in Pittsburgh, Pennsylvania. Ms. Bonenberger is one of the statewide coordinators for Dementia Friends Pennsylvania, a global initiative that is changing the way people think, act, and talk about dementia, and for Dementia Friendly Pennsylvania, helping to build inclusive communities for persons living with dementia in Pennsylvania. She is an active member of the Dementia-Friendly Greater Pittsburgh leadership work group. Prior to joining JHF, she was the assistant facility director of occupational therapy at UPMC Passavant and has 17 years of clinical experience as an occupational therapist in Colorado and Pennsylvania. Ms. Bonenberger received her bachelor's in psychology from the University of Massachusetts and her master's in occupational therapy from Chatham University.



Nicole Brackett, LPN, CEE, is a U.S. Army veteran with a nursing career spanning over 33 years, specializing in Alzheimer's and dementia care. Director of Care Delivery & Quality, Nicole co-developed the Homewatch CareGivers Certified Dementia Care Specialist Training Program with Dr. Al Power, a noted geriatrician, author, and dementia care expert.

A Certified Eden Educator, Nicole is part of a global movement transforming the culture of care. She actively participates in the Dementia Action Alliance Optimizing Well-Being Workgroup and its subcommittees, championing initiatives for people living with dementia.

Nicole is passionate about training and development to enhance quality care for individuals receiving care in their homes.

Connect with Nicole: *nbrackett@hwcg.com* and with Homewatch CareGivers: *www.homewatchcaregivers.com*



Pam Brandon is the Founder and CEO of AGE-u-cate Training Institute. Drawing on 25 years of personal and professional experience as a family care partner and developer of caregiver training for families and professionals, she is passionate about person-centered strategies and approaches. Pam is the creator of the Dementia Live® sensitivity awareness experience and program, transforming people's understanding of and empathy for persons living with dementia.



Jennifer Carson, PhD, Jennifer Carson, PhD, is a Clinical Associate Professor and Founding Director of the Dementia Engagement, Education, and Research (DEER) Program at the University of Nevada, Reno, School of Public Health. Through the DEER Program, which houses Dementia Friendly Nevada, she collaborates with nine community groups across the state to promote brain health, foster inclusive communities, and co-create innovative approaches to enhancing dementia care, support, and well-being. Guided by a commitment to authentic

partnerships, participatory research, and community-driven innovation, Jennifer leads efforts that inspire social change and drive lasting impact. In addition to Dementia Friendly Nevada, she and the DEER Program team lead several other grant-funded initiatives, including Nevada's CDC-funded BOLD Public Health Program, the ACL-funded Dementia Support Specialist Program, and the HRSA-funded Geriatric Workforce Enhancement Program. Jennifer's pioneering work in transforming dementia care and support has earned her national recognition, including the 2022 Mensa Foundation Laura Joyner Award and the 2024 UNR Foundation Established Innovator Award. A former family and professional care partner, Jennifer's lived experience deeply informs her research, shaping innovative dementia care strategies and meaningful engagement and support programs.



Christine Davis has been practicing law for over 30 years. She is also a gerontologist, with a focus on public policy to ensure people living with dementia have access to person-centered care and support in their homes and communities.

Chris can be reached at *christinedavis27@gmail.com*.

Dementia Friendly America (DFA), administered by USAging, launched in 2015 with a goal to ensure that communities across the United States are equipped to support people living with dementia and their care partners. DFA's mission is to increase dementia awareness, reduce stigma, and provide quality dementia-friendly resources, education, and support that fosters the creation of communities where people living with dementia and their care partners can live, engage, and thrive in community no matter where they live. DFA's community effort began with six pilot communities and has grown to over 350 communities across 42 states and territories. The national DFA team at USAging consists of Mary Ek, Darya Rahbar, and Aleiah Mann.

https://dfamerica.org/leadership/

Breana Dorame, Tribal Public Health and Aging Senior Associate for IA², is a Southern California Native of the Gabrielino-Tongva Tribe living in her homelands. A graduate of UC Santa Barbara, she brings expertise in Indigenous advocacy, environmental health, and education. Breana is dedicated to advancing culturally sensitive public health solutions tailored to the unique needs of Indigenous communities. Her work with IA² focuses on promoting healthy aging, with a deep commitment to the well-being of Indigenous elders.

Connect with Breana: *breana@iasquared.org* and IA2: *https://iasquared.org/*



Dr. Jennifer Drost serves as the Medical Director for Geriatrics at Summa Health in Akron, Ohio. She received her medical degree from Ohio University Heritage College of Osteopathic Medicine. Dr. Drost is board certified in Internal Medicine, Geriatric Medicine, and Hospice & Palliative Medicine. She serves as the Associate Program Director for the Geriatric Medicine Fellowship and is an Associate Professor at Northeast Ohio Medical University (NEOMED). She is a co-director for the HRSA-funded NEOMED Geriatric Workforce Enhancement Program. Throughout her practice, she focuses on ensuring patient-centered care through focusing on interprofessional communication and collaboration across the care continuum for older adults. Dr. Drost is a member of the AGS Public Education Committee and is the treasurer for the Ohio AGS Chapter. In the community, she is privileged to serve as the Chief Medical Officer on the Board of Directors for the Ohio 10A Area Agency on Aging, Direction Home and is part of the Summit County (OH) Age Friendly Coordinating Council.



Sherry Dupuis, PhD, is professor in the Department of Recreation and Leisure Studies and Co-Director of the Partnerships in Dementia Care (PiDC) Alliance at the University of Waterloo, Waterloo, Canada. She is also a Research Scientist of the Schlegel-University of Waterloo Research Institute for Aging and the former Director of the Murray Alzheimer Research and Education Program. She uses critical participatory action research and arts-based methodologies to prompt personal transformation and more humane, compassionate, and relational care practices and policies in dementia and long-term care.

uwaterloo.ca/recreation-and-leisure-studies/people-profiles/sherry-dupuis



Carla Eben is the Numaga Senior Services Director at the Pyramid Lake Paiute Tribe in Nevada. After reaching out to the University of Nevada, Reno Sanford Center on Aging, she began arranging training sessions to educate her elders, her community, and local departments. In 2018 she received the Dementia Friendly Nevada Grant "Pesa Sooname." She hosted the Nevada Tribal Summit on Brain Health and Dementia drawing 113 attendees with 14 tribes represented. She continues to educate her people. The Numaga Senior Services Program operates under 12 different Grants for the Elders of Pyramid Lake. Carla's efforts have been recognized and is featured in the CDC Alzheimer's Association Roadmap to Services across Indian Country.

iasquared.org/brain-health/brain-health-leadership/carla-eben-pyramid-lake-paiute/



Angela Edney, MSA, OTR/L, is a National Director of Clinical Services for Aegis Therapies. She provides field support for the company's Clinical Specialists and Advanced Practice Specialists. She also serves as a clinical resource for speech language pathology, occupational therapy, and physical therapy. She has over 30 years of experience in rehab and approximately 25 years of experience as a clinical director in post-acute care. She has co-authored several resources for therapists, including an article on falls prevention for patients with cognitive impairments. She is also a certified "Dementia Capable Care" instructor with Dementia Care Specialists.



Anne Ellett, MSN, NP, is a certified nurse practitioner with extensive experience in all aspects of dementia care and the founder of Memory Care Support. She established the company to provide access to quality resources, educational products, and services to improve the health and quality of life for older people, as well as those charged with their care. Recent projects include developing the Best Life Approach for the Green House Project and the LEAP memory care training program. In addition, she is a national speaker on culture change and how misperceptions about people living with dementia perpetuate institutions locked into outdated care practices. Her book, *Getting Dementia Care Right*, was published by HPP press in 2023.

memorycaresupport.com/about/



Molly Fisher is a clinical social worker who has worked in the field for over 15 years. As a psychotherapist, she provides quality general mental health psychotherapy services to adults, specializing her work with individuals living with a parent or person with dementia. Molly is a content expert on Alzheimer's disease and dementia-related illnesses, working nationally with nonprofits, educational institutions, and residential care facilities teaching and training staff and family on best practices in dementia care. Molly is an adjunct faculty member at New York University, where she received her master's degree in Social Work. Molly received her bachelor's degree in Criminal Justice from American University in Washington, DC.

www.mollyfisherlcsw.com



Emily Franke, LSW, MSW, is a Licensed Social Worker with extensive experience in grief recovery, end-of-life decision making, caregiving strategy, and sex and sexuality education. These skills were honed through her various roles in community mental health, inpatient hospital, and private practice. Emily earned her dual bachelor's degrees in Psychology and Gender, and Sexuality & Women's Studies from the University of Pittsburgh, where she went on to graduate with her master's degree in Social Work. Currently, Emily's work focuses on serving the diverse older adult population with a specific focus on LGBTQIA+ older adults.

Dr. John Geiss, DO, is the founder and CEO of Senior Doc and GeissMed Hospice and is the co-founder and president of Brigade Health. Since 2014, Senior Doc and GeissMed have been revolutionizing senior healthcare by offering comprehensive care for seniors in the comfort of their own homes. Dr. Geiss is passionate about integrating modern technologies and innovative care models to improve patient outcomes and support aging in place. He attended Midwestern University Medical School, in Phoenix, Arizona and completed his residency in Family Medicine at Chino Valley Medical Center. Dr. Geiss was born and raised in Southern California, which is where he lives with his wife and two children. He can be reached at *drgeiss@seniordoc.com*



Shadi Gholizadeh, PhD, MPH, MSc is a licensed clinical psychologist. Shadi serves as Head of Quality and Clinical Development at TheKey and Home Care Assistance, where she also heads their Scientific Advisory Board. Shadi completed her education at Stanford University, the London School of Economics and Political Science, and UC San Diego. She completed her clinical internship at UCLA, where she is currently a volunteer Clinical Assistant Professor. She has an academic background in behavioral medicine and epidemiology and clinical expertise in aging in place, coping with and adapting to chronic illness and cognitive changes, and health interventions targeting modifiable risk factors for cognitive and physical health. Shadi works with family and professional caregivers in training and support contexts and maintains a small private practice.



Amy Goyer, author of *Juggling Life, Work and Caregiving*, is a consultant and serves as AARP's national family and caregiving expert. A passionate champion for caregivers, she has been one her entire adult life, caring for her grandparents, parents, sister, and others. Amy has more than 35 years of experience working in the field of aging. She shares her caregiving journey and actionable tips for caregivers in her columns and videos. She is a sought-after speaker and moderates AARP's Facebook Family Caregivers Discussion Group (*facebook.com/groups/aarpfamilycaregivers*). Find more caregiving at: *www.aarp.org/caregiving*

Connect with Amy: *twitter.com/amygoyer* (Twitter), *facebook.com/AmyGoyer/* (Facebook), and *linkedin.com/in/amygoyer* (LinkedIn)



Long-Jing Hsu is a Ph.D. candidate at Indiana University Bloomington. Her research centers on designing and implementing robots to support older adults, particularly those living with dementia, in fostering a sense of meaning and purpose in life. Inspired by Jan Bays from the Dementia Action Alliance (DAA), Long-Jing envisions a world where individuals living with dementia can enjoy fulfilling lives and receive and provide compassionate care while engaging with technology and robots.

For more information, contact her at *longjinghsu@gmail.com*.



Jennifer Hudak, MPA, currently serves the Summit County Board of Developmental Disabilities, *https://www.summitdd.org/*, as a Senior Manager for the Service and Support Administration Department. In this role, Jennifer leads the I/DD Board's Technology and Employment First Initiatives. Additionally, Jennifer's leads the ACL Dementia Grant partnership to help guide professionals supporting people with I/DD and dementia. She currently serves as a Board Member for the Ohio Chapter of the Association for People Supporting Employment First (APSE) and as Advisory Board Member for Women in Leadership, Ashland University. Jennifer has 32 years of career experience dedicated to enhancing the lives of people with developmental disabilities.



Jason Karlawish, MD, is a Professor of Medicine, Medical Ethics and Health Policy, and Neurology at the University of Pennsylvania and Co-Director of the Penn Memory Center, where he cares for patients. He researches and writes about issues at the intersections of bioethics, aging, and the neurosciences. He is also the author of *The Problem of Alzheimer's: How Science, Culture, and Politics Turned a Rare Disease into a Crisis and What We Can Do About It* and the novel *Open Wound: The Tragic Obsession of Dr. William Beaumont,* and has written essays for numerous publications.

www.jasonkarlawish.com/about

Lauren Keeley, MA, is a doctoral student at Indiana University Bloomington in rhetoric. She received her undergraduate degree in English with a focus on Medical Humanities and has four years of volunteer experience with people living with dementia. She learned about the Dementia Action Alliance through a Mobilities-themed class she enrolled in at IUB.



Pia Kontos, PhD, is a Senior Scientist at KITE Research Institute, Toronto Rehabilitation Institute-UHN, and a Professor in the Dalla Lana School of Public Health, University of Toronto. She is committed to drawing on critical participatory and arts-based (visual arts, music, theatre, film) methodologies to challenge stigma associated with dementia and to promote inclusion, relationality, and the possibility of growth for everyone living with, and impacted by, dementia.

kite-uhn.com/scientist/pia-kontos

Raquel Arias Labrador is a first year PhD student in English concentrating in rhetoric at Indiana University Bloomington. She is interested in the intersection between rhetoric studies and cognitive sciences as pertaining to language use. Keystones of her work are multimodal and interdisciplinary work, but most importantly, person-centered and action-oriented approaches to research. Her collaboration with this edition of *Pathways to Well-Being with Dementia* emerged as part of a graduate course about Mobilities, where community engagement was a central component.

Jamie Lett is an Associate Instructor of reading, writing, and composition within Indiana University's English Department, working towards her PhD in rhetoric and composition. She is studying texts related to mobilities and disabilities rhetoric as well as the rhetoric of human rights. She believes in the importance of community-based work and outreach as well as the power of empathy in the process of writing and composition.



Nancy Emerson Lombardo, PhD, is Co-Founder of the Alzheimer's Association and Alzheimer Disease International. She is an Adjunct Research Assistant Professor of Neurology at Boston University School of Medicine and on faculty of BU's Alzheimer's Disease Center. An internationally recognized expert and researcher on brain healthy lifestyles with over 35 years of experience, Dr. Emerson Lombardo is President of the Brain Health and Wellness Center and HealthCare Insights LLC in Acton, Massachusetts. Much of the work at BHWC is focused on the sought after, evidenced-based, nutrition program, Memory Preservation Nutrition.

www.bu.edu/alzresearch/profile/nancy-emerson-lombardo/



Angela Lunde, MA, is an Associate in Neurology at Mayo Clinic. Her interests and research focus are in the emotional and quality of life factors experienced in those living with dementia and care partners. Ms. Lunde is involved in efforts to address stigma, improve well-being, and support the inclusion of persons living with dementia into everyday community life. Ms. Lunde co-authored the book, *Mayo Clinic on Alzheimer's Disease and Other Dementias* and has published research and written numerous articles. She has professional training in mindfulness-based therapies, grief and loss, Dignity Therapy, and Yoga.

mcpress.mayoclinic.org/healthletter/cultural-shift-underway-in-addressing-alzheimers-disease/



Cyndy Hunt Luzinski, MS, RN, is an advanced practice nurse and the first accredited SPECAL® (pronounced "speckle") practitioner in North America, credentialed by the Contented Dementia Trust in England. Cyndy enjoys sharing SPECAL strategies which make "living well with dementia" the expectation, not the exception. Cyndy's nursing background ranges from critical care to community case management. In honor of her dad, she founded and currently serves as executive director of Dementia Together, a nonprofit organization in Northern Colorado which offers education, enrichment, and hope, while cultivating joy and building stronger connections for people living with dementia, their care partners, and the community.

Catherine Maloney is a rhetoric PhD student at Indiana University and a graduate student instructional consultant for the University's Center for Innovative Teaching and Learning. Her interests rest in educational development and instructing graduate students on teaching skills. She is currently working with Dr. Katie Silvester on a Conference on College Composition & Composition (CCCC) Grant Proposal to Fund Community Engagement Activities in L762 and W240 Courses.



Sara Masoud, MPH, is a Community Outreach Senior Coordinator of the UT Health San Antonio. In this role, she collaborates closely with community partners to offer free events and resources to families living with dementia. She hosts monthly Memory Cafés and initiated the Texas Memory Café Network to support other memory cafés. She is the Project Lead on a Patient-Centered Outcomes Research Institute award to connect with Latino families impacted by dementia in South Texas to identify community-driven priorities for dementia care research. Sara is completing her PhD in translational science toward becoming a community-engaged researcher in dementia and caregiving.

directory.uthscsa.edu/academics/profile/masoud



John McFadden, MDiv, is an ordained minister of the United Church of Christ who served in parish ministry for 34 years and is now Pastor Emeritus at First Congregational Church, Appleton, WI. In 2012 he and his wife Susan McFadden co-founded Fox Valley Memory Project, a nonprofit organization in northeast Wisconsin that provides many programs serving people living with dementia and their care partners. With Susan, he co-authored *Aging Together: Dementia, Friendship, and Flourishing Communities* (2011, Johns Hopkins University Press).

www.linkedin.com/in/john-mcfadden-61a2566/

Lise McCarthy, PT, DPT, GCS (Emerita), LPF, NCG, joined DAA at the invitation of Jan Bays in 2019. Prior to that they collaborated with the American Physical Therapy Association's Geriatric Academy by forming the Cognitive and Mental Health Special Interest Group. The pandemic closed Dr. McCarthy's 20-year geriatric house-calls practice, but she remains professionally active as an Associate Clinical Professor and volunteer faculty at UCSF. She retired her board certification in geriatric physical therapy as she now works with Superior Probate Courts as a licensed professional fiduciary bringing her clinical knowledge to help vulnerable people sort out complex medical-legal problems often impacted by anosognosia.



Susan McFadden, PhD, is Professor Emerita of Psychology, University of Wisconsin-Oshkosh. Susan retired from the University in 2012, and with John, now volunteers in many capacities for Fox Valley Memory Project. Her most recent book is *Dementia-Friendly Communities: Why We Need Them and How We Can Create Them* (2021, Jessica Kingsley Publishers). She continues to write and give lectures on how communities can include people with dementia in community life and overcome the stigma associated with the condition.

uwosh.edu/psychology/faculty/mcfadden/



Alka Mehra OTR, CLT, RAC-CT, received her Occupational Therapy Degree from Delhi, India, in 1986 and has practiced in a variety of settings including hospital, acute rehabilitation, home care, outpatient/direct bill and long-term care.

She has been working with Aegis Therapies since September 2013, as a Regional Clinical Director.

She mentors Occupational Therapists, Physical Therapists and Speech Language Pathologists with evidence-based practice as well as continuing education courses in dementia/cognitive management, fall prevention/balance management, mental health management, geriatric strength training, pain management, and complex disease management. She has been an active member of the American Occupational Therapy Association, as well as the OT state associations in Minnesota and Wisconsin.



Jodi Melius, RN, BS, is Nurse Study Coordinator at the Mayo Clinic Alzheimer's Disease Research Center in Rochester, Minnesota. In addition to research study coordination, she facilitates caregiver support groups, and develops and presents education for professionals, community stakeholders, and families. Her focus is on understanding dementia and the diseases that cause it, with a primary goal of decreasing the stigma that is associated with dementia. She is also a community organizer and advocate of living well with dementia. Her work is in honor of her father, who lived with Lewy body dementia.



Matthew Neal is the co-founder and CEO of *Brigade Health*, a company dedicated to providing primary care and care management services tailored to the needs of individuals living with dementia and their care partners. With extensive experience in healthcare and senior care services, Matthew has built organizations that combine innovative solutions with a deep sense of empathy, all aimed at improving care for seniors and empowering care partners. He has an MBA from the Stanford Graduate School of Business and lives in Southern California with his wife and two children.

Matthew can be reached at matt@brigadehealth.com.



Anneliese Perry, MS, NHA, is a Program Manager of Aging Initiatives at the Jewish Healthcare Foundation (JHF) in Pittsburgh, PA. She is one of the program coordinators for Dementia Friends Pennsylvania and Dementia Friendly Pennsylvania. Prior to joining JHF, she worked in both home and community-based services as well as long-term care. She holds a Master of Science in Professional Leadership from Carlow University and a Bachelor of Arts in Psychology from Westminster College. In addition, she is a licensed Nursing Home Administrator and is certified in Ethics and Compliance Management from St. Louis University.



Daniel Potts, MD, FAAN, is a neurologist, author, educator, and champion of those living with dementia and care partners. Selected by the American Academy of Neurology as the 2008 Donald M. Palatucci Advocate of the Year, he also has been designated an Architect of Change by Maria Shriver. Inspired by his father's transformation from saw miller to watercolor artist in the throes of dementia through dignity-promoting care and the expressive arts, Dr. Potts makes similar programming available through his foundation, Cognitive Dynamics, started in his father's memory. He lives with his wife and daughters in Tuscaloosa, Alabama.



Tia Powell, MD, is the Director of the Montefiore Einstein Center for Bioethics and of the Einstein Cardozo Master of Science in Bioethics program. She holds the Trachtenberg Chair in Bioethics and is Professor of Epidemiology, Division of Bioethics, and Psychiatry. She focuses on bioethics issues related to public policy, dementia, end of life care, the LGBTQ+ community, and public health disasters. She has worked on many projects for the National Academy of Medicine and chaired the Decadal Survey on Behavioral and Social Science research on Alzheimer's disease. Her 2019 book, *Reimagining Dementia — Building a Life of Joy and Dignity from Beginning to End* from Penguin Random House, was featured on numerous media outlets.

www.tiapowellmd.com/about-tia/



Allen Power, MD, is an internist, geriatrician, and an international educator on transformational models of care for older adults, particularly those living with changing cognitive abilities. Dr. Power's book, *Dementia Beyond Drugs: Changing the Culture of Care,* was named a 2010 Book of the Year by the American Journal of Nursing. His second book, *Dementia Beyond Disease: Enhancing Well-Being,* was released in June 2014, and new editions of both books were released in 2017. He is currently working with Dr. Jennifer Carson and Patricia Sprigg on a new book about creating inclusive communities for people living with dementia.



Joanne Rader, RN, MN, has helped pioneer key advances in reducing the use of restraints and finding conflict-free ways of bathing in long-term care. She is the author of two books that received the American Journal of Nursing Book of the Year awards: *Individualized Dementia Care: Creative, Compassionate Approaches* and *Bathing Without a Battle*. Joanne is also one of the founders of the Pioneer Network.



Rachael Redman, MS Ed., CCC-SLP, is a speech-language pathologist for Aegis Therapies in southwestern Wisconsin. Rachael received her Master of Education in Speech-Language Pathology from Old Dominion University after receiving her Bachelor of Science in Communication Sciences and Disorders with an emphasis in geriatrics and dysphagia from the University of Wisconsin-Madison. Rachael has been the State Advocate for Medicare Policy for the Wisconsin Speech-Language Pathology and Audiology Association since 2017. She has published research on traumatic brain injury rehabilitation in the *Journal of Brain Injury, Archives of Physical Medicine and Rehabilitation*, and *Journal of Head Trauma Rehabilitation*. Rachael enjoys mentoring clinical fellows and working on education programs.



Katie Silvester, PhD, is a tenured professor of English and director of composition at Indiana University Bloomington. She is the author of *Living English, Moving Literacies* (NCTE, 2024), which documents the literacy journeys of Nepali-speaking refugee women as they navigate U.S.-based resettlement pathways later in life. She teaches undergraduate and graduate classes in rhetoric and composition.



Pat Snyder received bachelor's and master's degrees at University of North Carolina-Chapel Hill, taught school, worked as a certified paralegal in her husband's law office, and is a church deacon. She was the primary care partner of her husband, John, who was diagnosed with Lewy body disease in 2007 and who died in 2015. She authored *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease*. She founded the Wake Forest Dementia Caregiver Class and has served on the UNC Cognitive Disorders Clinic Caregiver Team. She received the 2018 LBDA Volunteer of the Year Award and 2021 Dr. Daniel Kaufer Outstanding Service Award by Dementia Alliance of NC.

YouTube Channel: *www.youtube.com/channel/UCrjzZYVyeopBjaslMmCLH3g*
Playlist: *www.youtube.com/playlist?list=PLjwUqlTKKiMqXfcxLYYmo6F-O72DyHE_z*



Beth Soltzberg, LICSW, MBA, directs the Alzheimer's/Related Dementias Family Support Program of Jewish Family & Children's Service of Greater Boston. This program includes the JF&CS Memory Café, Balancing Act support group, and the Dementia Friends public awareness program for Massachusetts. She leads the JF&CS Memory Café Percolator, a free resource-sharing network for Memory Cafés throughout the US and beyond, and is a lead advisor for the national Memory Cafe Alliance. Beth is a member of the leadership team for Dementia Friendly Massachusetts. She is a clinical social worker and holds an advanced credential in hospice and palliative care social work.



Steve Sonnenberg, MD, started his practice of Psychiatry in 1985 after completing residency at the University of Washington, where he also obtained a Master's degree in Philosophy. For the past ten years, he has focused on Geriatric Psychiatry. Retiring from full-time practice in 2019, Dr. Sonnenberg has since taught psychiatry to counseling students, medical interns, and psychiatric residents in Thimphu, Bhutan and facilitated a spirituality group for the Dementia Action Alliance. He is completing the Buddhist Chaplaincy Training program with the intention of pursuing further research into the experience of dementia from a Buddhist perspective and the application of a Mindfulness-based approach to living with dementia.

Elizabeth Stettler is a graduate student of English literature at Indiana University Bloomington. She is preparing to teach middle and high school English next fall; as an educator, she is committed to intergenerational literacy and community-engaged learning. Elizabeth's connection to the Dementia Action Alliance was facilitated through a graduate course entitled "Research in Composition, Literacy, and Culture."



Pat McHenry Sullivan is a mentor, writer, and speaker for people who want to live and work with integrity, purpose, joy, and creativity. She is the author of *Work With Meaning, Work With Joy: How To Bring Spirit To Any Job* and the creator of a legal education workshop for the California Bar Association, *From Stress, Burnout and Exhaustion to Energy, Resilience and Insight*. Pat and her husband John often write and speak about how they thrive with his dementia. Contact Pat at *pat@visionary-resources.com*.

Liz Thomae is an Associate Instructor and PhD student at Indiana University where she studies rhetoric and composition. In her studies (and outside of them as well!), she is committed to person-centered approaches and is drawn to the power of community and relationship to bring about change and healing. Because of this, she is excited to work with the Dementia Action Alliance: Nothing About Us Without Us.



Susan Wehry, MD, is the Director of AgingME at the Center for Excellence in Public Health and an Associate Professor at the University of New England College of Osteopathic Medicine. A physician, educator, and advocate with 40 years of experience, Dr. Wehry is passionate about promoting optimal living in later life, especially for people living with dementia. She is a former board member of the Dementia Action Alliance.



Marty Williman, BSN, Program Director for Ohio Council for Cognitive Health (*www.ocfch.org*) oversees community, family, and professional program development and implementation, including Dementia Friends and Ohio Dementia Inclusive Community initiatives. Marty holds a Bachelor of Science in Nursing degree from Madonna University, Livonia, Michigan and has worked in elder healthcare for over 30 years.

Connect with Marty: *mwilliman@ocfch.org*



Lynette Wilson, MSN, RN, has both a clinical and administrative background in public health, hospice care, and developmental disabilities. She serves as a volunteer faith community nurse at Wake Forest Presbyterian Church. Lynette cared for her husband, Roy, during his 10-year journey through dementia which was complicated by a traumatic brain injury. Lynette has been an active member of the Wake Forest Alzheimer's Support Group since mid-2014 and serves them in a clinical advisory capacity. She has co-taught the Wake Forest Dementia Caregiver Class since its inception in January, 2018, to continue her life-long commitment to bettering the lives of others through self-empowerment and support.



Julia Wood, MOT, OTR/L, is the Director of Professional and Community Education for the Lewy Body Dementia Association and is an occupational therapist who specializes in the treatment of individuals with Parkinson's Disease and related dementias. Julia has served as faculty for the Parkinson's Foundation's Team Training for Parkinson's program since 2016, and is certification and training faculty for the LSVT BIG® program. She serves on the Parkinson's Foundation Rehabilitation Task Force and co-authored the first American Occupational Therapy Association Practice Guideline for Parkinson's Disease in 2022.

SUGGESTED RESOURCE

Dementia Action Alliance, Words Matter– This document was developed by people living with dementia and care partners to heighten awareness and understanding about the impact words can have on the well-being and lived experience of people living with dementia.	*daanow.org/wp-content/uploads/2020/05/WORDS-MATTER-Revisions.pdf*

VISIT
Demetia Action Alliance
www.daanow.org

SECTION 1: Living Well with Dementia

Always focus on the CANS (what you CAN do).
We ALL are in this together.
No matter what don't give up; keep on going and press forward toward the next sunrise.

Terrie Montgomery, Manual Guide



Your journey to living well has begun. The starting point may be disbelief and fear—or relief at finally having some answers. The next step is building the path forward to taking charge, identifying your allies, finding purpose, and envisioning your future. Here you'll find powerful stories of those early and next steps—and you'll find inspiration.

Explore Section 1 and consider:

- Evaluation and Diagnosis
- Anosognosia and Its Impact
- Dementia's Myths and Misconceptions
- Empowerment, Purpose, and Advocacy

1.1 Identifying Cognitive Impairment/Dementia

This Manual is inclusive for people who are experiencing some cognitive changes, have been diagnosed with mild cognitive impairment, or who have been diagnosed with a form of dementia. Instead of writing cognitive impairment/dementia throughout the Manual, we use the term "dementia" for brevity to mean any type of cognitive change.

If you are reading this Manual, chances are you have received a diagnosis of mild cognitive impairment, dementia, or else you suspect something is going on with your cognition. You may be feeling sorrow, loss, and fear. If you have received a diagnosis, you may also feel a sense of relief to at least know what is going on. Even if you were expecting it, getting the diagnosis is tough. This Manual is a guide and resource to help you learn how to be proactive with your dementia symptoms and have a good quality of life.

Early on you might not even realize you have a cognitive problem. The symptoms are often more obvious to a family member or friend in day-to-day living. Not recognizing symptoms yourself can affect your ability to get evaluated.

It is important to see a physician who has expertise in this area and not, for example, your urologist, cardiologist, or gynecologist. While many internal medicine and family practice physicians can accurately diagnose types of dementia, not all have the specific training or experience. Some forms of dementia such as frontotemporal, Lewy body, and posterior cortical atrophy can be difficult to diagnose unless the physician has specialized expertise.

For instance, some people who have been diagnosed with Parkinson's disease actually may have Lewy body dementia. It is recommended that you see a geriatrician (physician with expertise in older adult healthcare) or a neurologist with expertise in dementia.

Not recognizing symptoms yourself can affect your ability to get evaluated.

"There's a belief that receiving an early diagnosis may add burden before it's necessary," says Angela Lunde, Associate in Neurology at the Mayo Clinic. "What I have heard from families is that by the time they are seeking a medical evaluation things have changed quite a bit, and they are looking for answers. Although receiving a diagnosis of Alzheimer's disease or a related dementia is not what anyone wants to hear, for many families knowing what is behind the changes and challenges they have endured offers some relief and becomes a source of empowerment.

Specifically, a diagnosis can:

- Validate what the person with dementia and their family are experiencing.
- Explain the symptoms and attribute them to a disease and not a personal failing.
- Increase the likelihood of developing positive coping strategies.
- Initiate action for drug and lifestyle approaches to manage symptoms.
- Offer access to support and resources.
- Provide time to learn about and prepare for potential care needs and encourage conversations around future wishes.
- Provide a possibility to participate in research.

Dementia Evaluation and Diagnosis

Navigate those bumps in the road to evaluation and diagnosis with these suggested steps:

- **Keep a list handy to write down changes you may be experiencing.** Also invite others close to you to write down changes they may observe. With lists in hand, you will not have to rely on memory when speaking to a physician.

- **Bring someone you trust with you when you visit the physician.** It can be hard to take in all the information yourself. Ask your companion to take notes so that you both can review and discuss the information later.

- **Ask questions!** You may feel uncertain about what is involved in a dementia evaluation. If so, call the physician's office and ask them to describe the evaluation process, where everything will take place, and how much time is involved.

- **It's okay to seek a second opinion.** If you (and your companion) don't feel confident or comfortable with the evaluation and/or diagnosis, seek a second opinion.

- **Ask your physician if they have the training and experience you need.** If the answer is no, ask them to recommend a specialist.



What I Wish the Doctor Told Us

Laurie Scherrer, Manual Guide

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http://dementiadaze.com

When I was diagnosed with dementia, the doctors told my husband and me:

1. My working days were over.
2. I needed to "Get my affairs in order and see an attorney."
3. The time would come when I wouldn't recognize my loved ones.
4. For any additional information, we should go to the Alzheimer's Association website.
5. I may experience "sun-downing" in the late afternoons.
6. Come back in six months to see how rapidly you have progressed.

What the doctors **should** have told us:

1. There are many things that can aggravate or enhance the confusion and agitation that comes with dementia. With observation and patience, you may be able to recognize what triggers these symptoms. For example, noise, stress, over-stimulation, or lack of sleep. These triggers are not the same for everyone.
2. Once you recognize the triggers you may be able to find ways to lessen their impact. For example, use earplugs when in a store or restaurant to reduce the noise, keep gatherings small to avoid over-stimulation, and when needed take an afternoon nap.
3. The more independence you give up and allow other people to take care of, the more dependent you will become on others. Change your thought process from "I can't do this anymore" to "How can I accomplish this task" (what changes or modifications can we make to assist me).
4. On days when you are using a lot of cognitive reserve, your symptoms may be strong (usually in the afternoon). This is your brain saying it is tired and needs a break. Try listening to some music or taking a nap.

5. It is OK to take some time to grieve for your losses and accept that life will change. Most people need to experience this after diagnosis and again as their abilities change. In addition to grief, you may experience shock, anger, denial, and sadness. These are normal reactions that can help you come to terms with your disease and hopefully help you to move on.

6. Get involved with others with dementia as much as possible. There are a number of groups that offer video chats with other people living with dementia so you can socialize, ask questions, and encourage each other. *dementiamentors.org* offers a mentor program so you can have weekly chats with someone living with dementia.

7. Stay active and socialize with old friends and new. Once you curl up into yourself, it is hard to get out. Enjoy life, friends, family, and activities for as long as you can.

8. Build your passion to fight back! Sometimes it is the passion within us that drives us to continue fighting. Get involved in advocacy work to educate about dementia. Contact Dementia Action Alliance at *daanow.org* to get started.

9. You will have good moments when you feel "normal" and think you should go back to work, and you will have bad moments when the world is a fog (dementia daze zone).You may feel confused and disoriented and find it difficult to think. There will be times when nothing seems to make sense and you can't remember how to do things and then the fog will go away (at least for awhile). It's OK to admit you are having a bad day.

10. Dementia is more than memory loss. You may experience problems with your balance, lights flickering in your eyes, hallucinations, develop fears, or smell things that aren't really there. Don't be frightened, and keep track of any changes or strange feelings to see how often they occur.

11. Dementia can progress fast, but in most cases it is a long slow progression. You may want to keep your affairs in order, but by implementing changes and strategies you will be able to overcome many obstacles and live a beneficial and happy life for some time.

Since your doctor may have said about the same thing as mine, I hope you find this helpful. Now go enjoy life — live, love, and figure out how to make adjustments to overcome your obstacles. **My motto is: I don't want just to survive — I want to live and thrive!**

Misdiagnosis Happens — Be Persistent

Getting the right diagnosis can sometimes be difficult, as our Guides, the Carson-Arand family, share. At Ray Arand's primary care doctor's office, a nurse gave him a Mini-Mental State Exam. The results led the nurse to write Alzheimer's across the top of Ray's advance directive form, with no explanation. Upon seeing this, Ray's daughter, Jennifer Carson, insisted the doctor come talk to them. He did, telling Ray he suspected he had Alzheimer's. Ray was very upset with the news, and Jennifer asked for a referral to a neurologist or neuropsychologist for a comprehensive cognitive evaluation, so that an accurate diagnosis could be made.

An evaluation at a memory clinic confirmed the diagnosis. But that wasn't the end of the story. Ray's initial diagnosis was Alzheimer's, and later changed to vascular dementia. As time went on, his daughter, herself a dementia specialist, thought that his symptoms seemed a lot like Lewy body dementia, so they requested a second cognitive evaluation. He is now diagnosed with both vascular and Lewy body dementia. A mixed diagnosis like this is common. The moral of the story: Be persistent and don't hesitate to get second opinions.

Understanding Anosognosia in Dementia

What is Anosognosia?

Anosognosia (pronounced a-nos-og-NOH-zee-uh) is a condition where a person is unaware of their own cognitive impairments or health condition. In the context of dementia, it occurs due to structural changes in the brain that affect self-awareness, insight, and perception. This is not the same as denial, which is a conscious decision to avoid accepting something difficult or painful. Instead, anosognosia means the person cannot recognize the changes happening to them, no matter how clear those changes may be to others. In other words, their lived experience differs from the reality experienced and observed by others.

How Anosognosia Shows Up

Anosognosia can vary from day to day and even hour to hour. In one moment, a person may have clarity about where they would benefit from additional support, and in another the person may be unaware of their challenges. It can appear in different ways:

- **Not acknowledging the diagnosis:** "I don't have dementia."
- **Overestimating abilities:** Attempting tasks that are no longer safe, for example getting in the shower alone, when this previously led to painful falls.

- **Refusing help:** Rejecting support with daily tasks, such as cooking, when there are clear safety risks without this support.

This can create challenges not only for the individual but also for one-on-one care partners and family members. It is very common for safety concerns to be a topic that brings on conflict and strong emotions ranging from frustration to sadness. It can be very challenging for everyone involved to know what to do when someone genuinely believes they are fine, despite clear evidence to the contrary.

The Impact of Anosognosia on Daily Life

When a person cannot accurately perceive their condition, everyday tasks can become risky. For example:

- **Driving:** Despite previous conversations and decisions about no longer driving, suddenly asking for car keys to "run a quick errand."
- **Medical care:** Refusing necessary medications or treatment, believing them to be unnecessary.
- **Personal safety:** Attempting to walk without a walker, despite being at high risk for falls.
- **Financial risk:** Resources such as Medicare benefits, savings, and property can be taken by others or exploited. When anosognosia affects the ability to perceive and respond effectively to safety risks, life savings and well-being can be at serious risk.

Understanding Anosognosia's Emotional Impact

Anosognosia affects more than general cognitive processing—it disrupts self-awareness and insight into one's own safety needs, and contributes to distressing or dysregulated emotional responses, such as rage or profound apathy. These challenges can significantly strain interpersonal relationships. When someone lacks awareness and insight into their condition, they may struggle to recognize that their actions cause great worry or deep sadness in others. For care partners, it's helpful to remember that the person isn't intentionally being difficult or confrontational. Rather, people living with dementia and anosognosia are simply not consistently living in reality due to their inability to recall and understand their functional limitations, and the full impact of their choices may be lost on them.

One care partner shares, "My father, who had dementia, would become very upset with me when I would come to the house to drive him to appointments because he insisted that he could still drive and nothing was wrong. It helped to have examples of times when my father had made some risky decisions when driving and gotten lost. But most important was to do

this gently and without a desire to blame or confront. Not being able to drive his own car was a trigger, so when he had the keys out of sight and his car wasn't in the driveway, he was more open to letting me drive my car to take him around."

When anosognosia is present, a person may unknowingly act in ways that are unsafe for themselves and others, and this can increase a care partner's stress as they remain vigilant to ensure safety. This balance of daily tasks along with safety management can be challenging. For example, care partners have shared anecdotes of loved ones inadvertently burning themselves or causing fires when making food at home. Others report their loved ones falling due to inadequate safety measures at home (such as grab bars), coupled with impulsivity in standing or moving. Programs that address these needs include peer support networks, training on safety risk management, or the involvement of professionals with knowledge of creating safer living environments for individuals living with dementia.

A Functional Assessment Approach

Sometimes professional assistance can be helpful. Health professionals such as occupational therapists, physical therapists, and speech and language pathologists who specialize in dementia care can do **functional assessments** to help identify anosognosia. These functional assessments focus on what one can actually do in day-to-day life rather than relying on cognitive screening tools like the MoCA (Montreal Cognitive Assessment) or MMSE (Mini-Mental State Examination). The MoCA and MMSE do not capture the presence of anosognosia because they screen for cognitive ability in a controlled artificial setting. Functional assessments test how a person navigates real-world tasks (driving, cooking, taking medication, etc.) while considering safety risks for themselves and others.

Functional assessment tools, like the Barthel Index (BI), help identify discrepancies between a person's perception of their abilities and their actual functional ability. This can be especially useful in opening up the dialogue when the person insists they are "just fine and don't need help." The BI is an internationally well-known screening tool that can be completed by individuals living with dementia, their care partners, and clinicians. (The modified version of the BI by Shah et al., is available here: *https://www.mdapp.co/modified-barthel-index-for-activities-of-daily-living-calculator-362/*.)

If BI scores significantly differ between a person and their care partner and the professional, this could indicate anosognosia. Having this objective information opens the way for meaningful conversation about potential risks impacting social, physical and financial safety. Understanding that anosognosia is a real condition allows one to determine what risks are acceptable and to put in place safeguards for protection.

Bridging Lived Experience and Clinical Understanding

Our growing understanding of dementia and anosognosia is important to supporting the well-being of both an individual living with dementia and care partners. Research shows that anosognosia is not an "all or nothing" situation. This condition fluctuates, and its impact on decision-making and safety varies. For individuals living with dementia, knowing this can help explain differences in perspective and understanding with significant others and help lessen conflict. For care partners, acknowledging this variability can help reduce frustration and may encourage more compassionate care. If something worked well the day before or you had a great conversation about the need for support, it doesn't mean this topic won't repeat itself.

With anosognosia so highly prevalent in people living with dementia, it is very important that they and their care partners receive understanding and support when they need it.

Encouragement and Practical Next Steps

If you or someone you care for is living with anosognosia, here are a few next steps to consider:

- **Write things down:** Keep a shared notebook to track appointments or important decisions or routines.
- **Use videos as reminders:** For difficult conversations, consider recording key messages to refer to later when needed.
- **Plan ahead:** Work with professionals to create safety plans, including setting up transportation alternatives, organizing medication routines, and getting hearing and vision tested by licensed professionals.
- **Seek legal support if needed:** If anosognosia is a significant concern because it interferes with finances, or there are other safety concerns, legal intervention (such as power of attorney and conservatorship) may become necessary. Contact Adult Protective Services in your area for further guidance.
- **Nurture a trusting relationship:** Knowing you are experiencing anosognosia is tricky. Developing a trusting relationship with someone who understands you, and what anosognosia is, can help bridge those difficult times.

Anosognosia: Support Strategies

Supporting someone with anosognosia requires patience, awareness, and flexibility.

Here are some strategies that can help:

1. Avoid one-on-one arguments and confrontation.

Trying to convince someone that they have dementia or need help often backfires. Remember that the person's lack of awareness isn't intentional; it's a result of brain changes. Instead, gently shift the conversation to focus on their well-being and what helps them feel good. Pick moments that are less tense when discussing concerns about safety or attempting to make a plan to address challenging situations. Recognize those situations which cannot be addressed one-on-one and seek help from others.

2. Create a safe environment with professional help as needed.

Make adjustments to the home to reduce risks. For example, use automatic shut-off devices for stoves, remove car keys, or install grab bars in the bathroom. This allows the person to engage as independently as possible while minimizing dangers or triggers for stress.

3. Use positive reinforcement that promotes the preserved strengths of the person living with dementia.

Focus on what can be done safely. For example, celebrate those wins when mobility aids are being used well or a routine is working well.

4. Leverage professional support.

Engage the help of licensed professionals: social workers, nurses, physical therapists, occupational therapists, and speech therapists. These services are highly regulated to help ensure standards of care are met and are often covered by Medicare and other insurances. Certified geriatric care managers and life care coaches can be helpful by providing extra personal attention, but these services tend not to be covered by health insurance. All of these professionals can help provide individualized strategies to address challenges in a way that feels more personal to the person living with dementia while being less confrontational for the concerned care partner. It's important to remember though that many licensed and unlicensed professionals lack education on topics such as dementia and anosognosia, so finding knowledgeable professionals who have legitimate credentials is key.

5. Build a larger circle of support.

Identify responsible individuals who can step in when necessary. Having several people available to provide consistent feedback can prevent care partners from feeling isolated or overwhelmed, and can reinforce a consistent and respectful message that there is an unmet need to better balance independence and safety.



Living with Anosognosia: Trust & Love

Jack George

From an interview conducted by Raquel Arias Labrador, Indiana University

Living with dementia and anosognosia has changed the way Jack George spends his days. Jack now dedicates much of his time to his role at Dementia Action Alliance.

Raquel: How is it living with dementia and what are the challenges that you experience on a day-to-day basis?

Jack: I actually don't think it's too bad. But of course, there have been some changes. For instance, my wife is now the breadwinner, and I stay home. I do the household chores, and she makes sure we have the money we need. But I wouldn't say that is necessarily something I consider a challenge but more of a change in the way each one of us spends their time.

I worked in middle management for 37 years in the manufacturing industry and now I dedicate my time to different tasks related to my role as a member of the Dementia Action Alliance (DAA) Advisory Board, and sharing my experience living with anosognosia and dementia at seminars and webinars. In fact, I even helped design the interview outline that you're using today!

Raquel: Oh, really?! [laughs] Well, I guess you did a good job because I am really enjoying this interview. I am glad to have the opportunity to talk with someone who is versed in advocacy and raising awareness about this condition. Which leads me to ask—If the changes in the way you spend your time and the role reversal between you and your wife are things that haven't really challenged your day-to-day life, what do you think is the thing that has had the most impact since you started living with dementia?

Jack: I think communication is probably the thing that got affected the most. Communication between my wife and me, I mean. At one point we were having the biggest problem in communication that we have ever experienced in our relationship—and we have been together for 34 years. And this is both our second marriage.

Raquel: So, when is it that you started having communication problems with your wife? It seems like you two have had a wonderful relationship so far!

For Jack, anosognosia's impact was felt in communication problems in the home. Jack explains that his brain would often replace his wife's words with something else he knew needed to be done, something that he expected his wife to request. And he was certain he was correct.

Jack: Yeah, one day [we were together] and [let's say that] if I was getting out of my chair, and she would maybe ask me to bring her a bottle of water… Right?

Raquel: Okay, yes.

Jack: But I thought she *would* have, or I *thought* she said, you know, "put the laundry… put the clothes in the dryer." So, [after getting out of the chair] I would put the clothes in the dryer and come back and sit down and she would say

- *Where's my water?*

and I would say

- *What water?*

And then she would go

- *The water I asked you to bring me.*

And I would respond

- *You didn't ask me to bring you water.*

And it would lead to an argument where I would reply

- *No, you said to put the clothes in the dryer.*

And she would keep insisting

- *No, I didn't. I asked you to bring me some water.*

And the argument would escalate because I've always considered myself to be a really good listener. For instance, during my 37-year career, I had attended tons of meetings, so whenever I was participating in one of those, if I had some comments, I would always wait to make my comments until everyone else was finished. So, I always thought I was really good at listening, and I didn't…. I [was *convinced*], "I don't hear things wrong."

So this problem of not hearing her correctly, part of it was (probably) me, wanting, expecting her to say something that I already had in my mind…basically, I heard what I was expecting to hear.

Raquel: Okay, let's see if I'm understanding correctly. So, in these situations, you will hear things that you probably expected to hear. For instance, if you were thinking of putting the clothes in the dryer, your brain would replace whatever she was telling you at that moment with that thing that was already on your mind and that you wanted to do, right?

Jack: Yes. Okay, not necessarily what I *wanted* to do, but [things that] I knew *needed* to be done.

Raquel: Oh, I see, like things that were in the back of your mind.

Jack: Yeah, something that I would have expected her to say instead of what she did.

And I was, you know, totally convinced that I heard her correctly and that she misspoke, and to the point that I would think, "I *know* that I'm right because I'm such a good listener. I don't make those kinds of mistakes. And *you* just didn't say what you were thinking. You were thinking something else."

And so, it led to arguments and a real breakdown in our communication. The more it happened, the worse it became. You know? It got [to the point] where we were walking on eggshells around each other because we were afraid to speak for fear that it might get misheard or misspoken or whatever it was. I didn't know anything about anosognosia at that time.

Raquel: That sounds awful. I can totally see this escalating because from each person's perspective the other is just talking nonsense, right? So I can imagine that from her perspective it was something like "I do not understand why Jack is acting like he doesn't believe in anything I say and he is always thinking he is right and then blaming me for misspeaking" and for you, you were probably thinking "Why is she insisting on things that I *know* she didn't say?" and then thinking "I know that I am a good listener and the chances I am mishearing her are low."

So, how did you realize that there was something else going on, that it was not your communication falling apart, but something else that was messing with your relationship?

Jack learned about anosognosia after joining DAA's Optimizing Well-Being Workgroup, understood for the first time what was happening, and began to

put into perspective those moments of misunderstanding that previously led to anger.

Jack: The "Aha!" moment, right?

Raquel: Yes, exactly!

Jack: That's when I got invited to join the DAA Optimizing Well-Being Workgroup. I got involved and found out what [anosognosia] is. And I said, "Oh, that would explain what's happening."

And so, first off, I apologized to my wife for all the problems *I* was creating.

And then I said [to myself], "Well, you know, between the two of us, which one has cognition problems? Is it her, or is it me? Well, it's me."

I also got to thinking about [the things] we were arguing about. A bottle of water? Yeah, that's very silly [to argue about]. It does not make sense.

So after that, I decided to take her at her word. So, how I do that is I will repeat back what she's asked me or said to me…

Or, if I hear her asking me for a bottle of water, and I go get it and bring it to her, everything's fine. But if I go and put the clothes in the dryer instead, and I come back without the water, I now understand and believe that she asked me the right thing, and I just didn't "process" it correctly.

Because I now understand there is this condition [called] anosognosia, I can deal with it. And like I said, it's not life-altering problems that we're talking about here, you know, She didn't ask me to go chop my head off or something!

[Laughs]

Jack recognizes that his wife is his trusted partner and she will stand up for him and his rights throughout his dementia journey.

Raquel: I am glad that you two found out what was going on and managed to figure things out, but what is more remarkable for me is that in order for you to do that, you kind of had to let go of some of the conceptions you had about yourself and honor the trust that you have in your wife by believing in whatever she is telling you.

Jack: This is a little thing [I've done] just to accept that… Yeah, I may be hearing her incorrectly, sometimes, not all the time, but sometimes, and if there is another problem like that [a situation where we disagree on things that were asked or said] I

just need to accept it and move on, because it's nothing that I want to come between us. And, you know, my wife, she's going to be taking care of me someday, when things are bad enough that I can't take care of myself; and I need to trust her and honor her now, while I can. So, yeah, that's what I did to kind of turn it around.

Raquel: Exactly, and that is remarkable. I guess the point that I am trying to make here is that it is not like you were disagreeing on something you both were perceiving, and each one was being just "stubborn." It's like this, from what you're telling me:

> "That moment when you asked me for water, that just never happened. I just never registered that and it doesn't exist in my mind. I am completely, 100% sure, that you asked me to put the clothes in the dryer. But I trust you. I trust you more than I trust my senses and what they tell me is 'real' or not."

It's extraordinary what you two have done.

Jack: You're right, and I also found out that I'm not infallible. I can, and do, make mistakes. Yeah, and I'm probably going to make more and more and more. But I do trust my wife to be my primary care partner. She has been with me since long before the beginning of my cognitive problems, and you know, we'll persevere together. I don't know how many times she says, "No matter what happens, I will be with you till the end."

And I know she will do everything to stand up for me and for my rights. I know she will be with me until the end. And, you know, just treat me right. Yeah, yeah, she'll take good care of me.

There's not a person that I would rather have by my side than her.

1.2 Why Some People Resist Being Diagnosed

In the past, dementia was considered a normal part of aging. Older people with "senility" have been part of literature for centuries, including Shakespeare's withering descriptions of old age and its "return to childishness." Still today, many people believe that dementia is not a disease or a medical problem, but a common condition that besets elders. For example, Berta Carbajal, from the Center for Innovation in Healthy and Resilient Aging at Arizona State University, explains in the *Dementia Untangled* podcast that in many Hispanic communities, dementia is considered "normal when you're old. It's accepted."

Others avoid getting diagnosed because they fear the cultural stigma that dementia carries, and they want to put it off as long as possible. Or they are worried about the implications for their job or insurance.

People also hesitate because they have gotten the message that "nothing can be done." It is true that there is no cure for dementia. The brain is extremely complex, and there are many types of dementia (see *Section 8*, page 405) caused by many factors. Genetics, the environment, lifestyle, and socioeconomic status all play a role. Even without a cure, there is much that you as an individual, and we as a society, can do to support the well-being of people living with dementia.

The bottom line:
It's important to get an early diagnosis.

For more on *why this matters*,
see *Making the Case for an Early Diagnosis*, Section 8, page 416.

Diagnosing dementia has come a long way, although it remains an imperfect science. According to the Keenan Research Center for Biomedical Science, approximately 20 percent of people may be misdiagnosed with Alzheimer's disease rather than a different type of dementia. Even with access to the best medical care money can buy, actor Robin Williams did not receive the correct diagnosis of Lewy body dementia during his lifetime. After Robin's death, his wife requested a brain autopsy that identified Lewy body dementia.

1.3 Personhood and Human Rights

Often people living with dementia are described by public media and in films as "empty shells" or somehow lacking in personhood. This couldn't be further from the truth. Sadly, it is a reflection of how misunderstood and stigmatized dementia is in our society, even by most of the medical and healthcare professionals. With dementia there are changing abilities but your personhood remains lifelong.

This is a global issue. The World Health Organization published a position paper, *"Ensuring a Human Rights-Based Approach for People Living with Dementia,"* to address the fact that people living with dementia experience discrimination, stigmatization, and other violations of their human rights. *www.ohchr.org*

I believe that one of the biggest and most ignored human rights for people living with dementia is the right to have hope, to be able to live positively, meaningfully, and as fully as possible.

Allen Power, MD, Contributor



Personhood



Anne Ellett, MSN, NP, Contributor

Personhood speaks to the uniqueness of each human being and their individual rights and privileges. Tom Kitwood, a pioneer in the field of person-centered dementia care, said that personhood "implies recognition, respect and trust."

Perceptions of personhood can be diminished by the perspective and actions of those around us. The perspective of others can erode our sense of person such as that experienced by people living with disabilities, or older adults who are deemed unproductive and less-than.

People living with dementia also struggle for recognition of their personhood, as they are often portrayed as "not all there." The stigma that our society attaches to the diagnosis of dementia is connected to the cultural value of equating independence and productivity with full personhood. It is important to recognize that personhood is not a transitory feature that can be switched off but rather is the very essence of each person throughout their whole life.

Dementia care in western culture is also influenced by the biomedical model that focuses on a person's losses and inabilities. The biomedical model has a bias that sees the person living with dementia only as a "patient" who is dependent and incapable. Medical professionals may tell a newly diagnosed person to "get your affairs in order" and offer no recommendations on how to maintain skills and independence or how to continue a meaningful life with purpose. "[Persons living with dementia] enter a social environment which results in the erosion of personhood and consequent invisibility for the person with

dementia," while making the consequences of dementia "very visible," as an article in the International Journal of Older People Nursing noted.

> *Dementia doesn't strip a person of their essential humanity. There's so much to who we are as human beings than our cognitive function. And if people can embrace all those other aspects of what makes us human, they can more readily live well with dementia.*

Jennifer Carson, PhD, Contributor



People living with dementia often find their individual rights and needs unrecognized or minimalized. For family members, friends, and healthcare professionals to better support people with dementia, it's essential to honor the history and qualities of each individual with attention to their unique talents, preferences, and retained abilities in order to acknowledge their personhood.

No matter where each person is along the dementia spectrum, they deserve to be recognized as an individual, not as their disease.

> *I am not half full. I am not half empty. I am a whole person and will continue to be a whole person until I draw my last breath.*

Richard Taylor, 2011





Dementia Does Not Define Me

Laurie Scherrer, Manual Guide

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https://dementiadaze.com

Dementia does not define who I am. It is merely a small part of the many facets of my life, affecting decisions and changes in how I live. I am Laurie Scherrer, and I am a wife, a writer, a scuba diver, an educator, and an advocate. I'm a traveler and a speaker. Oh, and I am also living with dementia.

People that live with dementia should not be reduced to simply a diagnostic label pronounced by a doctor. Nor should they be stigmatized by a society that sees the diagnosis rather than individual abilities and identities.

Living with dementia does not automatically equal total memory loss, inability to make our own decisions, nor undeserving of living an independent life enriched with purpose, beauty, and fulfillment.

We are not defined solely by a label of dementia. As with most people, we are the cultivation of our upbringing, culture, spiritual fulfillment, lived experiences, accomplishments, failures, and our many challenges.

The medical profession and those in our communities often perceive us as incapable of contributing to any aspect of daily living. We are viewed as dying of dementia rather than LIVING WITH dementia. We are viewed as having limitations, which makes us feel worthless and incompetent.

Together, we will lift our voices to shout out that we are not a label and dementia does not define who we are. Together we can focus on our abilities, not our inabilities, and on how we can be of help to others and thus help ourselves.

1.4 There Are Many Things You Can Do

Most of the narrative around dementia in our culture and in the medical community is about loss. And while it is true that there is loss and sorrow around dementia, the "tragedy narrative" is not a helpful perspective for moving forward. In fact, dwelling on the potential loss and fears about the future can become a self-fulfilling prophecy. The more you are isolated and stuck, the less opportunity you will have to continue to enjoy life and to extend the years of relative good health. Once you have taken in the fact of your diagnosis and allowed yourself a chance to grieve (see *A Time to Grieve*, Section 1.9, page 91), try to pivot towards a sense of possibility and hope.

> *People with dementia are still people who contribute a great deal in their life and in our lives. Dementia doesn't make them less of a person. It is an aspect of their behavior. It doesn't diminish anything that we contribute.*
>
> **Dave Baldridge, Manual Guide**



"This condition feeds on despair," says Anne Basting, founder of TimeSlips and an English professor at University of Wisconsin-Milwaukee. Chances are, your doctor will tell you to eat well, exercise, and stay socially connected. That advice is good for everyone. In addition, though, Basting suggests taking a "purposeful approach" that might begin by creating a chart of what brings you joy. It can be simple things like pausing to watch the sunset or chatting with a kid in the neighborhood. It can be listening to favorite music, singing or dancing, walking with a friend or talking on the phone, going to the movies or having pizza on Fridays, re-reading beloved novels or poetry, swinging a golf club, or playing cards. Or you can dream big and plan something you've always wanted to do, whether it's going up in a hot air balloon or seeing a Broadway play. For John-Richard Pagan, it was treating his mom to Disney World, where they'd both always wanted to go.

Add to your list over time as you pay more attention to what makes you feel contentment or laughter. "Over the next six months, dive in, keep connected, keep growing and challenging yourself," says Basting.

I have dreams that I used to put off for when I retire, when I get older. Now I look at how soon can I get them in. We went to Disney World, my mother and I, and we had a great time. My mom walked all four parks in four days. She was 77 … We just had a blast.

John-Richard Pagan, Manual Guide



Another list might be your strengths and talents. Although you may not be able to do complex tasks that you once were adept at, there are other strengths that you have or that you can discover. Making people laugh, being a good listener, playing pickleball, knitting, volunteering, caring for grandchildren, helping in your faith community — all of us have things we are good at that we may take for granted. Write them down or capture them in drawings or photographs. Joining a DAA discussion group can be an invaluable way to move forward. *daanow.org/virtual-discussions/*

1.5 Self Care

As you begin to accept the reality of living with dementia, be gentle on yourself. Try to be in tune with what your body and your emotions are telling you. You will find that at various times of day you have more energy. Pay attention and allow yourself to take it easy when you feel like it.

Expect the unexpected. Dementia is not linear. It can be a zigzag of feeling good and optimistic one day, only to feel lethargic and blue another. This is normal. Do not be hard on yourself.

At the beginning, especially soon after being diagnosed, people often report they are depressed and full of fear. If you are feeling this way, it will pass, as long as you work on it and have support.

Laurie Scherrer fell into a deep funk after being diagnosed with frontotemporal dementia. "I had no idea what FTD was — flowers on the brain?" she recalls. The doctor had no literature to enlighten her. "The doctor basically said go home and die. I started cleaning out closets and gave away some of my things that I wish I hadn't. You focus on dying. Therefore, your life is very depressing and sad. So I got to the point where I told myself, 'You've never lived like this.' I kicked myself in the tush and said I need to live."

For Laurie, that meant getting involved in DAA. "It's helpful to connect with and socialize with other people living with dementia, so you can talk about challenges and feelings. You have to have a reason to get out of bed and to make you smile." Many people, even those who never thought they would join a support group, find that talking to others experiencing similar things is very helpful. You can learn tips and strategies for how to deal with challenges that inevitably arise.

You might prefer going to the gym, taking a walk in the woods, talking to a friend, hanging out with your grandchildren, working in the garden, going fishing, or listening to music. Look for those things that calm you, make you happy, and engage you.

Remember that depression and dementia are not the same thing. Depression can and should be treated. If you find you are continuing to be isolated and apathetic, talk to your doctor or a therapist. Get help.

The following sections of this Manual will give you many ways to promote your well-being as you live with dementia. Will your life be the same as it was? No. There will be changes and challenges for sure. But there will also be many good times ahead of you.



Three Rules for Anyone Newly Diagnosed with Dementia

Terrie Montgomery, Manual Guide

1. Always focus on the CANs (what you CAN do).
2. We ALL are in this together.
3. No matter what don't give up; keep on going and press forward toward the next sunrise.

1.6 Myths and Misconceptions

There is an astonishing lack of knowledge and understanding about dementia, even among medical providers. Journalists, too, often repeat stereotypes and myths that are not grounded in fact. Educating the public about dementia helps reduce the fear and stigma. Below are a few of the most common misconceptions about dementia followed by the facts.

MISCONCEPTION: Dementia and Alzheimer's are the same thing.

FACT: There are many diseases which cause dementia. Alzheimer's is the most common cause, affecting roughly 60 to 70 percent of dementia cases. Other causes are Lewy body dementia, frontotemporal dementia, vascular dementia, and mixed dementia, among others.

MISCONCEPTION: If you live long enough, you'll get dementia.

FACT: While the prevalence of dementia increases with age, not everyone is impacted. According to the National Library of Medicine, the prevalence of dementia for people age 70 is 14 percent and increases to 37 percent for people age 90 and older.

MISCONCEPTION: If your family members had dementia, you will too.

FACT: Dementia is a complex disease caused by many factors, including genetics. Most cases of dementia are not solely due to your genes. A family history of dementia may increase your risk, but in most cases will not cause you to get dementia.

MISCONCEPTION: If you are able to read this Manual, you must not be living with dementia.

FACT: People living with dementia can live for many years functioning well and enjoying reading the daily news. Reading may become more challenging, though, especially long or complex books.

MISCONCEPTION: If you can speak clearly, you are not living with dementia.

FACT: Many people living with early symptoms of dementia can and do speak clearly. Some people may be more articulate early in the day, others later in the day.

MISCONCEPTION: If a person has trouble finding words, they also have trouble following a conversation.

FACT: Word retrieval and expressing language are controlled by a different part of the brain than understanding language.

MISCONCEPTION: People who have dementia cannot learn new things.

FACT: The brain has vast neural reserves and with stimulating triggers can form new neural pathways, resulting in learning.

MISCONCEPTION: You can tell by looking if someone has dementia.

FACT: Dementia is an invisible disability. You cannot tell by looking at someone if they have dementia.

MISCONCEPTION: There are no treatments for dementia, so there's no use getting diagnosed.

FACT: It is true there is no cure for dementia. There are some medications that help some people manage their symptoms. There is also growing evidence that a healthy lifestyle, staying engaged, and learning new things may extend the time of good health.

MISCONCEPTION: If you are living with dementia, you cannot live alone.

FACT: Many people living with dementia live alone safely. Studies estimate that one-third of people with dementia live alone, and this number may rise as baby boomers age (*Care Weekly,* 2016).

MISCONCEPTION: If you are living with dementia, you should not drive.

FACT: Many people living with dementia continue to drive a car safely early on. Many people, though, can no longer drive safely because their reaction times and decision-making ability are impaired. It is recommended that people diagnosed with dementia undergo an independent driving evaluation to determine their safety to drive.

MISCONCEPTION: Most people with dementia live in nursing homes.

FACT: Only 15 percent of Americans with dementia live in nursing homes (*Population Reference Bureau*). Nearly half of the total nursing home population, however, has dementia.

MISCONCEPTION: People who are living with dementia can't do things.

FACT: People living with dementia can and should continue to do things they enjoy and need to do as much as possible. The individual may need supports or assistance over time depending on the task, but many people are able to continue to grow, to learn new skills, to explore the arts, and to enjoy relationships with friends and family, even if maybe slower or with an adaptation. An occupational therapist can help you adapt to changing needs and maintain independence.

MISCONCEPTION: People who have dementia will wander and get lost.

FACT: Many people do have trouble with navigation. It depends what part of their brain has been affected. But there are tools to help, from keeping a simple note in your pocket to using a smartphone. Later in the disease, some people do leave their home and may become lost.

MISCONCEPTION: People living with dementia don't enjoy things.

FACT: People with dementia continue to laugh, dance, go places, and enjoy favorite pastimes. They may have challenges doing things the same way and may need to modify the previous activities or identify new interests. Identifying personalized interests and providing opportunities for engagement in personally tailored activities, with supports if needed, are important for well-being.

MISCONCEPTION: People living with dementia no longer recognize people.

FACT: They may not be able to pull up the name or articulate the right relationship, but they still know a familiar face or voice and that they share a special relationship. Watch the individual's face and you will see signs of recognition, such as a smile.

MISCONCEPTION: All dementias are the same.

FACT: There are many different causes of dementia and many symptoms. Getting a diagnosis is important in order to best manage your particular disease.

MISCONCEPTION: Doctors know best about how to live with dementia.

FACT: Unfortunately, many doctors are not well-informed on how to maintain a good quality of life after being diagnosed with dementia. Many people living with dementia report that support groups or advocacy organizations like DAA are more helpful in sharing strategies for how to live with cognitive loss.

MISCONCEPTION: All people with dementia have behavior problems.

FACT: There can be many challenging issues and concerns that people with dementia and their care partners confront. But by learning how to manage your environment, de-stressing, and taking care of your emotional and physical health, you can reduce the frequency or intensity of many problems. Remember, each person is unique.

1.7 Stigma

The myths and misconceptions surrounding dementia have led to a long-standing, deep-seated stigma. Stigma permeates our culture, affecting the medical community, the media, government programs and policies, employers, family and friends, and even well-meaning advocacy groups. Stigma can be internalized and affect the health and well-being of people living with dementia. Eliminating stigma about dementia is critically important for the well-being of people impacted by it.

A 2021 AARP survey noted that, "Fears over loss of independence, emotional and financial suffering, and perception of how individuals with dementia or cognitive impairment are treated, feed many of the stigmas around dementia."

"The stigma is very real and it still exists," says Manual Guide Terrie Montgomery. "In my case, I had to be my own advocate when I talked to the doctors and even when I talk to the family. Please let me talk for me. If anybody can explain it better, it's me. Sometimes our family is trying to help us, and society thinks we can't think, we're demented, we're damaged goods, or they think we should have this stare about us or that we can't say anything that makes sense. You can be having a friendly conversation and you say you have dementia and the person will stop talking to you."

Stigma in the medical community

The AARP survey found that "While one in five adults (19 percent) said they would feel ashamed or embarrassed if they had dementia, a staggering seven in 10 providers (69 percent) said their patients would feel ashamed or embarrassed." This misperception on the part of some doctors can lead them to avoid telling patients their diagnosis.

Laurie Scherrer contrasts her own experience with that of her mother when she was diagnosed with cancer. "They told my mom, 'Do as much as you can.' They told me I wouldn't be able to do anything. As I mentor people, 95 percent of them are told to go home and die, or 'stop living.' The amount of fear and negativity that some doctors give you and the whole stigma really brings down people living with dementia. It doesn't give them encouragement to live. That's sad."

> *This sets us up to live a life without hope or any sense of a future and destroys our sense of future well-being; it can mean the person with dementia behaves like a 'victim' or a 'sufferer' and many times their care partners as a martyr.*
>
> **Kate Swaffer**



Angela Lunde, from Mayo Clinic agrees, "Healthcare professionals have the job of providing clear and honest information about the diagnosis they are giving their patient. Often this includes sharing current and anticipated areas of loss and decline. However, it is critical to see the bigger picture — dementia is a medical condition and not an identity. A person who is diagnosed with Alzheimer's disease or a related dementia is still the same person they were before their diagnosis. Dementia changes some things, but not everything, and not all at once. What someone with dementia *can still do* is often overlooked or minimized. By focusing on preserved strengths and abilities we tap into potential and hope, which are essential to well-being."

The message from physicians should be one that instills hope, not despair, says Allen Power, MD, who has worked extensively with people living with dementia. Unfortunately, that generally is not the case yet. Most physicians believe the only treatments for dementia are drugs. There currently are no pharmacological cures for dementia, so from the medical world's stigmatized perspective, nothing can be done.

Kate Swaffer, a co-founder of the Dementia Alliance International who is living with dementia, famously coined a term — Prescribed Dis-engagement™ — to describe this stigmatized belief. Instead of being provided with information about how to live with and manage the symptoms of dementia when being diagnosed, people are left to their own devices to figure out this complex, chronic condition.

Stigma among friends and family

Stigma appears among people who have the best intentions, says Beth Soltzberg, director of Alzheimer's/Related Disorders Family Support Program, Jewish Family & Children's Service in Waltham, Massachusetts. "One thing I've run across is an assumption that support services should always be for the care partner," she says. Although care partners do need supports, too often the assumption is that the person living with dementia would not benefit from supports, which is not the case. "It's a subtle reflection of stigma," she says.

"Stigma is at the root of all of our problems," says Sherry Dupuis of University of Waterloo. "It's so entrenched in our society that family members can't help but to be drawn in. It's very hard for them to let it go. Part of it is caring for someone who has dementia that is causing changes that can be very emotionally and physically challenging. I've also met many care partners who are really good at being able to evolve themselves to be in the moment to wherever the person is evolving to."

Dupuis blames the two dominant narratives in society about dementia. "For decades and decades, dementia was only presented as a tragic event. I've got newspaper clippings and magazine stories and books and videos that portray it only as very tragic. It's hard for people to look at it another way. The other discourse is biomedical, which is only seeing it as a disease. As soon as someone is diagnosed, they become the disease. Everything that they do, whether intentional or not, is connected to a symptom of the disease."

She continues, "My work has been to find ways to present an alternative. That for sure is challenging, but also rewarding. People talk to me about their dementia being a gift and transforming them, about giving them strength and resilience they never thought they would have, taking them into possibilities they never thought would happen."

How advocates reduce stigma

People like the Guides in this Manual play a critical role in undermining the entrenched stigma. Many people living with dementia have become outspoken advocates. Their first-person perspectives about living with dementia are powerful and are helping to enlighten others.

Manual Guide Jim Mann talks about a woman who had been diagnosed with dementia who shut herself off, not even telling her daughter, because of the stigma. She later saw an item about Jim in the Alzheimer Society of British Columbia newsletter. "She read that and said, 'if he can do it, so can I.' She started coming to the support group I was attending, she did tell her daughter, and she began going out. It's that need for some of us who are more comfortable than others to be more public, to reassure people that there is a life after diagnosis."

> *With dementia, you have to get creative. If you don't, you are going to stay home — because of the stigma, because of that sense of 'what if I get lost,' 'what if …' And so you either create ways to do things outside the house, or you don't. And when you don't, you can easily become isolated.*
>
> **Jim Mann, Manual Guide**



A 2015 CDC Brief called *Addressing Stigma Associated with Alzheimer's Disease and Other Dementias: Role of the Public Health and Aging Services Networks* makes a number of recommendations, among them:

- Promote opportunities for people living with dementia to stay as engaged and productive as possible, focusing on their abilities rather on what they can no longer do.
- Enhance the public's knowledge about dementia and include people living with dementia as speakers, to talk about their experiences and the stigma they have faced.
- Include people living with dementia and their care partners in the planning and development of programs and policies that affect them.

Stigma Among Black Americans

Many believe that there is a particular stigma about dementia among Black Americans. Even though Black Americans experience dementia at twice the rates of white Americans, in many communities there is a reluctance to be diagnosed or to tell others. Manual Guide Rushern Baker notes that he shielded his wife, keeping her at home, in part because of the stigma in the Black community. As it turned out, once the family was open about his wife's diagnosis, they were embraced by the community.

Manual Guide Robert Reid agrees there is stigma, although he said his wife, Kim, has been spared that. "With Kim, because of her standing in our church and in the community, there hasn't been stigma, there's been more empathy.

With Kim, because of her standing in our church and in the community, there hasn't been stigma, there's been more empathy.

"But I will say overall there is a stigma in several areas. A lot of it does come from historical health-related issues. One of the prevalent things that has happened in Black families in the past is that someone who today would be diagnosed with Alzheimer's was considered a little crazy or that they were just old. I've seen that, especially being involved in the church and relating with different families, that stigma does truly exist in the Black community."

Part of the problem is lack of education and access to good healthcare. "I didn't know as much about dementia until we experienced it ourselves," he says. "There is a lack of education and lack of knowledge about the disease. Due to the prevalence of it, there needs to be more outreach and more education. Due to finances and different things, Black families have never really had a good track record of going to get a physical every year or even going to the doctor unless they absolutely had to." Black communities historically have had fewer healthcare facilities, he adds, and providers deal with day-to-day complaints and are less likely to suggest additional testing.

The LGBTQ+ Community's History of Discrimination and Progress

Reprinted with permission from: The GLOBAL COUNCIL ON ALZHEIMER'S DISEASE and DEMENTIA ACTION ALLIANCE
https://daanow.org/wp-content/uploads/2022/10/Calling-All-Voices_LGBTQ-FINAL.pdf

The LGBTQ+ community has experienced a long history of bias, discrimination, and marginalization. Their identity has been — and still is, in many parts of the world — considered criminal behavior. They have experienced discrimination from employment, housing, and healthcare. Rates of violence to the LGBTQ+ community are heart-breakingly high.[2]

In the United States, the three-day Stonewall Riots in New York City in 1969 began what many consider to be a turning point in history of advocacy for LGBTQ+ rights.[3] In 2009, the Matthew Shepard Act was signed by the U.S. Congress to expand the 1969 Federal Hate Crime Law to include crimes motivated by the victim's gender identity and sexual orientation. And less than a decade ago, in 2015, the Supreme Court declared same-sex marriage legal in all 50 states.[3] Progress has not been unique to the U.S. Globally other countries are moving to legalize same-sex marriage and offer protections to the LGBTQ+ community.[4] These milestones, of course, only paint part of the picture. Culturally, LGBTQ+ rights, advocacy, and acceptance have merged into the mainstream.

While there has been progress, challenges persist — particularly for those in the LGBTQ+ community living with dementia. We must confront these realities and give voice to a group that at present is unheard. By 2030, the number of LGBTQ+ older adults living with dementia is expected to surpass one million.[5] And the number of older adults who openly identify as LGBTQ+ is expected to at least double.[6]

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[2] Casey, Logan S., et al. *Discrimination in the United States: Experiences of lesbian, gay, bisexual, transgender, and queer Americans.* Health services research 54 (2019): 1454-1466.

[3] Milestones in the American Gay Rights Movement. PBS.

[4] Cameron, Darla. Johnson, Richard. *How gay rights have spread around the world over the last 224 years.* The Washington Post. 2015. *www.washingtonpost.com/graphics/world/gay-rights-history/*

[5] McGovern J. The forgotten: dementia and the aging LGBT community. J Gerontol Soc Work. 2014.

[6] Caceres BA, Travers J, Primiano JE, Luscombe RE, Dorsen C. Provider and LGBT individuals' perspectives on LGBT issues in long-term care: a systematic review. Gerontologist. 2020.

Sharing will help others in the LGBTQ+ community live well with dementia and help the broader community to become more understanding and better equipped to support and advocate for LGBTQ+ individuals with dementia.[7]

[7] GCAD, Calling All Voices: Stories from the LGBTQ+ Community on Learning to Live Well with Dementia, 2022.

A Rallying Cry Against Stigma



Pia Kontos, PhD, Contributor

I've thought about and written quite a bit on stigma, focusing largely on the sources of stereotypes, prejudice, and discrimination associated with dementia. At the root of stigma is the dominant assumption that dementia leads to a total erasure of the self, and that people living with dementia are incapable of purposeful communication and the pursuit of relationships and activities.

We see this in how they are represented in mass media, policy documents, academic literature. Dementia is characterized as a monstrosity by the lay media — there are countless metaphors and representations that liken dementia to a living death, a never-ending funeral, and construct people living with dementia as zombies.

The consequences of this "tragedy narrative" are multiple — not just for people living with dementia, but for their families. There is considerable evidence that receiving a dementia diagnosis leads to being defined solely through the disease and the stigma that it engenders. Opportunities for engaging in social life are significantly limited — whether it's work, volunteering, or engaging in arts. When stigma is internalized it leads to feelings of shame and inadequacy, depression, anxiety, and even suicide.

Stigma can become a barrier to help-seeking. Even in instances when help is sought, stigmatizing attitudes of healthcare professionals can be a barrier to timely diagnosis and can delay access to treatment. Stigma not only affects the person living with dementia but similarly affects the family; it is linked to embarrassment, shame, fear, increased career stress, and isolation. It poses a significant barrier to the social inclusion of people living with dementia and their family care partners, and it negatively affects their health and well-being.

The "tragedy narrative" fuels prejudice and discrimination. The assumption that people living with dementia are not people anymore, that they've effectively lost their self, enables and legitimizes restrictions on their freedom and their treatment as disposable.

There is no affront to human dignity with such practices if you believe that the person is not a person. Yet this is not so. There is meaning, creativity, humor, joy, sadness, and so much more human potential, and it is imperative that we support this. People living with dementia should have equal access to health, well-being, privileges, and opportunities. Regardless of their cognitive impairment, race, ethnicity, sexual preference, economic status, they should have equal access. They don't.

There are individuals and organizations across the globe that are doing really important advocacy work. There are dementia activists who have spoken at the United Nations, the World Health Organization, with the Senate of Canada and are fighting hard for dementia to be better supported. We need to work collaboratively to challenge stigma and then mobilize the practices and the political processes to assure the rights of people living with dementia are upheld.

We need a more just, inclusive, and caring society. We need to provide life-enriching opportunities for people living with dementia to support their engagement in social life to the fullest extent possible. We must prioritize the quality of human interaction. That requires strong leadership and a commitment to relational caring. It's recognizing at an individual level, an organizational level, and more broadly at a societal level that we can and must do more. Let this be our collective goal.

1.8 Dementia As a Disability

Is dementia a disability? A growing number of people say that it is. With proper support, many people living with dementia would have a better quality of life and be able to engage more fully in the wider world. Changing our perspective from one of a dreaded disease to a manageable disability can affect everything from employment to transportation and accessibility to cultural events. It can also push back against deep-seated social stigma.

Dementia is the leading cause of disability in older adults, but few countries provide disability assessment and support.

"Dementia is the leading cause of disability in older adults, but few countries provide disability assessment and support," says Pia Kontos. "The importance of recognizing it

as such is about ensuring the same kind of support and assessment as people living with other disabilities."

Jennifer Carson says we need to move beyond the biomedical view. "We have to start thinking in terms of rights. We have to stop thinking of dementia as a disease only," she says. "Not to negate that there is underlying pathology, but there has to be an additional frame."

That said, many dementia advocates feel strongly that they do not want to be defined as "disabled." "By legal definition and social recognition it is very much a disability as it decreases abilities I have traditionally been expected to fulfill," says Manual Guide John-Richard Pagan. "But how I personally perceive it must be beyond that label, beyond that limitation. I must see that it is only a part of who I am, and I can do more to move through it than simply accept and wallow in it as a disabling thing."



Dementia as a Disability Reframes My Thoughts

Kirsten Jacobs

Senior Director, Shared Learning Initiatives, LeadingAge

Reprinted with permission from: LEADING AGE
https://leadingage.org/what-happens-when-we-see-dementia-as-a-disability/

If I think of dementia as an illness, for example, I might focus my attention on the medical aspects of the condition, and how its symptoms can be "fixed" with medication. I might see people with dementia as "patients" on the road to inevitable decline and diminishment.

Thinking of dementia as a disability, on the other hand, reframes my thought processes completely.

It makes me think about human rights and empowerment, about the Americans with Disabilities Act, and the international human rights treaty known as the Convention on the Rights of Persons with Disabilities.

It helps me see that people living with dementia have hopes and dreams, skills and talents, and the desire to keep learning and growing.

It stirs me to imagine modifications to our language, environment, and attitudes that could open doors for people with dementia, just as ramps and curb cuts opened doors for people with physical disabilities so many years ago.

1.9 A Time to Grieve: A Normal and Natural Process



Rev. Dr. Cynthia Huling Hummel, Manual Guide

I remember the day that I went to my first class on "Understanding Alzheimer's." I had read about the free 8-week class in the newspaper and figured, if this is what I have, then I better learn more about what's ahead. I called the 800-number, signed up, and double-checked the directions to the Big Flats Community Center where the classes were being held. As I pulled into the parking lot, I felt a wave of sadness come over me. I turned off the car and just sat there as my sobs came in waves. I went through every tissue in my purse and every napkin in my car, wiping away my tears. Why me? Here I was at the peak of my career, and it felt like I had the rug pulled out from under my feet. I was mad at life and mad at God. And it took me a while, but my sobs gradually subsided enough for me to pull myself together, to get out of my car, and head into class.

The classes helped me to begin to come to terms with my dementia diagnosis and to begin a new chapter in my life — one that I had not planned on, one that I did NOT want. I grieved my old life — the life I had before dementia snuck in and changed everything. I was also grieving a future that was not going according to *my* plans.

The reality is that life happens and our dreams for our futures are sometimes dashed. In times like these, our reactions may include rage, depression, exhaustion, and grief. It's important to remember that grief is a normal reaction to loss. And throughout our lives, we will experience times of loss and grief; for example, the death of a loved one, the loss of a significant relationship, an unexpected ending, or even receiving a difficult diagnosis like dementia.

In times like these, grief moves in — like an uninvited guest, disrupting our lives. Grief turns things upside down. Maybe we can't eat or maybe we binge on comfort food. Maybe we can't sleep and walk the floors all night or just the opposite: that we can't keep our eyes open and sleep all day. Grief affects each of us differently and differently on different days.

Please be gentle with yourself and patient with your grief — because grief is helping you to adjust to a new reality, in this case LIVING WITH DEMENTIA. Grief may be helping you to move from "why me?" to "what next?" If we let it, grief can help us begin to move to a place of acceptance, where we can begin to rediscover joy in our lives and in our journey. Grief may help us to move from despair to hope.

My mother used to tell us kids, "no one ever promised you a rose garden." What Mom wanted us to know, from very early on, is that EVERYONE faces disappointments, heartaches, and losses in life, and she reminded us to focus on our blessings. Some people will keep a blessing journal and take note of the good things and good times in their life. Some will keep a blessing jar where they jot a blessing on a piece of paper and watch the blessing jar fill.

- **Don't focus on what you can no longer do, but how you can still make a difference.** One of the best ways that I have found helpful in times of grief is to use our experience (our loss) to help someone else who is going through a time of loss.

- **When we help others, we help ourselves.** Volunteer at a food pantry. Call or visit someone who is homebound. Become a dementia buddy to someone else who has been recently diagnosed.

- **Keep moving.** Get up. Get showered. Get dressed. Set yourself small daily goals. Exercise! A walk around your backyard or neighborhood can do wonders for the weary soul. Think about joining a discussion group or Memory Café. It's a great way to hear how others have navigated this new chapter called *Living with Dementia*. DAA has many groups for people living with dementia and for care partners, too. Interested in art? We have an arts group! Interested in sports? There's a group for you. Check out the DAA calendar on the website. *daanow.org/virtual-engagements/* Be part of a group! Build connections! Make friends!

- **Grief often comes in waves.** Sometimes the waves are gentle and sometimes they are more like tsunamis knocking us to our knees. You may feel like screaming — if so, scream into a pillow, not at loved ones. Some people find it helpful to write their angry thoughts down on a piece of paper and flush that paper in the toilet. I have a friend who took up boxing so he could punch a bag, rather than take his anger out on his family.

- **Reframe your experiences of changing abilities.** Here's an example: I have a friend living with dementia who, after much soul searching, decided to give up driving. Instead of being angry about NOT being able to drive, he reframed his experience, by deciding he wanted to be chauffeured. He asked his wife and friends to be his chauffeur. By changing his mindset, he was able to let go of his anger and grief.

- **Try something new.** This is the time in your life to try a new hobby, take a class, or try a new activity. After my diagnosis, I decided I wanted to learn how to kayak, and discovered I love it. Hey, you never know until you try. I have a friend with dementia who joined a hiking club. I have many friends who discovered their inner artist and that they love painting. Starting a new hobby or sport is not only good for the spirit, it is good for our brains.

Many people find comfort in their spiritual practices — by attending worship services, by incorporating a time for meditation and prayer into their daily lives, and by reading their sacred scriptures. Some have found great solace in sharing their diagnosis with their faith community, asking for prayer and care. Some have started programs in their houses of worship and helped their congregations to become "dementia friendly."

- **Check out what's happening in your community.** Many activities and events are free or available for a modest charge. Your local library might be offering classes or programs. These are wonderful opportunities to learn more and make helpful connections.
- **Learn to ask for help.** This is a hard one for many of us, especially those of us who in the past were the ones providing the help. If you need a ride, ask a friend, ask a neighbor. Check in with your local office on aging to find out what kinds of community help are available. For example, you may be eligible for Meals on Wheels or for transportation to/from a doctor's appointment. Check in with your faith community, let them know your need, and see what help might be available.

— Blessings, Cynthia

If you find that your grief is debilitating …

… or you have thoughts of hurting yourself, please make an appointment to talk to your primary care physician and/or a grief counselor to explore other options that can help you move from sorrow to acceptance.

DAA is here to help you as you navigate this new chapter in your life — a chapter that has the possibility of adventure, of service, of joy!

1.10 Acceptance and Moving Forward



Barney Nelson, Contributor

Barney Nelson was diagnosed with Lewy body dementia in 2018. He writes:

Acceptance is where the living can really start — when you can accept the situation and realize you still have a lot of control over your life, it doesn't have to be a tragedy narrative. There's a lot of power that can come from acceptance. People compliment me on my positivity, but I think it's really acceptance. It's a very powerful thing.

You may decide you're going to pivot — maybe there's something you can't do anymore, so you pivot to and do different things. You're gaining a new life because of the choices you're making and you're facing that.

> *Viktor Frankl in his memoir,*
> Man's Search for Meaning*, wrote:*
> *Everything can be taken from a man but one thing: the last of the human freedoms — to choose one's attitude in any given set of circumstances, to choose one's own way.*

Viktor Frankl talks about the last of the human freedoms, the last thing that anybody can hold on to, is the power to choose and take one's path. It's ultimately your attitude that you take towards things, that is the thing that people cannot take away from you.

You can still live a meaningful life, discovering what you can do. There's the joy of meaning, as opposed to just being happy. Being happy makes you feel good at the time but it lasts only for a little bit. A meaningful life is connecting with something deeper and connecting to your core. Meaningful things have the bigger impact.

We don't let dementia define us. It's the same thing with grief and loss — they are going to happen. One thing I've discovered, though, is loss can be such a powerful thing. I've become more empathetic than I used to be. I had covered up my feelings of grief and loss. As I've allowed myself to really feel those things, I've felt this level of empathy that I haven't had

before. I was a business executive working for tough companies — it's been an adjustment for me to find that empathy. And I didn't find it until I looked at the loss and grief I've had. You can get to the point you celebrate the grief because you realize what it can do for your soul.

1.11 Envisioning Your Future



Rev. Dr. Cynthia Huling Hummel, Manual Guide

When my kids were little, I was asked to be a fortune teller at the East End Elementary School fair — not because I had any special powers of prognostication, but because all parents were expected to help out. On the day of the fair, I put together a makeshift costume, donned a long black wig, and headed to the school carrying a small, plastic crystal ball. Children and adults were already lining up outside my tent and, for just 25 cents, they could ask me about their futures and hear my amazing predictions. "You will meet a tall, dark stranger!"; "Your teacher will give you homework", and the always popular, "Someone really likes you." Amazing, I know!

As children, many of us not only predicted but started planning for our futures. We pictured ourselves as teachers, doctors, or plumbers and took classes to reflect those interests and help us reach our life's goals. Envisioning our future was not and is not a one-time event. Life happens. Life changes. And because of those changes, our hopes and dreams often change as well. Many of us have not only changed careers multiple times, we have moved in and out of different relationships. That's life! Many of us now find ourselves living a very different life than the one we had once dreamed about. (Trust me, I never imagined being a pastor with dementia.) ALL of us have been through good times and hard times (sometimes at the same time.) We've had to learn to adjust and adapt along the way and begin to accept our new life. Acceptance is the key that will help us move from "Why me?" to "What next?" Acceptance helps us move from bitterness to happiness.

Some of you who are reading this essay might still be reeling from the news of your dementia diagnosis and perhaps YOU are wondering what the future now holds. You may be fearful that the dreams that you had for yourself and those whom you care about were dashed to pieces on the day of your diagnosis. As a former amateur fortune teller, I have something important to share with you. Your future may not be unfolding the way you had planned but it's still unfolding. Your future may be different than what you dreamed, but different can still be good. It's like getting on a plane to visit Italy and ending up in France because of a mechanical problem with the plane. Getting angry and upset will not help

or change the situation. It is what it is. You're in France now. You can sit there and stew, or you accept this unexpected change. Instead of focusing on your disappointment, you could, IF YOU CHOOSE, begin to look for the silver lining. There will be detours in life, so try to find joy in your journey. Please don't let a dementia diagnosis put an end to your dreams.

There are so many possibilities waiting out there that are still open to you. Dare to dream BIG! Make a list of the things that you would still like to accomplish. Make a list of the places that you would like to visit. Jot down a list of the people you would like to see. Today, I would like to invite you to start envisioning a new and a bright future because we have the power to shape our futures and that visioning starts with introspection. As we dream our dreams, as we make plans, as we set goals, our future will begin to take shape. Sometimes people with a diagnosis will restrict themselves in the present (and in the future) by mentally setting up barriers and saying to themselves: "Well I can't do THAT anymore." Why do we do this to ourselves? True, we may not be able to live out the vision exactly as we planned, but that doesn't mean we can't reach for the stars. We may have to adapt. That's okay. We may need to change our direction a bit. But I can tell you that we can still find purpose and joy in life — in spite of a diagnosis of dementia. Start by shifting your perspective.

You can sit there and stew, or you can accept this unexpected change. Instead of focusing on your disappointment, you could, IF YOU CHOOSE, begin to look for the silver lining."

Instead of focusing on what you can't do, shift your focus to what you can still do. Here's an example: I can no longer serve as a Fire Chaplain and race to the scene of the fire. It is far too dangerous for me now. But I can still be part of the fire department and offer support (and goodies) to my friends who are serving. Think about adapting an activity that you enjoy. I have a friend who loves to bowl, but his symptoms made bowling difficult for him and Larry dubbed himself the "King of the Gutter Balls." Larry was embarrassed and discouraged and was ready to drop out of the league. The manager of the bowling alley learned of this and provided bumper cushions — no more Mr. Gutter Ball! Larry continues to love bowling with the boys. Our friend from DAA, Laurie Scherrer, had a dream to skydive and didn't let a dementia diagnosis slow her down. Dream big, my friends. Dream big!

Thinking about your future, you may be open to trying a new activity or sport. Join a golf league, try softball, pickleball, or soccer. Sports are a wonderful way to make connections, build friendships, and keep active. Keeping active is good for body, mind, and spirit. Take an art class. Learn to paint, crochet, or garden and share what you know with others.

As you envision your future, think about how you might use your work experiences and life experiences to help others. Could you tutor a child in math or reading? Volunteer at a food pantry? Shovel snow for a neighbor? One of my friends living with dementia volunteers at the library helping people with the computer. It's a win-win! Part of our life review is being thankful for those who provided guidance and leadership to us (and others). In this new season of our lives, how might we pay it forward?

As you envision your future, you may want to check with your financial advisor about how to secure your financial future. You may want to seek the advice of an eldercare attorney who can guide you in your planning with special attention to the laws in your state. It's important for all of us to take care of "getting our house in order" so to speak — to make sure that we have identified a family member or friend as power of attorney, someone who can and will speak for us when the time comes that we are unable to speak for ourselves. It's important for us to make our wishes known. (You will find helpful information on this topic in *Getting Your Financial and Legal Affairs in Order*, Section 4.8, page 250.)

No one knows for sure what the future will bring, but we can dream our futures and shape our futures. A dementia diagnosis is not the end of our life or our dreams. We are still the same person we were before we got the news. Dementia may signal the beginning of a new chapter in our lives — one that is full of possibilities. Don't let your diagnosis define you. There will be changes and challenges ahead, but life is always full of changes and challenges. Keep going and growing. Keep learning and exploring. Cultivate an attitude of gratitude. Be a blessing. Follow your dreams, and we here at DAA will be here cheering you on.

— Blessings, Cynthia

1.12 The Importance of Having Purpose and Goals

Having a sense of purpose is basic to our sense of well-being and confidence. Someone's purpose can be as grand as fighting world hunger or as personal as making those around you smile. Your purpose might be living the best life that you can, given a diagnosis of dementia.

Researchers have been studying how a sense of purpose affects our well-being. A 2022 online article in the journal *Social Work Today*, "Cultivating a Sense of Purpose in People with Dementia," notes, "Individuals with dementia still understand that helping out, being

busy, lending a helping hand, giving to other people, being listened to, and feeling that they belong are important indicators of quality of life."

But people living with dementia often feel — or are made to feel — that their life no longer has purpose. This can contribute to depression and anxiety. "Studies have shown that individuals diagnosed with depression and anxiety score significantly lower in purpose in life measures than those without," the article stated. And conversely, "Studies also show a correlation between greater purpose in life and lower rates of depression and sadness."

> *You need to have a reason to get out of bed and things to make you smile. The Dementia Action Alliance has become a huge part of my purpose.*
>
> **Laurie Scherrer, Manual Guide**



A 2017 review of 31 studies on purpose and aging, published in the *International Journal on Aging and Human Development*, found that although a sense of purpose does tend to decline as people grow older, "Nevertheless, the potential to experience purpose persists across the life span, by providing opportunities for older adults to continue contributing roles, participate in meaningful activities, and sustain their social value and sense of relevance."

> *My purpose now in life is to be an advocate for dementia and people living with dementia.*
>
> **Mark Timmons, Manual Guide**



To fulfill your sense of purpose, it's a good idea to set personal goals and to write them down or record them, to remind yourself. Anne Basting suggests, "Ask yourself: 'What are my goals?' It might be about being open to creative and artistic languages … capturing the world as I want to see it. Having more intergenerational relationships. Becoming an ambassador to these [dementia] coalitions. I want to teach my doctor how to accompany me on this journey. What are your goals for this?"

Your purpose and goals will likely change along with your condition and circumstances. There are inspiring stories of people living in nursing homes who refuse to become castoffs. They may pursue painting or singing. They may organize a quilt-making project or collect funds for employees' Christmas gifts. One woman who had always been an active volunteer before moving to the nursing home continued to do so over the phone, managing other volunteers at her church's food bank. Or they may simply show kindness in small ways to other residents.

Our Manual Guides readily share their purpose. Kim Reid says her purpose continues to be to ensure their children, now in their 20s, "keep going in the right direction."

With dementia, says Manual Guide Rev. Dr. Cynthia Huling Hummel, "It's all how we frame it. We can look at it as half empty or half full. Part of it is going through the grief process. It was a huge loss. But if you reframe it and look at all I've found: I've met new people. I have a new purpose that God's given me. It's been a huge blessing in a strange sort of way."

> *I'm a longtime canine search and rescue dog handler. We tend to develop close relationships with our animals, with sophisticated levels of understanding. The care of my two doggies — we're radically bonded — is my purpose. They are my reason for staying alive.*
>
> **Dave Baldridge, Manual Guide**



The Four E's of Finding Purpose

Laurie Scherrer, Manual Guide

Many people with dementia continue to derive joy from activities that were meaningful to them before their diagnosis. Redefining purpose, however, doesn't require the same activities or goals as before; instead, it's about embracing what brings joy and fulfillment in the present.

To help someone living with dementia rediscover or adapt their sense of purpose, start with the *Four E's*:



Educate: Education should start with the person living with dementia, with care partners and care community staff becoming knowledgeable about dementia and about the individual. Dementia Action Alliance's tool "What Matters to Me" (*https://daanow.org/papers-webinars/*) can be used to document and communicate the "wants, needs, desires, and hopes" of the person living with dementia.



Engage: Staying engaged with other people who are living with dementia can provide valuable strategies and solutions to individuals and their care partners. Continuing to socialize with friends, participate in spiritual fellowship, play in bowling leagues, and more can slow cognitive loss and provide needed support.



Empower: Recognize the person living with dementia for their retained abilities, not their disability, and help them find strategies that will make it possible to maintain dignity and create a feeling of living with purpose. There is much they are able to do—just differently!



Encourage: As Manual Guide Mark Timmons says, "Dementia is not the end of my book, it's the end of a chapter." For many, diagnosis is followed by a variety of emotions, including depression, denial, anger, grief, and helplessness. With encouragement—Do With Me Not For Me—a dementia diagnosis can be the beginning of a whole new journey toward new experiences, challenges, strategies, and opportunities.

1.13 Autonomy: Empowerment and Enablement



Rev. Dr. Cynthia Huling Hummel, Manual Guide

I recently received a call from a care partner, whom I will call Lois. She called because she was concerned about her husband's lethargy. She told me that Bob used to be active, but since his diagnosis of dementia, he just sat on the couch all day watching TV. I asked Lois to tell me more about Bob, about what he did before he retired and about his hobbies. Lois said that Bob was a repairman and loved to tinker in the garage, but after his diagnosis, the family felt that was dangerous and put an end to his tinkering time. I asked if Bob did any work around the house and yard, and again, Lois said, "Not anymore. He used to do the gardening, but we felt he might get hurt so we locked up the mower and the tool shed." I learned that Bob used to balance the checkbook and pay the bills, and the kids told him that someone else in the family was handling those things. Sadly, Bob had been stripped of all his responsibilities. I asked Lois if Bob was still driving — and she said, "No. We told him he couldn't drive and that we would take him if he needed to go somewhere."

Lois was coming from a place of love, and making all the decisions in order to keep Bob safe so that he wouldn't have to "worry" about anything.

I was frank with Lois that it sounded like Bob was a prisoner in his own home. I repeated the things that she had shared with me that: she chose Bob's clothes and decided what he would eat and drink and when he would do those things. She never asked Bob what HE wanted to do. She made all the decisions for him. When they went to the doctor's, Lois would answer on Bob's behalf and before he could even express himself. Lois thought she was doing the right thing, but my hunch was that she had made matters worse by her controlling behavior and that Bob was angry and depressed and was shutting down.

I suggested an experiment: that Lois would ask Bob questions about what HE wanted and wait for his answers — and that she would loosen the reins and let Bob make decisions about his day-to-day choices. Lois loved her husband and wasn't trying to be mean to him, but she admitted being more than a bit overprotective. Lois was coming from a place of love, and making all the decisions in order to keep Bob safe so that he wouldn't have to "worry" about anything. Bob, I'm guessing, was feeling bored and useless. He had nothing to do but sit

and watch TV. He had lost his autonomy, and autonomy is the ability to make decisions for ourselves. Who wouldn't be lethargic or depressed?

Weighing the dignity of risk over and against the duty of care means honoring the right of a person to make choices even if those choices may cause harm, such as getting cut with a tool.

Lois was more than willing to try my experiment and called me back two weeks later with some wonderful news. She began to ask Bob about his preferences and honored those choices. She urged Bob to weigh in on the matters that mattered to him. Bob was happier and more engaged. He got off the couch and headed back out to the garage to tinker. Lois shared that she learned a lot about herself and her relationship by honoring Bob's autonomy and his right to make decisions. She acknowledged that she was sometimes nervous about Bob being in the garage tinkering and possibly hurting himself, but also understood the joy that tinkering gave him. Lois was trying hard to weigh and to balance the risks versus benefits.

Counselors will sometimes use the expression: **weighing the dignity of risk over and against the duty of care**. What does that mean? Giving people the freedom and honoring their right to make choices even if those choices may harm them in some way: that the chance of being hurt is the price, if you will, for being able to engage in a desired activity. For example, Bob might cut himself on a tool — but that was a risk he was willing to take. People living with dementia have the right to make choices and sometimes care partners may not agree with the choices being made. Sometimes it's helpful to have a third person weigh in — a doctor, a social worker, or a counselor to help to find a resolution or common ground.

Where this difference of opinion becomes problematic and/or more nuanced is when a person's choices may put another person in danger. An example would be if someone living with a dementia diagnosis had multiple fender benders, and was a clear and present danger on the road. If this situation should arise, it is imperative that a care partner, family member, or friend intervene before a tragedy happens. Please don't ignore a situation like this or put it off. It would be terrible, for example, if Bob were to take the car on the road and hit someone or something. That's why weighing the dignity of risk over and against the duty of care is so important.

Those of us living with dementia should have the right to autonomy, that is the right to make choices about our lives, but at the same time, we may not always be the best judge of our abilities. We need trusted family and friends to help us to weigh the dignity of risk versus the duty of care so that as our dementia progresses and things get harder for us, our trusted friends and family will intervene. I have a "circle of care" — that is, a few dear friends who have agreed to "hold up the mirror" to help me to recognize that my abilities have changed. They will let me know when I may be lacking in capacity to make wise decisions and to flag some activities, such as driving, if it is no longer safe for me or for those on the road.

I trust that I will be able to accept their guidance with grace. I trust that together with my team, I'll be able to live my life as fully as I can for as long as I can. — Blessings, Cynthia

1.14 Growth: Continuing to Learn New Things and Having a Sense of Accomplishment



Rev. Dr. Cynthia Huling Hummel, Manual Guide

My beautiful daughter Emily is a good seven inches taller than I am — even taller than that if she's wearing high heels. Em jokingly calls me "My Mini-Mommy." Needless to say, Emily takes after her father. She and I were together one day, and a friend looked at us and asked me, "So when did you stop growing?" My reply? "I haven't!" We all laughed. Oh, I knew what my friend meant. She was talking about my physical height, and I did tell her that I stopped growing taller in about 5th grade — but the reality is that I am still growing. Growth is more than just physical — it's about learning new things about ourselves and our world. And that growth can be attained actively (like taking a class) or passively, through interacting with others on a day-to-day basis. What about you? Are you still growing?

I often describe myself as a lifelong learner. After I was diagnosed with amnestic mild cognitive impairment due to Alzheimer's disease, I moved to Elmira, New York, and I was thrilled to discover that Elmira College was just five blocks from my house. I thought, "Oh boy! Maybe I could be a student there, and I could even walk to classes!" I filled out an admissions application and sent a copy of my transcripts. I called and made an appointment to see the Graduate Dean of Students to inquire about the possibility of my auditing classes. On the day before my interview, I went to the campus bookstore and bought an Elmira College t-shirt and matching purple and gold socks. I wanted to make a good impression and show my school spirit. During the interview, I shared my diagnosis and my hopes of being able to attend EC. As the meeting came to an end, the dean stood up, hugged me and welcomed me as the newest student.

Being a student meant more than just taking classes. Being a student meant that I could attend cultural programs, sporting events, and lectures and even eat in the cafeteria. Woo-hoo! It was so much fun to be around young people and learn from them. To date, I have taken 40 classes — from Art History to Ice Skating to The History of Pandemics. I try and complete as many of the assignments as I can, just to challenge myself, but I don't have to worry about tests or grades. I'm not there for a degree. I am there to grow.

There are so many ways for us to grow. We can take classes — and we can also teach classes! I'm not talking about teaching on a college campus (though you could), but teaching a grandchild how to change the oil in a car or teaching a friend how to crochet. There are many things that we know how to do. We can grow and help others to grow too, when we share what we know. Don't let that knowledge you've stored up go to waste.

When we challenge our brains, we grow, I like to do puzzles and love the satisfaction I feel when I put in the last of a 300-piece jigsaw puzzle that I've been working on. I also like crossword puzzles and word finds. What about you? Are you a person who likes to do Sudoku? These are all wonderful ways to exercise our brains and to grow.

Exercise is so important for brain health. Walking is a great exercise. Meet up with a friend and walk in your local park — or take up golfing and walk the course instead of taking a cart. I like to swim and make it a point to get to the school pool several times a week. Many exercise programs are available at no cost or online. Check with your community center or your local office on aging to see what's available in your area. Pickleball is the big rage where I am! Who knows, maybe I will try that next.

There are many things that we know how to do. We can grow and help others to grow too, when we share what we know. Don't let that knowledge you've stored up go to waste.

I'm not able to read books anymore, but that doesn't stop me from learning new things. I love listening to podcasts. I especially enjoy listening to *Dateline* murder mysteries. I spend time every day reading my newspapers (online) and following the news. I try to keep up with what's happening in our world. I want to know and I want to grow.

The arts help us to grow. I love all kinds of music (well, except rap). I enjoy singing along to Broadway tunes, singing in a choir, playing folk songs on my guitar, and singing rock and roll and country tunes with our band. I am always amazed when I remember the words to

a song that I learned in high school. Sing in the shower! Enjoy a night of karaoke. Sing along with the radio. Music is good medicine for the brain and the soul.

In the past few years, I've discovered photography and love to take photos with my phone, especially pictures of nature. Not long ago, I saw an ad for painting classes at our community center and discovered that painting helps me relax and my creative juices to flow. Recently, I took up painting using coffee as paint and have taught that to others via Zoom. Who knew?

Some believe that their education ends when they graduate from high school or college. I would disagree. There are always to things to learn, new hobbies to explore, new insights to learn. Being a lifelong learner is a gift you can give yourself. So get going and get growing!

1.15 Tell People or Not

When you have received a diagnosis of dementia, you will need to think about how and if to share this with your friends, family, and co-workers. Some people are naturally open and comfortable sharing information freely, while others are more guarded and would not share medical information with others, no matter what the diagnosis. The stigma associated with dementia adds an extra layer of complexity when considering whether or not to tell people. Reactions from those who know you will vary and can often be unpredictable. Consider the strength of your relationships before sharing the news.

If you are still working, be especially careful about revealing your diagnosis. In her book, *The Spectrum of Hope — An Optimistic and New Approach to Alzheimer's Disease and Other Dementias*, Gayatri Devi, MD, notes that employers and co-workers can begin to view you through "Alzheimer's-colored glasses," meaning they will overnight assume you can't function, even if they had no previous problem with your job performance. "It is important to understand that a dementia diagnosis does not automatically disqualify a person from working. Depending on what type of dementia a person has and what skills are affected, he or she may continue working for many years."

Richard Taylor, one of the first vocal advocates living with dementia in the United States and author of *Alzheimer's From the Inside Out*, concealed his dementia diagnosis from his employer and taught college-level psychology for three years thanks to considerable help from his teaching assistant. Others, including some of the Guides in this , had careers involving complex financial details and their symptoms soon affected their job performance. (For more on *work and dementia*, see *Cognitive Changes and Your Job*, Section 4.1, page 226.)

"If you're younger than 65 and very dependent on that job, it can be dangerous to reveal [a diagnosis of dementia]," says Tia Powell, director of the Montefiore Einstein Center for

Bioethics and author of *Dementia Reimagined*. "The more people who are able to do it, the more safe it will be for everybody to do it. We owe a huge debt to the advocates who say 'this is the face of dementia'."

Telling people, Dr. Powell adds, "takes bravery. You have to appreciate that you may be disappointed in some people. You may also find that someone says, 'hey me too.'"

Pia Kontos encourages people living with dementia to be open about their diagnosis. "How can you thrive in relationship if you're hiding?" she says. "Of course disclosing this with the current culture that really is not supportive, we can see why there's fear, but we need to challenge that."

> *I had friends who disappeared, and my professional friends disappeared. That's okay. It was painful at times, and it's painful when you're newly diagnosed and people distance themselves. Sometimes they're afraid to face it, or what it means. They have this horrific view in their minds of what it could represent. I encourage people to talk with family and have an open discussion. Some of those fears are misfounded. You find new friends, if you're willing to. I really feel sad for the person who locks themselves in their home and stops living. You prevent yourself from experiencing all kinds of things.*
>
> **John-Richard Pagan, Manual Guide**



Explaining to your friends what you hope for may be helpful, suggests Anne Basting. "We have to say to our friends, 'this is going to be hard on all of us. I don't care if we don't talk. Let's go for a walk.' We have to be able to learn. That said, it's not just loss. There are all kinds of strengths that can be built upon." Even if the disease progresses and words are hard to find, there are ways your friends can share with you, through art, singing, movement, and music, she adds.

"We toyed with it, then we decided to tell our friends," says Laurie Scherrer. "You definitely lose some friends — like you're contagious and they don't know how to deal with you. But that happened to my mom with her cancer. People don't know what to say. We lost some of our friends, but are still glad we did tell our friends."

She recalls being at a party with their scuba friends (Laurie and her husband continue to love scuba diving). "I asked a friend, 'how's your dad?' Well, he had died a year ago, and I was at the funeral. When you don't tell people, they'll think you're not paying attention to them or not listening. They are going to think that what they said didn't matter to you."

The best advice is to follow your heart AND confide in someone close to you before sharing any information further. This gives you a chance to say how you're feeling as you become more comfortable with the diagnosis. After a few conversations with those closest to you, you can decide what you want to say to others.

> *There's a need for some of us to be more public about the diagnosis to reassure people that there is a life after a diagnosis.*
>
> **Jim Mann, Manual Guide**



SUGGESTED RESOURCES

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Dementia Alliance International is an independent self-advocacy organization of people with dementia.	*www.dementiaallianceinternational.org/*
Dementia Friendly Airports is an international collaboration of professionals, academics, and volunteers in aging and dementia services and support systems.	*www.dementiafriendlyairports.com/*
Dementia Map is a free guide to the resources needed by those diagnosed with a form of dementia, family members, and professionals providing care or services.	*www.dementiamap.com/*
The Lewy Body Dementia Association is a nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and care partners and promoting scientific advances.	*www.lbda.org/*
TimeSlips is a non-profit alliance of artists and caregivers bringing meaning and joy to late life through creative engagement.	*www.timeslips.org/*

SUPPORT
Demetia Action Alliance
www.daanow.org/donate

SECTION 2: Well-Being — Your North Star

I once read, "If they don't give you a seat at the table, bring a folding chair."

Jim Mann, Manual Guide



Well-being along the unexpected dementia journey is possible, and you are empowered to seek and find the interests, passions, and relationships that give your life quality, meaning, and purpose. People living with dementia, care partners, and dementia advocates share their knowledge and wide range of experiences here to help guide your next steps.

Explore Section 2 and consider:

- The Seven Pillars of Well-Being
- Spirituality and Dementia
- Community Diversity and Supports
- Dementia Advocacy
- Living Alone With Dementia

2.1 Supporting Your Well-Being

For thousands of years the North Star has been a guidepost for navigators and travelers enabling them to cross wide expanses, often into unknown territories. The North Star serves as a steady beacon and has taken on a symbolic meaning of hope, inspiration, and guidance. The North Star is a good symbol for living with dementia — an unknown territory that each individual experiences in a unique way.

The concept of "pillars of health" has emerged over the past decade or so to identify key practices that are necessary to support overall health and well-being. There are many variations of the pillars but the general pillars are: healthy food, movement, sleep, and connection. Additional foundation pillars have been identified for living well with dementia. We call these "pillars of well-being," and they are essential whether you are living with dementia or are a care partner:

- **Stay connected**
- **Find fun and interesting things to do and stay engaged**
- **Limit stress and stressful experiences**
- **Eat and drink healthily**
- **Get restorative sleep**
- **Be physically active**
- **Keep your spirits up**

Each of these essential pillars are detailed in the following pages.



The Guys

Angela Lunde, M.A., Contributor

Sharing a story that captures the essence of nurturing a sense of well-being

I know a group of friends who call themselves "the guys." Each month they meet at the same restaurant and have lunch together. They all have dementia.

One afternoon as we were talking, I asked them, "How would you rate your quality of life right now, on a scale of 1 to 10 — one being extremely poor, and 10 being exceptional?" None of them would give me a single number, instead they responded with a range, like 3 to 7, or 4 to 9. So, I asked, what makes a day a 3 and what makes a day an 8?

The responses I got from all of them were similar. "A low day, such as a 3, is when I feel like I'm a burden to my wife or family. An 8 day is when I feel I am contributing to something or someone in a meaningful way." They did not say, an 8 day is when I can remember everyone's name or remember what I had for breakfast or to take the garbage out.

For these guys, what diminished the quality of their lives most was not about forgetting things. Rather, it was about the absence, or presence, of purpose and sense of self-worth.

While we cannot restore good memory in a person living with dementia, we can play a large role in improving the quality of their life by supporting their need to feel connected, valued, and to contribute to their family and the community in meaningful ways.

2.2A Pillars of Well Being: *Stay Connected*

As Angela Lunde's story of "The Guys" illustrates, having relationships is fundamental to our well-being. Your network need not be vast, but it needs to be meaningful. It can include family members, friends — both old and new — people in your congregation, or neighbors.

Many studies find a correlation between social connection and our health and well-being. To be health-promoting, our relationships should provide us with a sense of belonging and make us feel competent and valued. Having a strong network of people who care about us is entwined with a sense of purpose, as we look out for others, and they look out for us. Good relationships appear to act as a buffer, protecting our bodies from ills such as inflammation and high blood pressure.

In contrast, loneliness and isolation lead not only to depression and feelings of sadness. Loneliness can also harm our physical health. Studies have found that loneliness can contribute to high blood pressure, heart disease, obesity, a weakened immune system, cognitive decline, and even death, according to the National Institute on Aging.

As we grow older it can become harder to maintain our social ties. Aging can bring with it physical problems that make it difficult to get out and about or to connect with others. Loss of mobility and poor vision or hearing can be obstacles. So too can lack of reliable, affordable public transportation, if driving is no longer an option. Long-time neighborhoods can change, with new people moving in who may have little interest in connecting with older residents.

Living with dementia can add another layer of difficulty. Some people living with dementia report that they have lost friends who felt uncomfortable once they learned of their diagnosis.

In addition, some people living with dementia say that it can be hard to go to public places they once enjoyed, like a crowded restaurant or shopping mall. Noise, commotion, many voices talking at once, can be stressful and difficult to manage.

Develop and Maintain a Caring Support Network

Being intentional about maintaining or building social connection is important. Even if you are a person hard-wired to "do things myself," now is the time to gracefully accept that you need support to maintain your independence for as long as possible. If you find it hard to ask for help, the good news is that asking for support gets easier each time. Surround yourself as much as possible with people who are positive and supportive. Be with people who make you feel good about yourself and see the upside and humor in life.

You'll find that most people want to help and be supportive, but some may not know how. You may not know how they can support you either, in which case say so and ask them to work with you to figure it out.

Opening yourself up to others can be a bonding experience for you both. Let your friends know how much you appreciate and value their support. If someone becomes overly protective, taking over doing something for you, gently tell them you would rather do it yourself but with a little support from them.

"We have to say to our friends, 'This is going to be hard on all of us. I don't care if we don't talk. Let's go for a walk.' We have to be able to learn," says Anne Basting.

Opening yourself up to others can be a bonding experience for you both. Let your friends know how much you appreciate and value their support. If someone becomes overly protective, taking over doing something for you, gently tell them you would rather do it yourself but with a little support from them.

Thankfully there are a growing number of opportunities to be connected to others. Support groups initiated by the Dementia Action Alliance, local Alzheimer's Association chapters, and others give people living with dementia a chance to share their feelings and strategies for living well. Memory Cafés, dementia-friendly neighborhoods and towns, arts courses, and senior center programs are among the options that are spreading. (For *more ideas*, see *Community Supports*, Section 2.4, page 145.)

The people I have met living with dementia are amazing. We were at a big Alzheimer's forum in D.C. In the evening about 12 of us — six living with dementia and our care partners — were in the bar, laughing and joking and telling stories. People around us were amazed. They were buying us drinks, and saying, "Can we sit with you guys?" "How can you talk about [dementia] and laugh?" And we say, well, because we don't want to cry! It opens your eyes, the joy you can get in being around people who understand what you are going through.

Chuck McClatchey, Manual Guide



2.2B Pillars of Well Being: *Find Fun and Interesting Things To Do and Stay Engaged*

There are endless ways to find fun and interesting things to do. Being socially engaged is one avenue. You don't have to join a party circuit!

Being social can involve activities large and small, such as having coffee together, going to the movies or out for a meal, taking your dog for walks and seeing people along the way, shopping, and going on a trip. Some of these you may find stressful. Others will sound fun. Each person is different.

You might try taking up a new hobby such as making pottery. For others, a new hobby may be a frustrating experience instead of something enjoyable. Others like to return to former hobbies that they didn't have time for while they were working.

Humans are hardwired for social engagement but the amount and type of engagement is individualized. Some people enjoy a lot of socializing while others just a little, one-on-one. What is important is not to become isolated. Social connections with people we are close to can be mood boosting, fulfilling, and enjoyable. These are valuable to the balance of your overall well-being. It is important to invest the time to stay socially engaged and connected. Being socially active online with chat groups and helping others can be enjoyable and helpful if you live in a rural area or have limited access to transportation.

Throughout life your brain needs to be engaged in regular cognitive activity. While growth of neurons and synaptic connections weaken with age and dementia, it does not stop altogether. Your brain needs stimulation to continue triggering the generation of neurons and synaptic connections to form new neural pathways. Research shows there are important things to do that can make your brain less vulnerable to the effects of disease and aging. There are lots of fun and interesting ways to stimulate and give your brain a workout.



TIP **WALK AROUND YOUR NEIGHBORHOOD** regularly to keep you in touch with neighbors and activities going on around you.

TIP **GO OUT AND EXPLORE NEW THINGS**. Try a restaurant you've never been to before. Go for a walk with friends. One person, who lives near a city zoo, walks once a week with friends through the zoo. It's great exercise, and they always see interesting things.

TIP **LOOK FOR A MEMORY CAFÉ** near you. State listing: *www.memorycafedirectory.com/*

TIP **ENROLL IN A CREATIVE ARTS COURSE** for writing or poetry. You may find you have an inner artist.

TIP **TAKE UP A HOBBY** such as photography. If you can't manage some parts, it's a fun opportunity to do something with a spouse, friend, neighbor, former colleague, or grandchild.

TIP **CONSIDER BEING A DEMENTIA MENTOR** and helping others. See *www.dementiaallianceinternational.org/*.

TIP **JOIN A DEMENTIA ACTION ALLIANCE ENGAGEMENT GROUP.** Or two or three! This is a great way to connect with others and enjoy interesting discussions and activities. *www.daanow.org*

2.2C Pillars of Well Being: *Limit Stress and Stressful Experiences*

Stressful situations cause your central nervous system to respond by releasing stress hormones, such as adrenaline and cortisol, which prepare your body for action. Your heart beats faster, your muscles tighten, your blood pressure increases, your reaction time speeds up, and your senses become sharper and more focused.

Experiencing occasional stress is okay. Regularly experiencing stress, however, isn't okay for your body as it can disrupt your immune system, increase the risk of heart attack and stroke, and negatively impact your emotional, social, and spiritual well-being.

Living with dementia symptoms can produce stress, so it's very important for you to establish ways to deal with stress in a healthy way. Sometimes stress cannot be avoided, such as holiday events that can feel overwhelming. When there are stressful situations that cannot be avoided, find ways to limit your exposure to the stress. For example, during an event that includes a group of people, make sure there is a quiet place to get away if you start to feel overstimulated. Bring earbuds or headphones. You can listen to music or something else soothing. Both earbuds and headphones have noise cancellation options (depending on the model you buy) if you just need quiet.

Overstimulation can also affect other senses such as sight. Some individuals feel overwhelmed by too much color or pattern, or too many items such as in a store or on a restaurant menu.

When stress can't be avoided, have healthy ways to release the stress, such as take a walk, watch or listen to something funny, or ask your spouse or a friend for a back and shoulder massage. One person chops up a mass of vegetables to deal with stress and another likes to pull weeds from the garden. There are many ways to release stress; the key is finding what works for you.

Ways to Ease Stress

The Cleveland Clinic Foundation offers "20 Ways to Ease Stress." *health.clevelandclinic.org/how-to-relieve-stress/*

In addition to our other Pillars of Well-Being (such as eating well, getting a good night's sleep, exercising), the Cleveland Clinic Foundation suggests:

- **Practice relaxation techniques** such as deep breathing, progressive muscle relaxation, and meditation.
- **Assert yourself.** It's okay to say no if you don't have the time and energy to do something. You don't have to meet the expectations of others.
- **Set realistic goals and expectations.** No one is successful at what they set out to do 100 percent of the time. Remind yourself of what you can and cannot control.
- **Sell yourself to yourself.** When you're feeling overwhelmed, remind yourself of what you do well. Have a healthy sense of self-esteem.

Remember, life for all of us includes stressful times. Although we can't eliminate the negative stress, we can do our best to reduce and manage it.



TIP

AVOID PEOPLE WHO ARE UNPLEASANT

and negatively oriented. If you cannot avoid them altogether, you can limit the amount of time you spend with them. Set a time limit; knowing ahead of time, for instance, that you will only spend 20 minutes together can help you feel empowered and lessen stress.

TIP

DECIDE IF YOU NEED TO KEEP DOING IT

if you find something has become frustrating and stressful to do, such as paying bills and managing your finances. Perhaps your spouse or a trusted family member or friend would be willing to take this on for you. In return, you could reciprocate and do something special for them that doesn't cause you stress.

TIP

TALK ABOUT HOW YOU ARE FEELING

with people to whom you are close. Verbalizing what causes you distress can be a benefit.

2.2D Pillars of Well-Being: *Eat and Drink Healthily*

Eating is about nourishment, connection, and enjoyment. Eating the right foods can keep our brains healthy. For example, things like fish, spinach, blueberries, and nuts are especially good for brain health. Scientists are studying the relationship between nutrition and our brains. There is still much to learn, but generally diets that are good for the heart are also good for the brain. These include the American Heart Association diet, the Mediterranean diet, and the MIND diet, among others.

Drinking plenty of water also promotes health, especially when taking multiple medications. Dehydration is common in older people, in part because the thirst sensation may decline.

There are also changes in the water-sodium balance that are common as we age that can contribute to dehydration. Here are some key points to keep in mind:

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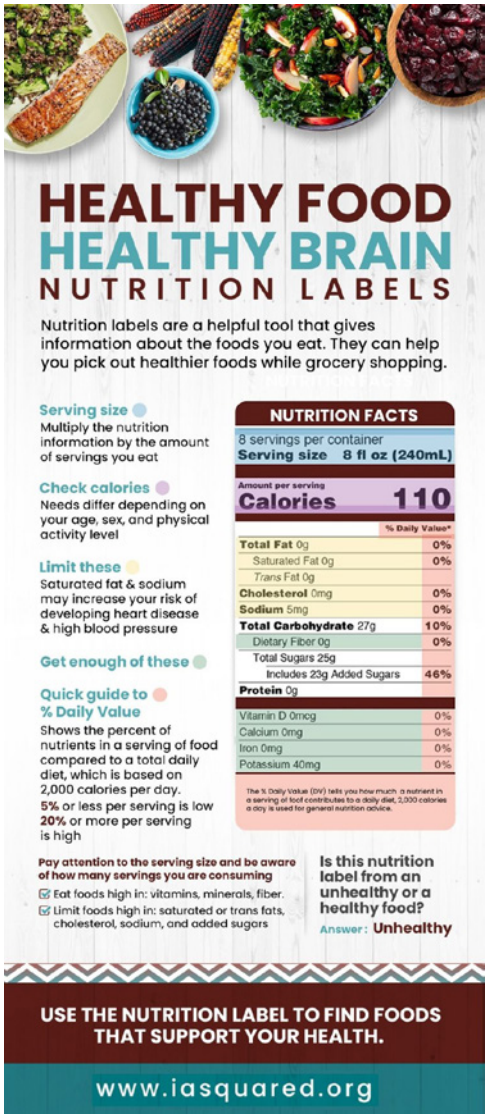
Mind Your Sugar

Sugar can have good, and not-so-good, effects. Our brains use a lot of energy, and they need glucose (a simple sugar that is the source of this energy) to function. But excessive sugar is too much of a good thing and affects the hippocampus, a key part of the brain for memory.

"Research shows that rats eating high-sugar diets were less able to remember whether they had previously seen objects in specific locations before. The sugar-induced changes in the hippocampus were both a reduction of newborn neurons, which are vital for encoding memories, and an increase in chemicals linked to inflammation," according to "A Neuroscientist Explains What Sugar Really Does to Our Brains," a 2019 article by Amy Reichelt in *Science Alert*.

One study by researchers at Washington University in St. Louis looked at the effect of sugar on mice that had been genetically modified to have Alzheimer's-like plaques in their brains. When the researchers infused the mice with sugar water, the plaques produced faster.

"A doubling of blood glucose led to 20 percent higher levels of beta-amyloid compared with mice that had normal blood



glucose levels," according to "Could High Blood Sugar Be a Cause of Alzheimer's Disease?", a 2015 article in Medical News Today. When the team repeated the experiment in older mice that already had amyloid plaques in their brains, beta-amyloid levels rose by 40 percent. (Note: Not all findings in rats and mice translate to humans, but they can be informative.)

Excess sugar also contributes to Type 2 diabetes, which in turn increases your risk of developing dementia. "We don't really know the safe amount of sugar for the brain," says nutritionist Nancy Emerson Lombardo. She advises limiting sugar to six teaspoons a day. This translates into 24 grams of sugar, which is how food labels list it (four grams equal one teaspoon of sugar). One 12-ounce can of Coke, for example, contains 39 grams of sugar.

"The modest amounts of sugar in whole foods such as fruit and root vegetables are not a problem," she adds.

Bye-Bye Burgers?

Nutritionists generally say to significantly reduce red meat for brain health. The rationale is that meat is not good for the heart, and therefore is probably not good for the brain. Studies are inconclusive. A 2020 review of the scientific literature on meat consumption and cognitive function, published in the journal *Nutrients*, found inconsistent results and urged more research be done.

Some dementia specialists encourage a vegan diet, based completely on plants. "The best studies show that if you eat well, plant-centered, your risk [of Alzheimer's] goes down as much as 53 percent," according to Dean Sherzai, a neurologist at Loma Linda University, speaking of brain health in the video "Alzheimer's — What You Can Do."

Vegan diets can be quite healthy (not to mention good for the planet by reducing methane from livestock production). Lombardo cautions though that vegans need to be sure they are getting adequate amounts of Omega-3s; algal oils made from algae contain Omega-3 fatty acids. Vegans also need to be sure they are getting B-complex vitamins, she adds, found in meat, fish, eggs, and dairy.

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Until more is understood about the effects of diet on our brain, it's a good idea to limit the amount of beef and pork we eat. Some suggest one serving a week, with a serving about the size of a deck of cards. Instead of red meat, get healthy fats from fish, nuts, avocados, and olive oil, among other sources.

What About Alcohol?

Not surprisingly, experts agree that too much alcohol is not good for brain health. According to the National Institute on Alcohol Abuse and Alcoholism, "Alcohol interferes with the brain's communication pathways, and can affect the way the brain looks and works. Alcohol makes it harder for the brain areas controlling balance, memory, speech, and judgment to do their jobs, resulting in a higher likelihood of injuries and other negative outcomes. Long-term, heavy drinking causes alterations in the neurons, such as reductions in their size."

Some neurologists urge their patients to refrain from alcohol altogether. Others range in their advice, from an occasional glass of wine to one or two servings a day.

According to the Alzheimer's Society in the United Kingdom, "Excessive alcohol consumption over a lengthy time period can lead to brain damage and may increase your risk of developing dementia." However, drinking alcohol in moderation has not been conclusively linked to an increased dementia risk, nor has it been shown to offer significant protection against developing dementia.

"As such, people who do not currently drink alcohol should not be encouraged to start as a way to reduce dementia risk. Conversely, those who drink alcohol within the recommended guidelines are not advised to stop on the grounds of reducing the risk of dementia, although cutting back on alcohol consumption may bring other health benefits."

Remember to ask your doctor if alcohol should not be consumed with any of the medications you are on.

Remember to ask your doctor if alcohol should not be consumed with any of the medications you are on.

Spice It Up

Lombardo urges people to generously use herbs and spices that can add exciting flavors to every meal. Some small clinical trials looking at spices and the effects on dementia suggest some short-term benefits. Among the most promising spices: saffron, turmeric, lemon balm, cinnamon, and aloe vera. For example, a randomized double-blind clinical trial (considered the gold standard of testing) in Iran of 54 people over 22 weeks compared the effects of saffron versus donepezil (Aricept) for people with mild to moderate Alzheimer's disease. The results were similar, based on two cognitive assessment scales, according to a 2010 article in Psychopharmacology.

More research is needed. Unfortunately, Lombardo notes, funding is limited for non-pharmaceutical approaches to treating dementia.

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2.2E Pillars of Well Being: *Get Restorative Sleep*

A growing body of research finds that a good night's sleep is important for our brain health. But an enormous number of people are plagued with insomnia. An estimated one-third to one-half of adults in the United States have sleep problems, and the condition increases with age. A 2021 article in *NIH Research Matters* reports that people in their 50s and 60s who slept six hours or less per night were more at risk of developing dementia later in life.

For people living with dementia, sleep disturbances are especially common. Some causes of sleep problems are not directly related to the dementia disease process and may be treated or self-managed. These include conditions, such as:

- Depression
- Anxiety
- Stress
- Chronic pain
- Prostate or bladder problems (needing to use the bathroom in the middle of the night)
- Menopause (hot flashes)
- Restless leg syndrome
- Sleep apnea

Sleep apnea, a condition where you momentarily stop breathing many times throughout the night, deprives the brain of oxygen. Being overweight can contribute to sleep apnea. Sleep apnea can contribute to high blood pressure, memory loss, and depression, according to Gayatri Devi, MD, in *The Spectrum of Hope*.

Poor sleep-related habits

- Too much screen time before bed (video games, social media, TV in bed)
- Eating too much before bedtime
- Drinking caffeine or alcohol in the evening
- Irregular bedtimes
- Too sedentary in the day
- Exercising vigorously less than four hours before bedtime

Medication side effects

According to the Mayo Clinic, "Many prescription drugs can interfere with sleep, such as certain antidepressants and medications for asthma or blood pressure. Many over-the-counter medications — such as some pain medications, allergy and cold medications, and weight-loss products — contain caffeine and other stimulants that can disrupt sleep."

Reading the fine print of medication inserts can be daunting. But it's worth checking to see if something you are taking has a side effect of insomnia. Your local pharmacist can be a helpful resource to educate you on the potential side effects of medications, including insomnia.

Dementia-related sleep problems

Three-quarters of those who have Lewy body dementia, for example, have a REM (rapid eye movement) sleep disorder. They may act out their dreams, and call out or violently thrash around, and may harm themselves or their bed mate.

"Thanks to good ol' Lewy, my dad is prone to night terrors and sleep disruptions," says Jennifer Carson. "Good sleep is so important. If my dad doesn't get good sleep, his cognitive function takes a serious nosedive."

People with Alzheimer's disease also have changing sleep patterns, often becoming more tired in the day and restless at night. This can be challenging for them and for those they live with.

Ways to Sleep Better

There are several strategies for promoting sleep, depending on which of the above causes is at the root of the problem.

Depression, anxiety, and chronic pain should always be treated, for a host of reasons, including sleep. There are pharmacological, psychological, and behavior modification strategies to treat these.

Restless leg syndrome may be alleviated by good sleep hygiene (see below) and by soaking in a warm bath and doing gentle massages. Use of heat or cold packs or alternating these may help. Or try a vibrating pad or specially designed foot wraps.

Sleep apnea is most commonly treated with a Continuous Positive Air Pressure (CPAP) machine that sits by your bed. A plastic hose connects the machine to a mask that you wear throughout the night to push pressurized air into your airway as you sleep. There is also a dental device that can be worn to keep your airway open while you sleep. Weight loss and sleeping on your side may also help.

Maintaining good sleep hygiene can help a range of issues. Sleep experts offer these suggestions:

- **Your bedroom:** Keep the temperature at 66 to 70 degrees. Reduce light as much as possible, although you may need a small nightlight to safely get to the bathroom. Keep the room as quiet as you can, given where you live. A white-noise machine may help block out external noise. Invest in a good mattress and pillow. Keep your clock faced away from the bed, and do not check the time during the night.

- **Your bedtime routine:** Go to bed at the same time each evening and develop a regular bedtime routine. Aim for 7 to 8 hours of sleep at night. Avoid screen activities, such as watching TV, looking at your smartphone, reading on a smart device, and, instead, listen to relaxing music, take a warm bath, or do gentle yoga.

  Get up at the same time each morning, even if you have to set the alarm, to get your body used to a regular sleep schedule.

Be sure to let your doctor know if you are having trouble sleeping. Ask if any of your medications may be contributing to your sleep disturbances.

- **Food and drink:** Avoid large meals close to bedtime. Reduce alcohol, caffeine, and tobacco close to bedtime. Caffeine is found not only in coffee and black tea, but also chocolate and some soft drinks. Reduce all liquids in the evening.
- **Reduce stress:** Avoid heated conversation or work before bedtime. If you are feeling stress, write down what's triggering it in a journal, so these thoughts don't keep you up.
- **Daytime:** Don't nap more than 30 minutes a day. Exercise regularly and try to get outdoors. Get exposed to bright light in the mornings.

  Even the best sleep habits won't solve all problems. Sometimes your doctor will determine you need medication.

"After many sleepless issues, we finally did request a prescription for trazodone," says Jennifer Carson of her father who has Lewy body dementia. "Trazodone is the better sleep aid option for older adults, according to the American Society on Aging BEERS Criteria." (For more information, see *Medications and Medications to Avoid*, Section 5.4, page 287.)

The Alzheimer's Association advises —

Any time you are prescribed a new medication, make sure to ask your healthcare team:

- What are the benefits of this medication?
- What are the risks of this medication?
- What other treatment options are available?

Ongoing Research on Sleep and Dementia

Recent research finds a relationship between sleep (too much or too little) and the buildup of beta-amyloid plaques in the brain. In rodent studies, scientists found that during sleep, the glymphatic system clears away "junk" in the brain. This cleansing appears to reduce beta-amyloid, helping to keep brains healthy. In a study of a subset of the Baltimore Longitudinal Study of Aging, 70 participants were asked about their sleep patterns. The researchers then did brain imaging. They found that those participants with greater amyloid build-up also slept fewer hours and had less restful sleep. It is not clear, though, if poor sleep causes the amyloid to increase, or if the amyloid is contributing to poor sleep.

According to an Alzheimer's Association "In Brief" article for health professionals, "Further studies in other cohorts are needed before we can say poor sleep promotes AD [Alzheimer's disease] pathology. If similar results are found, sleep length and quality could be early, modifiable risk factors, and interventions to improve sleep or maintain healthy sleep may help prevent or slow AD."

> *At nighttime I've had a delusion, a bad episode where I thought people were trying to break into the house. Again, part of me also knew that something about this was wrong and wasn't really happening. I have my cell phone close at hand. I have night terrors, I have active dreams, REM sleep disorder. A lot of swinging and kicking, I've thrown myself out of bed, so I have rails on both sides.*
>
> **John-Richard Pagan, Manual Guide**



2.2F Pillars of Well Being: *Be Physically Active*

A mountain of evidence shows the importance of exercise and movement. "Exercise is the silver bullet," says nurse practitioner Anne Ellett, CEO of Memory Care Support. "Don't give up being active. Whether or not you're living with cognitive impairment or dementia, the best predictor of quality of life while we age is are you able to walk from here to there and stand up, remaining mobile, and having strength."

Being sedentary is one of the worst things we can do for our bodies, our minds, and our moods. "People who sit down all day and then stand up feel dizzy," explains Ellett. "We need that homeostasis in our inner ear to help us maintain our balance. We lose that ability if we're sedentary. It's a cascade of bad things that can happen."

One recent study on exercise and our cognitive health compared mice who were sedentary and those who had a running wheel. "Older mice that were active showed increased generation of new brain cells called neurons and higher levels of nerve cell growth factors than sedentary mice," according to the National Institute on Aging (NIA) in a 2020 article. "Exercise-induced protein may reverse age-related cognitive decline." The older active mice also made fewer errors in learning and memory tasks.

Before launching a new exercise program, talk to an expert. Ask your doctor to refer you to a physical therapist to design a program for you. Go to a gym and talk to a trained staff member. If you can afford it, hire a trainer to tailor a fitness program just for you and to encourage your progress.

Exercise is so critical and I'm not as good at doing it. I have an exercise bike. When I exercise rigorously, it certainly improves my mental abilities, capacities, and outlook.

Dave Baldridge, Manual Guide



Why Exercise?

Exercising and staying active have all sorts of benefits. Among them:

- Improving balance and reducing falls
- Managing or preventing some diseases like arthritis, heart disease, osteoporosis, diabetes, and many types of cancer
- Controlling blood pressure (high blood pressure increases your risk of vascular dementia)
- Controlling weight gain
- Sleeping better
- Improving your state of mind

You can exercise at no to little cost, depending on your choice of activity. The amount of time exercise takes can fit into anyone's schedule. Experts recommend we get at least 150 minutes of vigorous exercise a week — just over 20 minutes a day.

Exercise Right!

The National Institute on Aging recommends we strive to do four types of exercise.

What kind of exercise is best? Whatever you will do regularly. Find something you enjoy and stick to it!

Get your heart and breathing rates up with Endurance (Aerobic) exercise.

- Dancing
- Raking Leaves
- Riding a Bike
- Walking Briskly
- Climbing Stairs
- Swimming
- Playing Tennis or Pickleball

Use Strength training to build your muscles for ongoing independence and to protect your bones.

- Carry Your Groceries
- Lift Weights
- Squeeze a Tennis Ball
- Do Wall Push-Ups

To prevent falls that can send you to the hospital or land you in a nursing home, improve your Balance.

- Learn Tai Chi
- Practice Standing on One Foot
- Stand From a Seated Position—Without Using Your Arms

Flexibility will make it possible to continue to perform daily activities.

- Do Muscle-Stretching Exercises
- Practice Yoga

Staying Motivated

Sometimes we begin an exercise program with a burst of enthusiasm, only to find we fade over time. Just ask any gym how many new members they get after the New Year — and how many are still coming a few months later.

> *I have participated in physical therapy and speech therapy to help me to continue with living life. I started a gym membership which I do 2–3 times a week at a pace that is comfortable for me and does not overdo it. This has improved my mobility, assisted me in improving weight loss, and has generally given me new energy to enjoy each and every day.*
>
> **John-Richard Pagan, Manual Guide**



To stay motivated, **get an exercise buddy**. It could be a family member, a neighbor, a new friend, or someone you meet in an exercise class. Exercising with a friend has the added benefit of staying connected to others — a key part of living well.

Some people find motivation from one of the many smartphone tools or wearable devices, such as those that count how many steps we take each day or computer programs where we report on our daily exercise.

- **Take a class.** Senior centers, the YMCA, public libraries, neighborhood organizations, parks departments, and gyms are among the many places with classes for all levels and all ages. Some Medicare plans and employer-covered health insurance pay the cost of SilverSneakers, an exercise program for people 65 and older. If you can't get to a class in person, there are now many exercise and dance classes offered over Zoom or through online videos.

- **Sign up for an organized sport.** All kinds of sports have teams, many of them for older people. Some are competitive, some are just for fun. Bowling, basketball, baseball, softball, pickleball, tennis, ping pong, golf, swimming — anything that is appealing to you and keeps you moving is beneficial. Try something new or return to a sport of your youth.

Try not to be discouraged if exercise feels like a chore. Start small and build up.

Anne Ellett stresses that getting fresh air is also good for our well-being. If you can safely do so, get outdoors every day. "There's value in getting out," she says. "There are benefits to sunshine and fresh air." She tells the story of a Green House, a type of small-house nursing home in northern New York State, that was determined to get residents outdoors on a cold winter day. "They bundled them up, took them out, and brought them hot chocolate." Even though the outing was brief, "people were talking about it for days." It was fun and it felt good.

> *I'm very adventurous and always have been. My husband and I scuba dive. Since my diagnosis I've been parasailing in South Africa, hiking, kayaking. Life isn't all peaches and roses. With FTD [frontotemporal dementia] I have agitation. I go for a run. My husband will go out with me.*
>
> **Laurie Scherrer, Manual Guide**



I've begun to walk. That gives me a chance to forget everything. I'm into my walk, I pay attention to the sky, to birds, to nature. It's my quiet time. I told my doctor I wanted to get up to eight miles. I did make eight miles one time! I'd be content with three or four.

Terrie Montgomery, Manual Guide



2.2G Pillars of Well-Being: *Keep Your Spirits Up*

In 1964, Norman Cousins, editor of the *Saturday Review*, was diagnosed with a painful and crippling collagen disease that his doctors thought was incurable. Determined not to give into the fear and pain, he did what he could to remain positive. He famously self-prescribed heavy doses of laughter. Beginning with a hospital stay, he convinced the nurses to bring him clips of the TV show *Candid Camera* and old Marx Brothers movies. He maintained that 10 minutes of hearty laughter led to at least two hours of pain-free sleep. He went on to pioneer "laughter therapy." He also beat his illness, although not even Cousins claimed that laughter is a cure-all.

Since then, researchers have looked at why laughter is such good medicine. Among the potential benefits:

LAUGHTER ...

- Relaxes your whole body. It relieves physical tension and stress.
- Boosts your immune system by decreasing stress hormones and increasing immune cells and infection-fighting antibodies.
- Triggers the release of endorphins, the body's natural feel-good chemicals. Endorphins promote an overall sense of well-being and can temporarily relieve pain.
- Protects the heart by improving the function of blood vessels and increasing blood flow that can protect you against a heart attack and other cardiovascular problems.
- Strengthens relationships. Sharing experiences that make you laugh with others is a bonding activity. Laughter can unite people during a stressful time and diffuse conflicts.
- Can help you release distressing emotions. You can't feel anxious, sad, angry, or frustrated when you're laughing.
- Is also free and abundantly available!



TIP **SMILE**, it's the beginning of laughter. Spend time with people who put humor and laughter into their daily lives. It's contagious.

TIP **WATCH A FUNNY MOVIE**, TV show, or family videos.

TIP **LAUGH AT YOURSELF**. You'll take yourself less seriously when you can laugh at your mistakes and antics.

TIP **RECOUNT FUNNY THINGS** that happened to you with others. Not only will it make you laugh again, but likely will spur others to share their funny experiences.

TIP **WATCH LIVE ANIMAL VIDEO CAMS**. It's hard not to chuckle at puppies or kittens crawling over each other.



Sometimes You Just Have to Laugh!

Laurie Scherrer, Manual Guide

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https://dementiadaze.com

I knew I shouldn't. I knew it was a bad idea — but I tried it anyway. There are times when things go so wrong you just have to laugh. That was my evening last night.

The day started out fairly well. With the help of my alarms and lists, I had a very productive day. Three loads of wash — complete; clean the refrigerator — complete; find a ride to take me to two appointments — complete. I felt so accomplished. And then ...

Towards the late afternoon, I began to feel out-of-sorts. As my world became clouded and disoriented, and my speech was slow, I decided I was going to make dinner anyway. That's where I went wrong! Lesson number one: how to ruin a perfect day — when you know your dementia symptoms are taking over — stay out of the kitchen!

First let me say, I HATE cooking anyway. I call it "the dirty four letter 'C' word." I don't have the knack for it, and by the time I'm done, my kitchen looks like a war zone. Honestly, I'd rather change the oil on the car than "cook." In 34 years of marriage, I have not been able to escape the horrors of the kitchen. OK, I digress — back to the bad day.

While retrieving two eggs, I knocked a bottle of Italian Salad Dressing on the tile floor. This caused me to jump, tossing the two eggs in the refrigerator. One actually survived — the other, not so much! There was egg on all the condiments (ketchup, mustard, relish, salad dressing, horseradish, etc.). There was egg all over the racks, which of course seeped down to the next rack. There was egg on the door and egg on the floor (that could make a song). There was egg on me.

How I wish I could tell you my tale ended there, but no. As I began the process of cleaning out the refrigerator for the second time, the ketchup lid was not on tight, so I added some ketchup to the other end of the kitchen — the floor, the sink and the cabinets.

Poo — "What's that burning smell? Oh no! — Dinner!" Well done does not describe it! Looking around at the kitchen, which was covered with egg, ketchup, and salad



dressing. I called my sister and cried. Unfortunately, I did not heed her wisdom; "Stop crying, get out of the kitchen, and let Roy clean it up." I didn't want him to come home and see this mess!

Feeling totally overwhelmed and frustrated, I headed to clean the kitchen. Dementia symptoms often cause balance issues. When there is ketchup, salad dressing, and egg on the floor — it's just inevitable. BOOM! I slipped, knocked over the dog's water, and fell smack into the mess.

At which point my husband Roy walks in the door, sees me on the floor — wet, wearing ketchup, dressing and egg. And simply says: "Oh, you've been cooking again! I think I'll put the groceries in the dining room for now."

What he did then really made the difference! He pulled out a towel, sat next to me on the floor, gave me a hug, and said; "Oh, by the way, I decided to pick up a Stromboli so you don't have to cook tonight!" We just burst out laughing. We laughed and we laughed until, yes, I started to cry! I cried with laughter and happy tears over how blessed I am to have him as my husband.

Cleanup took a while, but we got it done. Today, I see last night in slow motion, I see the egg flying through the refrigerator, the ketchup splatting all across the room, and my wonderful husband holding me and making me laugh. I love you, honey!

2.3 Spirituality



Steven J. Sonnenberg, M.D., Contributor

What is spirituality? Spirituality is what provides meaning to our lives. Spirituality differs widely from person to person. For some, spirituality involves a longstanding relationship to the personal God of their childhood with an abiding faith supported by hymn, liturgy, and ritual. Often this religious spirituality is grounded in the social life of a church, mosque, or synagogue. Sometimes our faith evolves over the course of a lifetime into a more general sense of a higher power. And some find spirituality outside of religion — often in nature.

For some, spirituality is found in love and devotion to family. For others, it is their service to a wider community. Music, poetry, theater, or the visual arts can be the source of a spiritual life. The beauty, peace, and solace of nature are transcendent for some.

How does a life living with dementia affect spirituality? It differs from person to person and even over the course of the condition. Like any serious illness or anticipated loss, living with dementia can be a challenge to our religious beliefs in a caring, loving God, leading sometimes to a rejection of faith that has sustained us. At other times it can enhance our faith as we rise to the challenge. Faith changes over our lifetime and it's important to recognize that it may continue to change over the course of living with dementia.

> *Your loved one's mind is changing but their heart and soul are still there. A lot of spiritual stuff is going on that we don't even see … but there's such beauty.*
>
> **Cyndy Luzinski, MS, RN, Contributor**



What can be at risk living with dementia is a loss of access to our spirituality. When meaning and transcendence are found in our relationship with nature, limitations to our mobility or our ability to navigate independently may put a walk in the woods or a stroll along the beach out of reach. Lack of understanding from others or our own social withdrawal out of fear or

embarrassment can limit our ability to get to concerts, galleries, or places of worship that fill our spiritual needs. Worship services may become too long to sustain our attention, leading us to withdraw further. When it becomes too complicated to serve our community in the ways we are accustomed to, finding new ways of serving and accepting our limitations can be challenging.

> *I'm blessed that God has given me a purpose. I believe that the purpose is what has kept me going… God let me get dementia, but He also has given me so many friends, so many people I can help.*
>
> **Laurie Scherrer, Manual Guide**



How do we maintain our spirituality, our connection to what is most meaningful in our lives, in the face of this progressive illness? First, start early. Begin by exploring what has brought meaning to your life, discussing this with your care partners, your family, your friends, and your faith leaders. Writing these thoughts down can become an invaluable guide to others when communication becomes difficult further down the road. This process may need to start with an honest acknowledgment of the fact that you will be living with dementia, a discussion of what the future may hold, and an openly expressed hope that others will support you and help you maintain those activities that provide meaning.

Flexibility and adaptability, personally and in our system of support, is essential. Increasingly, worship leaders are recognizing that shorter, less complicated worship services focusing on familiar text, liturgy, and song are needed to meet the needs of aging congregations. Brief, accessible religious services are widely available on YouTube when mobility becomes a problem. When communication makes active participation difficult, familiar prayer, psalms, and hymns read or sung by care partners can provide that essential connection to the divine. Keep in mind that spiritual needs may change. Familiar songs and prayers learned early in life can provide solace and comfort near the end of life, even when that faith practice was long neglected or abandoned.

Flexibility is crucial wherever your spiritual center lies. Helping your neighbors with their taxes or chairing the local garden club may become too complicated for you, but you may still be able to serve at the local community supper or help with the neighborhood cleanup.

Sometimes isolated elders blossom when they enter a care home and simply have the opportunity to help others with their meals. Music and the arts shared at home can be just as satisfying if the social context of viewing with family or friends is added. A chair by an open window with plants and a bird feeder brings nature to you.

Meeting your spiritual needs throughout living with dementia can be a challenge. Meeting that challenge begins with exploring where you've found meaning, remembering that you are loved by others who want to help, and working together with flexibility and creativity.



Alter — A Pioneering Program for African American and Faith Communities in Georgia

Fayron Epps, PhD, RN

Fayron Epps, PhD, RN, a nurse scholar at Emory University, is pioneering programs to promote the quality of life for families impacted by dementia through her research, education, and service efforts. One such service effort, the Alter program, addresses the lack of resources and awareness for dementia in African American and faith communities in the state of Georgia. Dr. Epps founded the Alter program in 2019.

Even as dementia symptoms advance,
spirituality can shine through
and religious traditions can comfort.

Alter's mission is to encourage culture change, shift perceptions of dementia, and inspire and equip faith-based organizations anchored in African American communities to better support families and create Alter Champions.

Alter Champions are people who:

- Accept and value people regardless of their cognitive abilities;
- Ensure that individuals living with dementia and their care partners are supported through their journey;

- Make sure that individuals living with dementia and their care partners are spiritually and pastorally supported and nurtured; and
- Are supportive to what individuals living with dementia have to offer so that they may participate in their faith community.

The Benefits of Spirituality

John-Richard Pagan, a Manual Guide who is living with Lewy body dementia, is a contemplative Christian, who was formerly trained in Buddhism. "Being closer to my Creator has definitely helped me to see a bigger picture and to be okay with where I'm at right now," he says. "I'm also in 12-step recovery. I've really gotten to know a Higher Power and that it's important to not live in the future and that I cannot control everything."

He values his mindfulness practice. "I do centering prayer, which is a lot like meditation," he says. Living in the here and now is fundamental to his well-being. "When you're living in the past and thinking about what you used to be you're living with regret. It's not only depressing, it brings up anxiety. When you live in the moment, you're not worried about when the next doctor's appointment is or when you may have a bad day. You're enjoying the present."

A number of studies have looked at the potential benefits of spiritual and religious practices for people living with dementia.

- One literature review in *International Psychogeriatrics* found: "Participants who used their spirituality or religion more, through their faith, their practices, and in maintaining social interactions, their cognitive impairments tended to decrease or stabilize. Other studies found the use of spirituality or faith in daily life enabled people to develop coping strategies, maintain their relationships, maintain hope, and find meaning in their lives, thereby improving their quality of life."
- A 2019 "meta-synthesis" in the journal *Dementia* found "the ongoing importance of spirituality to people living with dementia and its importance as a means of finding hope, meaning, and linkage with past, present and future."

Even as dementia symptoms advance, spirituality can shine through and religious traditions can comfort. John McFadden reflects on his experience of being a chaplain serving people with advanced dementia who live in nursing homes.

"I spent 30 years serving as pastor to very privileged people, and then I left to do memory care chaplaincy and to experience this beautiful, quirky, profoundly moving world. Among the things I would note is that many of my residents became spiritual mentors to me. My friends with advanced dementia only have the present moment and

they taught me how to live there. Dementia could not take away deeply memorized hymns and sacred scriptures and prayers, which they found centering and calming. I had residents who were largely aphasic [unable to communicate through speech] but could say the 23rd Psalm with me as long as we did the King James version. A man came to mass in a wheelchair, [seemingly] with no awareness of what's going on. When he was approached with the Host [the sacramental bread that is part of the communion ritual], he responded with complete receptivity. It's a deeply practiced thing that for the older age cohort comes out of their faith traditions.

"I also learned that people with dementia who can't cognitively absorb your words are still picking up on things. Often you cannot fool someone with dementia by covering up if you're in a bad mood or faking friendliness. One woman with very advanced dementia reached out and rubbed my arm because she perceived me as someone who was hurting and in need. Some of my colleagues have said to me 'I know what they get out of it, but what do you get out of it?' What I got out of it was being cared for. Spiritual journeys can deepen within advanced dementia."

Faith has given us hope that we can live through this, that we can make it, that it's going to be alright.



Kim Reid, Manual Guide and living with dementia

Kim might forget a lot of things, but whenever we're talking scripture, those things automatically come back up. When a Christian song comes on, she remembers all the words to the music because it lives inside her. She still knows how to pray and say our daily prayers even though she may forget other things.



Robert Reid, Manual Guide and Kim's care partner



My Faith Keeps Me Going

Rev. Dr. Cynthia Huling Hummel, Manual Guide

A minister reflects on how spirituality helps her live with dementia

Many years ago, I joined an Adult Education class at the high school to learn how to play the recorder. Not the tape recorder — the musical instrument. Once we learned the fingering to play different notes, we started with simple songs like the "ABC Song" and "Row, Row, Row Your Boat." Our teacher decided that we would have a concert for our family and friends on the last night of class to show off our amazing musical skills AND — drum roll, please — that we would play the finale by memory.

I immediately panicked and decided to cheat and came up with this plan: to write the notes of the final selection on my hand in INK. The night of the concert came, and I was relaxed and good to go — that is until I noticed that the notes on my hand were gone. Yep. You guessed it. During the intermission, I went to freshen up and just like that, the notes were washed down the bathroom drain. I wondered how I would make it through the finale! So much for my "handwritten notes."

Those of us with memory problems often will write ourselves notes to help us get through the day and week — and some will even write a note or two right on their hands. Did you know that there is a passage in the Bible about this? It's Isaiah 49:16a. The passage says that God has already written OUR names on the palm of his hands. Amazing. As a person living with early-stage Alzheimer's disease, this passage gives me great comfort. It assures me that even though I may forget my name and the names of my loved ones, God will never forget me. God loves us more than you can imagine.

As a pastor, I often have conversations about faith, especially as folks struggle to find meaning in what is happening in their lives. Those who have been diagnosed with dementia often wonder: Why ME? Some look at a dementia diagnosis as a punishment for a perceived wrong committed earlier in their lives. The reality is that life happens. There is illness. There are accidents and, yes, death. Life is full of pain and of physical, mental, and spiritual challenges. Instead of focusing our energies on "Why me?", I invite you to ponder, "What's next?" Who will you meet on this dementia journey? Who will walk with you? Help you? And who will you offer your hand to in support and friendship? Remember, when we help other people, we help ourselves. You just might be the answer to someone else's prayer. Really!

I have been a Presbyterian pastor for more than 25 years, and I am especially blessed because I grew up in an interfaith family. What about you? Did you grow up going to temple on Friday or attend Sunday school or prayer services at the local mosque? I am so grateful to my parents for the gift of faith. It sustains me on my dementia journey. It's interesting, we come from many different faith traditions (or no faith traditions at all) and have different spiritual practices, prayers, and rituals — but dementia and love connects us all. I am at home attending a Catholic Mass, a Friday Shabbat service, or a Baptist revival.

When we pour out our hearts to God
(or to the universe),
we often find peace.

I love singing the great hymns of the church and hearing the sound of the mighty organ. I've sung in church choirs and praise bands. I spent the summer of my sabbatical as a cook in a Benedictine Monastery and Friday evenings singing Hebrew prayers. If you aren't in a faith community now, I would invite you to check out the faith communities in your area — perhaps the one you attended as a child or a new faith community of like-minded folks who are worshiping and working together and growing in faith, hope, and love. Being part of a faith community can be a HUGE support for those of us living with dementia as well as our care partners.

In times of adversity, many find great strength in reading the holy books of their faith tradition. As a pastor, I often invite people to share something out of their spiritual tradition. Sometimes a person will tell me a favorite story, a parable, or a prayer that gives them strength, hope, comfort, and more. What about you? Do you have a sacred text that you turn to that gives you peace? Perhaps it's a song of faith that helps you to get centered? Even if you are not a believer, you may be inspired by meaningful poetry or literature or by songs that move you. I often invite people living with dementia to reconnect with the spiritual practices of their childhood — to dust off the sacred texts to see what speaks to them.

Our faith often evolves over the course of our lives, and perhaps we want to explore another religion or a humanist tradition. I have friends who have attended the same services every week of their lives and others who are visiting different communities looking for answers to their spiritual questions. Attend a prayer service. Join a Bible study. Meet with a spiritual leader (pastor, rabbi, priest, Imam) to talk about the challenges and the blessings of your dementia journey. Join a meditation group or try a spiritual retreat in nature.

There are many faith communities that offer programs for those living with dementia and care partners — programs like memory choirs, arts classes, support groups. A few years ago, my friend Diane and I started a singing group that we called "Faithful Friends" for those living with dementia, care partners, and community members. We then visited nursing homes to sing with those living in memory care units. Singing together was a blessing for all. Speaking of blessings, think about starting a blessing or gratitude journal where you can write down some of the "day-to-day blessings" that you might experience, such as talking to an old friend, hearing a song on the radio that puts a smile on your face, or holding a puppy. I know many folks in various congregations where I have served over the years who talk about their "God Sightings" — that is, the occasions during the day, when they witnessed God's presence and God's peace.

Prayer can be a wonderful way of helping folks find healing and peace and trust me, I did a LOT of praying the night of the recorder concert. I wanted to walk out the door, but I prayed and stayed and played what I could remember and faked my way through what I couldn't and before I knew it the finale was over and the audience was giving us a standing ovation. Who would have guessed? Not me. But by centering myself in prayer, I was able to calm myself to get through a difficult situation. Prayers don't have to be long or elaborate. *Please Help Me* or *Thank You Lord* are simple and calming. Some people find that breathing deeply and focusing on their breath helps bring calm.

When we pour out our hearts to God (or to the universe), we often find peace.

Some of us pray in the morning, some pray at night. Some pray throughout the day. Some pray in the car, others in the shower. Some get down on their knees. Others stand with outstretched arms. Some will pray with eyes open wide, others with eyes shut. Some repeat a mantra and meditate each day. There are many different ways to pray. But instead of just praying for ourselves and our situations, why not take the time to lift others up as well? Cultivate an attitude of gratitude. Help others. Make a difference, and you might just find joy and meaning in your dementia journey.

Blessings and peace.

SUGGESTED RESOURCES

Agli, O., Bailly, N., Ferrand, C. 2015. Spirituality and religion in older adults with dementia: systemic review. *International Psychogeriatrics* (27)5:715-25. *www.cambridge.org/core/journals/international-psychogeriatrics*

Daly, L. Fahey-McCarthy, E. Timmins F. 2019. The experience of spirituality from the perspective of people living with dementia, : A systematic review and meta-synthesis. *Dementia* 18(2):448-470. *journals.sagepub.com/home/dem*

2.4 Community Supports

Local organizations and diverse networks throughout the country are working to support people living with dementia. Here are a few of the many excellent initiatives.

2.4A Change Will Not Happen If People Are Not Aware: Stories From Asian Community Members

An Excerpt from DAA's Calling All Voices *series*

The Asian community faces unique and growing challenges related to dementia. In the United States and Canada, the Asian community is the fastest growing minority group[1,2] with a projected threefold increase in the U.S. by 2050[3]. Currently, nearly one in ten Asian adults 65 years or older lives with dementia[4], and as the Asian population continues to grow and age, so too will the number of people affected. Indeed, in Canada, by 2050, nearly a quarter of all people living with dementia will be of Asian descent, up from under one in ten in 2020[5]. Together, these numbers highlight the urgent need for targeted interventions and support.

Prevalence is not the only concern. Asian community members also face substantial systemic barriers to treatment and care. When receiving care, over one third of Asian Americans report experiencing discrimination[6] and nearly half believe that medical research is biased against people of color[7]. Further, language barriers coupled with a lack of linguistic and

[1] Lim, Andrew. "U.S. Census: A Closer Look at the Fastest Growing Minority Group in the United States." Immigration Impact, May, 2022, *https://immigrationimpact.com/2022/05/02/u-s-census-a-closer-look-at-the-fastest-growing-minority-group-in-the-united-states/*

[2] "A Statistical Snapshot of Asians in Canada." Statistics Canada, May, 2024, *https://www.statcan.gc.ca/o1/en/plus/6178-statistical-snapshot-asians-canada*

[3] Liu, Dandan, et al. "Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers." Journal of Cross-cultural Gerontology,2008, *https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2958058/*

[4] "Dementia." Cleveland Clinic, *https://my.clevelandclinic.org/health/diseases/9170-dementia*

[5] "The Many Faces of Dementia in Canada - Landmark Study, Volume 2." Alzheimer Society Canada,2024, *https://alzheimer.ca/sites/default/files/documents/ASC_The%20Many%20Faces%20of%20Dementia%20In%20Canada_Landmark%20Study_Vol2.pdf*

[6] Ty, Diane., et al. "One Size Does Not Fit All: Asian Americans and Dementia Risk." American Society on Aging," 2023, *https://generations.asaging.org/asian-americans-and-dementia-risk-not-homogenous*

[7] "Asian Americans and Pacific Islanders and Alzheimer's." Alzheimer's Association, *https://www.alz.org/help-support/resources/asian-americans-and-alzheimers*

cultural competency in care systems makes it more difficult to access appropriate cognitive testing, diagnosis, and treatment.[6]

Within the Asian community, cultural stigma and standards for elder care can create barriers to living well with dementia. Dementia is often seen as an embarrassment, related to fate, and/or a natural part of aging[8]. These perceptions can heighten feelings of isolation and resistance to seeking medical care[8]. Many are also reluctant to consider long-term residential care options[9] which can increase the at-home responsibility of family care partners.

Despite these obstacles, there are reasons for optimism. Community-based programs and culturally specific initiatives are providing much-needed support and resources to Asian families[10]. Increased awareness and education efforts are helping to break down stigma and encourage earlier intervention[11]. These efforts are creating more resources and pathways for Asian individuals to live well with dementia.

Raising Awareness in the Broader Community

In response to the stigma and silence that often surround dementia, individuals in the Asian community are working to change cultural perceptions, bolster understanding, and improve the lives of people living with dementia. They are creating podcasts and awareness campaigns, sharing their stories, and educating their communities.

> "I participate in webinars and podcasts and public forums to create awareness about dementia. I also participate as a patient partner for several universities across Canada to help researchers and students understand the sensitivities and needs of people living with a disability. We need more people affected with the disease to share their lived experience. We need to have families not to hide their loved ones and share strategies on how to cope with daily living with a person with dementia."
>
> - Mario Gregorio, living with dementia

[8] Martin, Lauren. "Dementia in the Asian Community." Medical News Today, 2021, *https://www.medicalnewstoday.com/articles/dementia-in-the-asian-community*

[9] "Survey: Asian American New Yorkers Worry About the Quality of Nursing Home Care in New York." AARP, *https://states.aarp.org/new-york/survey-asian-american-new-yorkers-worry-about-the-quality-of-nursing-home-care-in-new-york*

[10] "Health Education and Community Outreach." Asian American Health Initiative, *https://aahiinfo.org/health-and-community/*

[11] Tinkelenberg, Jennifer. "Empowering diversity: Bridging gaps in dementia care and cultivatingcollaboration." ACC Senior Services, *https://www.accsv.org/uncategorized/empowering-diversity/*

"I'm not shy - there was an opportunity to be interviewed in the paper, I asked my parents' permission, and have been working to bring some of these issues to my community."

- Mary Huang, care partner

Sharing Amongst Friends and Family

Every conversation about dementia matters, and sometimes the most impactful ones are the small-scale, informal discussions between friends and family. This could include simply sharing the diagnosis, talking about care plans, exchanging tips on how to cope with change and challenging situations, and discussing resources that could be helpful on the dementia journey. Talking more openly about dementia can help reduce stigma and increase understanding and acceptance of dementia. It can also foster strong bonds of support and feelings of community which can help people live better with dementia.

"I bring it up all the time when I'm talking to someone."

- Wendi Yen Huestis, care partner

"I take all of my experience and make sure anyone I come into contact with can go forward with some knowledge of how to investigate, where to go, how to plan. These conversations shouldn't be these uncomfortable things. They should happen on Friday night when you go out for cocktails – 'hey, how are your parents doing? What do you think their plan is? Have you talked to them?'"

- Neela White, care partner

"We were the first in our network to go through this, but now people are now coming to me saying 'how do we handle this?'"

- Ron Beleno, care partner

Finding Joy, Purpose, and Gratitude

Asian community members share that, just as they have experienced challenges in their dementia journey, they have also found joy, purpose, and meaning alongside them. Some have embraced practices that bring relaxation and purpose, and some share that the journey illuminated new parts of themselves. Many express gratitude for being able to give back to their parents and enjoy precious time in one another's company.

"I like to have a purpose every day. I like to walk and go for a swim three times a week. I love taking pictures of nature and everyday sceneries. I always love gardening; it's nice to have a space for quiet moments and be close to nature, it's a way to help calm the mind and lead a less stressful life."

- Mario Gregorio, living with dementia

"My experience as a caregiver allowed me to actually enhance some of the things that I didn't know were important to me – providing care, finding a way to support. I was able to meaningfully contribute to my dad's life, which I'm proud of. If he had experienced something like a heart attack instead, I wouldn't have had the time to contribute in the same way."

- Ron Beleno, care partner

2.4B If We Don't Raise Our Voices, Nobody Will Listen To Us: Stories From Latino Community Members

An Excerpt from DAA's Calling All Voices *series*

In the U.S., the Latino community bears disproportionate health, economic, and care burdens of dementia. Currently, Latinos are 1.5 times more likely to develop dementia than non-Latino whites and over one in eight Latinos aged 65 or older has dementia.[1] These numbers are only expected to increase. By 2060, the Centers for Disease Control and Prevention predicts Latinos will have the highest prevalence of dementia among all racial and ethnic groups and the U.S. Census Bureau estimates that the number of Latinos with dementia will quadruple to nearly 20 million.[2]

Latinos also face significant challenges in accessing and participating in dementia health care. One-third of Latino Americans report experiencing discrimination when seeking health care, and dementia clinical trials disproportionately exclude minority groups, including Latinos.[1]

[1] Alzheimer's Association. Hispanic Americans and Alzheimers. *https://www.alz.org/help-support/resources/hispanics-and-alzheimers*

[2] "Alzheimer's Disease and Related Dementias in the Hispanic/Latino Community." Dementia Friendly America *Spotlight*, September 2021.

Adding to the challenge, Latino families are significantly under-resourced in income, retirement benefits, and pension benefits. Moreover, it is estimated that by 2060, dementia will cost Latino families a staggering $2.3 trillion.[3] This paints a bleak picture: as the number of Latinos with dementia increases, families, communities, and systems of support will have insufficient resources to respond.

Despite these challenges, Latino community members have made progress living well with dementia. New clinical trials[4], care and care partner programs[5], and efforts to raise awareness[6] are creating more resources for Latino individuals and families affected by dementia. Community members are further demonstrating creativity, perseverance, and the readiness to respond to systemic barriers.

Addressing Friends, Family, and Oneself

Addressing dementia stigma and lack of awareness requires a multi-level approach that spans large-scale, public initiatives, and day-to-day, personal conversations and introspection. Every day, community members champion the latter by sharing their diagnosis with friends and family, reflecting on their own bias, and addressing it in others.

> "Once I had the proper diagnosis, I created a whole list for myself of people to tell. My husband said, 'Why do you have to do that? Why don't you just take it easy?' But I said 'No, no, I need to share so people are aware.' I felt that I had this important piece of information of who I am and why I do things a certain way. So, I started with my close family and then, little by little, I started telling all my friends across the country. It was very healing."
>
> - Myra Garcia Solano, living with dementia

> "Now I'm comfortable with this journey. I'm slowly but surely embracing it. It's taken a lot of effort to get here, but once you do, you understand there's resources that can help."
>
> - Carlos Olivas III, care partner

[3] "Latinos and Alzheimer's Disease." Us Against Alzheimer's, *https://www.usagainstalzheimers.org/networks/latinos*

[4] "Promising new Alzheimer's drugs may be less effective for Black patients." NBC News, 2023, *https://www.nbcnews.com/news/nbcblk/alzheimers-drugs-leqembi-donanemab-may-benefit-black-people-less-rcna97298*

[5] "Care and Caregiver Programs." Latino Alzheimer's and Memory Disorders Alliance, *https://www.latinoalzheimersalliance.org/care-caregiver-programs*

[6] "How to Raise Awareness About Dementia in Hispanic/Latino Older Adults." MHP Salud, 2021, *https://mhpsalud.org/dementia/*

"I was having a conversation with someone who said, 'People with dementia stop being who they are, my grandfather is a different person now.' I respond, 'But I'm also a different person than I was seven years ago - I don't speak the way I used to. I don't believe certain things that I used to. Every cell in our body changes.' The idea that we define ourselves by our memories is problematic, and the idea that we define personality as something that's fixed is incorrect."

- Juan Carlos Zaldivar, care partner

Finding Community Through Support Groups

As individuals and their families contend with the plethora of challenges that can accompany the dementia journey, many have found support from their peers. Community members consistently share that support groups provide them opportunities to process feelings, give and receive advice, cultivate lasting friendships, and find validation in their journeys.

"I'm very active with the Alzheimer's Association where I'm in a support group that is absolutely wonderful. We are all in similar stages, we all have stories - sometimes sad, sometimes funny, and we help each other. It's really important to have people who understand what you're going through, without judgment, and for them to acknowledge that this is real."

- Myra Garcia Solano, living with dementia

"I attend about six caregiver support groups now. Some are weekly, some are bi-weekly, some are monthly. I learn techniques, what does work, what doesn't work? I'm able to give feedback, support others, build relationships, and vent when I need an outlet."

- Carlos Olivas III, care partner

"We run a daycare program. It helps the person with dementia feel like they're still independent. They get to hang out with others like them in an environment that's culturally competent. Then, at the end of the day, they go back home to their families."

- Ana Castanda, Elderly Programs Manager, United Community Center

"Thanks to Dementia Action Alliance, I feel like I've had plenty of support and I've built great friendships. It's helped me realize that there are other people on the same journey, having the same problems. I realized that I wasn't alone. They pull you in and they hold on to you."

- Yoli Alvarez-Bell, living with dementia

Finding Joy and Meaning in the Journey

Latino community members share…that the journey has created more space for art and hobbies, others say it has brought their families closer together and afforded them precious time for enjoying one another's company.

"One of our routines is waking dad up, getting him in the shower, and then heading off to our favorite bakery. From the bakery, we go to a park that's along the river. We sit there together and enjoy a donut, just being at peace."

- Carlos Olivas III, care partner

"I volunteer in three different choirs. Anything I can do to keep myself viable. I do physical exercises with a Peloton bicycle – that's my morning routine. I cook, take care of the house, and I enjoy going to the movies, I go by myself and it's my me time."

- Myra Garcia Solano, living with dementia

"Mom and I are closer now more than ever since the diagnosis. She even says I love you; she never said that before. A nicer side has come out of her and she's such a loving grandmother."

- Susan Delgado, care partner

"I sit here all the time and work on my art. I have all the colors here. I imagine pure water, in the middle of the ocean when the sun is going down."

- Carlos Olivas II, living with dementia

2.4C Dementia's Impact: Individuals with Intellectual and Developmental Disabilities



Salli Bollin, MSW, Jennifer Hudak, MPA, Marty Williman, BSN, Contributors

With the support of three Administration for Community Living Alzheimer's Disease Programs Initiative (ADPI) grants, Aging and Intellectual and Developmental Disabilities (IDD) professionals across the state of Ohio have developed a better understanding of both IDD and dementia, and are sharing this information throughout our state and beyond.

In 2019, as grant work began, we recognized there was much to learn about how dementia impacts individuals who live with intellectual and developmental disabilities. We needed education about:

- The growing incidence of dementia within the IDD population.
- The unique risk factors and signs and symptoms of dementia.
- How to screen and assess for dementia.
- How to determine the best resources, services, and supports needed for those diagnosed with dementia, their care partners, families, and caregivers.

As we embarked on this effort, one of our grant partners asked if we were familiar with any health care providers in our community with experience caring for individuals living with IDD and dementia. We contacted several providers in our community; those we reached indicated they did not have experience with this population. We recognized we were unprepared to support individuals in our community living with IDD and dementia and could not identify local resources. **We had knowledge to gain and much work to do.**

Fast forward to four years later, in **2023**, when Salli interacted with a family member of Ray, a man living with Down syndrome. Ray's brother had noticed some mild changes in Ray's cognition, noting that he did not seem to remember some events that happened the day before but otherwise felt generally fine. Was there a knowledgeable health care provider who would be able to provide a good baseline assessment and course of care?

As a result of all we had learned between 2019 and 2023, Salli was able to assist this family, providing information and resources about a widely accepted tool, NTG-EDSD (Early Detection Screen for Dementia) – a baseline screen to measure cognitive decline over time in people who are living with IDD. We also discussed local services and providers with experience serving this population, common signs and symptoms of dementia in individuals who are living with IDD and dementia, and factors to consider that impact this unique

population. Ray was diagnosed with moderate brain atrophy and dementia.

About six months later, Ray was not remembering things he used to recall and was sleeping more than usual. We were able to discuss with Ray's family some strategies for talking with Ray's primary care provider about these new developments. Ray's provider should consider possible underlying medical concerns like reaction to medications, infection, thyroid issues, depression, or sleep apnea. The previous baseline screening and ongoing monitoring helped to inform diagnosis and initiate a course of care. Ray has since begun attending an adult day center to participate in activity programming and increase his engagement in the community.

The individual experience of Ray, his family, and his service providers highlights what can be achieved with an investment in learning and understanding, and with growing collaboration between Aging and IDD systems. This **multi-year period of growth** has also been beneficial in other ways:

- ✦ It has initiated increased collaboration within the Aging and DD systems in Ohio at the local and state levels.
- ✦ The Gerontological Society of America created companion materials specifically for IDD and Dementia for the KAER Toolkit for Brain Health.
- ✦ Individuals living with IDD can now recognize early symptoms, be diagnosed and manage symptoms, remain engaged in the community, and maintain the highest quality of life possible.

Finally, for communities, organizations, and individuals to serve and support persons living with IDD and dementia, **we recommend the following**:

1. Increase your knowledge, understanding, and awareness of unique risk factors and early signs and symptoms of dementia in those living with IDD.
2. Recognize the unique circumstances surrounding individuals living with IDD related to aging and dementia, including advance care planning.
3. Expand your knowledge about screening, assessment, and diagnosis of dementia in persons living with IDD.
4. Identify and develop appropriate courses of care interventions, recognizing these will need to be adapted as a person's dementia, and other health concerns, progress.
5. Review information and resources from organizations such as:
    - Administration for Community Living's National Alzheimer's and Dementia Resource Center *https://nadrc.acl.gov/home*.

- National Task Group on Intellectual Disabilities and Dementia Practices (NTG) *https://www.the-ntg.org/*.
- Gerontological Society of America's KAER Toolkit for Brain Health Companion Guide for IDD and Dementia *GSA KAER Toolkit IDD*.

6. Engage in community education and awareness programs such as:
   - Dementia Friends *https://dfamerica.org/state-programs*.
   - Dementia Friends for Individuals Living with IDD *https://ocfch.org/df/dementia-friends*.
   - Project ECHO Education series *https://www.the-ntg.org/training*.
7. Familiarize yourself with Aging and IDD Services, Supports, and Systems within your local community and ask:
   - Are there opportunities to work together and expand collaborations?
   - How can you build effective relationships between the person living with IDD and dementia, their family members and caregivers, the healthcare community, and support and service providers?



Engagement, Enjoyment, and Purpose: Ray's Story

By Jeff and Robert Cole

The early advice we received from a community-based agency familiar with IDD and dementia was invaluable. We had learned previously that the aging Down syndrome community was especially at risk of dementia, and when we first started noticing signs with Ray, the NTD-EDSD was provided as a baseline tool. First assessed in August 2023, this formed the basis of Ray's early medical testing and eventual diagnosis.

In following up with this agency, I expressed that Ray seemed somewhat detached – partly because my mother, with whom he lived all his life and who had been a caregiver of sorts, was experiencing some health issues. He does not express emotions well, but it was clear he had difficulty dealing with her failing health. Fifty-two years old at that time, Ray had earned a high school diploma and worked in general population jobs for nearly 30 years. His last company (for whom he had worked 24-plus years and was employee of the month numerous times) ceased operations just prior to the Covid pandemic. We had recently started to explore re-employment opportunities for him, but we were also concerned with his cognition.

The agency suggested that its adult day center program might provide the opportunities Ray needed. He first enrolled in July 2024, and I am pleased to say his experience has wildly exceeded our expectations in so many ways:

- It gives him daily **mental and physical stimulation**, which had been diminishing while living with our aging mother.
- His attendance has also provided a **diversion** from sitting at home with less to do while his mother/co-caregiver is able to do less with him.
- Most importantly, Ray truly experiences a **sense of enjoyment** while attending the adult day center. Like many families exploring adult day services, we took a cautious approach and had him begin by attending only two or three days a week for a few hours each day. He now attends daily for much of the day and looks forward to each day there.

- His involvement also provides a **sense of purpose**. As Ray has become acclimated to the center, he is driven to care for others and welcomes guests as they visit the center. He also expresses his enjoyment in what he does to others.
- Finally, his involvement provides a **respite for family**, who aren't always able to spend as much time with him during the week as they would want to.

In addition to all of this, the staff at the agency has opened doors to other services for which Ray is eligible, especially resources within the county Department of Developmental Disabilities. Ray now has a dedicated service provider (SSA) who has helped to arrange Medicaid assistance, home-delivered meals as needed, non-medical transportation, and para-transit services. As with the adult day center, we have regular ISP (Individualized Service Plan) assessments with this agency.

Worth noting, our family used the NTD-EDSD screening tool again in September 2024 to compare it against the baseline in 2023. There were indicators where we noted adverse progression, and the adult day center closely examined these during our most recent ISP with them.

Bottom line: We cannot underscore enough the delight Ray exhibits while attending--and later expressing his enjoyment about his experiences at--the adult day center.



2.4D *Rural Community Living with Dementia – Detrimental & Beneficial Impact*

Laurie Scherrer, Manual Guide

From an Interview conducted by Barb White, *Pathways* Project Manager

Aww the fresh air of the country! OK maybe not today, the farmer just fertilized his field, but on most days the air is filled with earthy scents that invite me to be part of nature. To listen to the birds and crickets, and to hear the babbling brook and the wind blow through the trees. Perhaps, every once in a while, the sounds will be interrupted by an airplane, a tractor or a car, but the fresh smell of pure environment remains unscathed.

I am a person living with dementia in a rural community in Alabama. Country living provides an opportunity to embrace nature with all our senses and I enjoy every bit of it. Five years ago, I moved from a rural community in Pennsylvania to an even more remote area in Alabama. The majority of my neighborhood consists of cows, goats, pigs, some horses, and some humans, which provides a calm atmosphere except when one of the critters gets loose.

I was not always a country-type girl. In my early twenties I lived in Northeast Philadelphia and totally enjoyed city life on the weekends. Dancing, plays, shows, and friends were the highlights of my single life. When I married, my husband and I found that housing was much more affordable if we lived one hour north of the city, the next house was 1 1/2 hours and then two. I'm not sure what I would call our closest city now, but I know it's too far to go to a show and then drive home.

Today, I find the noise, traffic, rushing, and emotions of the city (and even most suburbs) to be extremely stressful. And the smells – ugh! Exhaust fumes and machinery smells seem to permeate the air stealing any essence of nature. For us, a traffic jam is when we are stuck behind a tractor.

Although exploring our world through walks, kayaking, biking, and breathing fresh air is fabulous, rural living does have some downsides. These are most evident in medical and transportation resources. Last year I called 911 for my husband who was clutching his chest. They rushed him to the local hospital and determined that he needed a

bypass. Since they do not have a heart surgeon, they transported him almost two hours away where he had a triple bypass. Since I do not drive at night or in traffic, I was unable to be with him until a friend or family member was available to drive me. This was the most traumatic of a number of medical concerns that have mandated us driving 2 to 4 hours from home to receive the proper care. Finding good veterinary care is also challenging.

People living with dementia in rural areas seem to drive longer. The number of back roads and lack of traffic or pedestrians makes it a bit easier to keep driving safely. In a way, we don't have a choice. There are no Uber services and I have not yet met a cow who drives! Limited public transportation for disability is sometimes available within "city limits only" (the town proper zone). Our little senior center offers some local transportation, but we are 35 minutes away.

When I was diagnosed with dementia, we lived in a rural community in PA. I first went to my family doctor, who passed me to another, then to another…my fifth doctor visit was to a "neurological specialist" in a large, well-known hospital in Philadelphia. And he said, "I just wanted to tell you what the other doctors didn't want to tell you, you have early-onset Alzheimer's and probably FTD." But that's the hard part of being in a rural area. Philadelphia was 2.5 hours away, almost 4 hours coming home in traffic. And parking was $20/hour. It was too far to take a train into the city.

During the office visit, the neurologist would turn to my husband and give him instructions as if I wasn't in the room. I'm here, look at me! They make you feel like you don't exist, like you don't matter. That attitude filters down to the way people living with dementia are perceived and the way they feel about themselves. The general message from the doctor is that you can no longer take care of yourself and it is downhill from here so get your affairs in order and prepare to die. Since that was the doctor's instructions – that is what you prepare to do.

My involvement in virtual activities did not come as a result of my being in a rural community. It came as a result of me searching and searching and trying to find someplace where I could get answers, where I could talk to people. The local Senior Centers and church groups did not want me because I was only 55 (I wasn't a senior). The first group I found to accept me was a virtual group, Dementia Mentors, and I had the pleasure of meeting Robert Bowles, Susan Suchan, Paulan Gordon, Truthful Loving Kindness and Harry Urban. They helped me realize that I could not just survive - - I could thrive. In spite of dementia I could live a purpose-filled life. This changed my life.

Even though we don't have many programs close to home, I don't lack for social engagement. I am extremely involved with lots of people living with dementia. I do

believe this is my calling, it's where God wanted me to be. I am virtually connected to over 250 people living with dementia and/or their care partners.

DAA (Dementia Action Alliance) offers a variety of virtual programs every week. As Program Director, I started most of our programs and stay involved in all of them. I average 14 meetings per week. All our programs are virtual (on Zoom). Virtual programs allow people a place to gather to engage, encourage and learn strategies, and socialize. We have people from all over the US and a few in Canada. They represent a variety of cultures, education, types of diagnosis, and locations.

This is where I would say to people, more so than anything, the most important thing you need to do for yourself is find a purpose—something that stimulates brain and body, something that makes you feel like a person again. Learn how to live a purpose-filled life. DAA has a group called Helping Hands and our entire function is helping people find a purpose. The best source to learn about living with dementia is from people who are living with dementia. Socialize and learn from others, we know and understand way more than the doctors.

Go to *daanow.org*! Take a look at our virtual engagements, contact us, and get involved!

Rural Community Living With Dementia

If you are thinking of relocating to a rural area, it is important that you weigh the detrimental and beneficial impacts of that decision and find work-arounds to overcome obstacles.

The benefits of rural living:

- **A community spirit**--people know you or know of you. They are willing to go out of their way to help a neighbor.
- **A more relaxed and less stressful environment**, with less noise and confusion.
- **More opportunity to be "in" nature** as nature surrounds your environment--stop and smell the flowers.
- **Finances--Housing is much less expensive.** If you need to transition to a one-level ranch, you have a better chance of finding one you can afford in a rural area. As a whole, most expenses decrease including car insurance, homeowners' insurance, and taxes.

The challenges of a rural setting:

- **Transportation**--There may be little to no public or paid transportation. Not every town has taxi service or Uber.
- **Medical resources** may be available, but often at a less-qualified level. For example, a family doctor who thought Alzheimer's is the only type of dementia and never heard of Lewy body dementia. Or the dermatologist who said there was no reason to rush to have Melanoma treated. Misunderstandings can happen anywhere, but they seem to be more frequent in the rural areas. Be prepared to travel if needed.
- **Hair salons** lack the constant training received in larger areas.
- **Limited vet services**--None of the vets around where we live care for the animal overnight so animals must be moved after surgery.

In all communities, of all types and sizes:

- **Grocery stores.** This is where living in a rural setting has been positive for me. I went to my grocery store and couldn't find something I was looking for. I started to cry. Someone came up to me and asked if they could help. They helped me and then went and got the manager. I handed the manager this DAA card:



- **ALL Businesses.** Airports, restaurants, laundromats, banks, and more!. All businesses could help people living with dementia by learning about noise, overstimulation, confusion, and possible triggers.

Be a dementia advocate where you live! Share DAA's *Please Be Patient With Me* Cards—with your new pastor, your waiter, your airplane steward, your librarian. It's great education that helps train individual businesses to welcome their customers living with dementia. Contact *daanow.org* for DAA Cards and to set up training for your local business.

2.4E Raising Awareness in Indian Country



Contributor Carla Eben, Director of Numaga Senior Services for the Pyramid Lake Paiute Tribe in northern Nevada, knew little about dementia when she was hired. She had years of experience working for the tribe and was eager to learn more about her new area of responsibility. When she received a flyer from the state of Nevada, offering training on dementia and hoarding, she asked her boss if she could go. She ended up driving three hours north to Winnemucca for the four-hour training.

As the training wrapped up, she realized that she knew people who might be living with dementia. "It was an eye opener," she says. She also noticed, looking around the room, that "there were no brown people, no Natives there. I asked the lady when we were packing up if they send their flyers out to Indian country — to the Nevada tribes. The lady said, yeah, but they never come."

Driving home, Carla thought about how many people she knew who fit the description and patterns of what she'd heard in the training. She wanted to learn more and to share it with others. And the woman's comment that "They never come" stayed with her.

The next day Carla dropped into the clinic, which is in the same building as her office. "I asked one of the nurses, 'Do you have any programs for elders? Do you guys do any trainings through IHS [Indian Health Service]? Do you have a doctor who deals just with elders?' She said no. I asked, 'could you bring us a training?' She said, 'probably not.' It was no, no, and no."

Carla didn't give up. She next tried the University of Nevada Cooperative Extension Service, which eventually led her to Jennifer Carson, Director of the Dementia Engagement, Education and Research Program at the university. Jennifer was happy to lead a training, and she and Carla soon met to make plans for an information session, open to anyone.

Around the same time, Dementia-Friendly Nevada announced they were awarding three grants. Carla applied and received a grant to accomplish three things: "Educate my elders and caregivers. Educate our tribal departments and agencies outside of our department — social service, EMS — and community members. Educate my neighboring tribes."

Dementia Friendly America, Carla found, had resources on how to work with hospitals, banks, and restaurants. But that didn't apply to her work. "We had to be creative," she says. "We don't have banks, we don't have restaurants — that's why I geared it towards tribal departments. We do have the visitor's center, housing, and clinics."

The first year they established the Pesa Sooname Advisory Committee and a board. (Pesa Sooname translates as "good think" — there is no word for dementia in the Paiute

language.) Jennifer Carson and her colleague Casey Acklin held four training sessions in the first year. "That helped us meet our first and second goal," says Carla. "For our third goal we decided to hold our tribal summit." They reached out to all the tribes and elder programs as well as Dementia-Friendly Nevada partners.

Participants were asked to register online ahead of time. As the day grew closer, few people had signed up. "Jennifer and Casey were freaking out. I told them, people will come and register that day. I said just relax," says Carla.

The summit was a big success, with 114 participants. Out of the 27 tribes in Nevada, 14 were represented. "One hundred percent of the surveys said they'd like to do it again," she says. The speakers covered topics like the Healthy Brain Initiative, the need for comprehensive geriatric assessments, and diabetes and dementia in Indian Country. At least half the participants were Native elders or caregivers.

Unfortunately, there are no reliable data on how many tribal elders are living with dementia. Diagnosis of dementia is virtually unknown on the reservation.

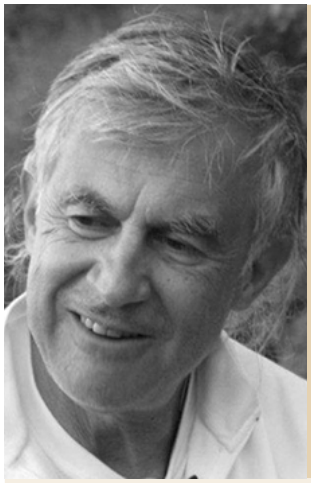
Unfortunately, there are no reliable data on how many tribal elders are living with dementia. Diagnosis of dementia is virtually unknown on the reservation. The IHS focuses on "life and limb," says Carla. "There's like a priority list of what they deal with. Dementia is at the bottom. Now that COVID has hit, dementia is probably further down. Even within families it's not an open subject."

She worries about the number of elders who are isolated. "We have elders that live alone," she says. "Our meal delivery might be their only contact. Their house may be one-eighth of a mile from another house. Their best friend is their cat or dog. It's sad to think that. If we hold our elders in such high esteem as we say we do, we should be doing more."

Carla's experience in Indian country is not unusual. According to Manual Guide Dave Baldridge, founding director of the International Association of Indigenous Aging (IA2), "Dementia has not been addressed formally or historically. There's a lot of denial, and a great lack of education. It's been a challenge just to get it on the radar screen in the communities we're trying to serve.

"There are some long established principles that we have used to do work with Indian country. The elders are an extremely important voice and as they are most affected by dementia, we go to them to get their input. Nothing about 'em without 'em." To reach elders, they go through Title VI Senior Service meal programs like Carla's. "Those directors and staff are on the front lines with anything dealing with elders."

IA2 received a five-year National Healthy Brain Initiative award from the U.S. Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging program. This Healthy Brain Initiative promotes brain health and addresses cognitive impairment and dementia. According to IA2, the award establishes them as a national hub for dementia information resources for tribes, tribal leadership, healthcare and public health staff, Urban Indian Health Centers and organizations, and tribal elder services advocates across the country. To learn more, visit: *iasquared.org*



Staying Positive with an Unexpected Diagnosis

Dave Baldridge, Manual Guide

Executive Director of the International Association for Indigenous Aging (IA2)

Reprinted with permission from Dave's IA2 blog post

Last year, I unceremoniously collided with the greatest irony of my ongoing 30-year career/mission as an Indian elder advocate. The day before my 74th birthday, the director of a local cognitive assessment center called me into her office to explain her unexpected diagnosis of PSP — progressive supranuclear palsy. This is a terminal neurological disease, loosely related to Parkinson's or Huntington's disease.

Overall, it's kind of like winning the lottery in reverse — it affects only five out of every 100,000 people. Causes are unknown but may include genetics, although there's no verified link. It has to do with damaged tau proteins in the brain.

A primary symptom is frequently the loss of executive function (Ruh Roh!) — an expression of dementia. At the time of the diagnosis, I felt a bit overwhelmed by the irony. IA2 is among the first Native organizations to engage in national work to

recognize and cope with ADRD [dementia], and then earned the CDC BOLD grant [Building Our Largest Dementia Infrastructure] that now brings us together.

Symptoms also include imbalance (I was/am having plenty of that). This has been a long time in the making — a formerly-avid bicyclist, l remember on a guided mountain bike adventure in Nepal 18 years ago inexplicably losing my balance and falling off of a steep cliffside trail. There were other incidents.

"Even though it's progressive," she explained, "you've probably got 8–10 good years left." So here I sit, a year into this new adventure, pondering what "8–10 good years" means.

Will I miss scheduled meetings? Lose my train of thought while presenting at a conference? Break my ankle while walking to the bathroom? Get lost while driving to an appointment? Become wheelchair dependent? Jeez!

The doubts are constant and troubling. They've led me to take closer control of my options — refinancing my house, exploring in-home care, should it become necessary, and updating my will and advance directives.

Interestingly, my personal circumstances haven't seemingly affected my work with ADRD. I'm very appreciative for being able to continue to contribute to our ongoing efforts to help American Indians and Alaska Natives to address ADRD within their communities and families. The issue is top-of-the-ladder for many of my generation and will become even more central as time progresses. Our mission is important.

I'm keenly aware that many of you — my colleagues and friends — have and continue to experience far greater health issues and difficulties than I do. I admire your courage and dedication to our work together.

And I'm constantly reminded that many of the folks we serve — Indian elders — face far greater obstacles than most of us ever have.

I'm convinced that the best solution for me — perhaps for all of us — is actually pretty simple — to stay positive and to keep trying. So I'll offer up my best to you, and to Indian elders, as we continue our important work together.

2.4F Dementia-Friendly Initiatives

"Innovative Communities Expand and Redefine the Dementia Experience: The movement that's changing the culture from stigma to inclusion"

Beth Baker

Article first printed in *Next Avenue* (www.nextavenue.org) on May 4, 2021.
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Updates for this 2nd Edition provided by USAging's Mary Ek, Darya Rahbar, and Aleiah Mann, Contributors.

Ron Grant of Oklahoma City was 55, enjoying his career as a chaplain and happily married, when he began to experience memory problems. After undergoing a battery of tests, he received an unexpected diagnosis: young onset Alzheimer's disease. "Nobody in my family had it," he says. "I knew it was a bad disease, but I did not know anything about the progression." When he pressed his doctor about what to expect, Grant was told he'd likely be dead or in a nursing home within two to seven years.

That was 14 years ago. Today, Grant continues to live fully. As co-chair of Dementia Friendly America, an initiative that began during the White House Conference on Aging in 2015, he is a leader in the movement to change societal views of what it means to live with dementia. "We do not lose our humanity and our right to dignity just because we have this disease," he says.

The Dementia Friendly America network promotes communities, organizations, and individuals who are committed to keeping people living with cognitive impairment/dementia and their care partners engaged and thriving in their communities.

Too often, though, the "tragedy narrative" prevails, says gerontologist Karen Love. Instead, communities can seek "to empower and enable people and instill a sense of positivity. It's important to support their abilities rather than focus on diminished abilities," she says.

Anecdotally, Love has found that engagement and hope may help extend the time of cognitive health. Grant agrees. He continues to have purpose and meaning. He credits his faith and the changes he and his wife, Vicky, made early on with taking him as far as he's gone. "We learned that our worst enemy is stress, fear, and anxiety," he says. "We

purposefully tried to de-stress, to try to overcome fear and avoid all anxiety that we could."

He also found help in a support group he organized. Support groups, often led by those who have the disease, are among many activities cropping up around the country to improve the quality of life for people living with dementia.

Memory Cafés that offer the chance to socialize and build new networks, volunteer opportunities for those living with dementia, concerts and special art gallery tours are spreading. There is even the nation's first dementia-friendly airport in Tulsa, Oklahoma.

Dementia Friendly America has registered 350 communities so far. That number does not include several other dementia-inclusive communities not under the organization's umbrella. "This is a movement that's gaining momentum," says Sandy Markwood, CEO of UsAging.

The momentum continued during the pandemic. In 2021, 25 more communities joined, pledging to include in leadership people who are living with dementia and to work across sectors, including local government, business, and faith- and community-based organizations, to implement dementia-friendly practices. Dementia Friendly America developed a toolkit to guide communities that wish to become dementia-friendly.

"The key is being dementia-inclusive," says psychology professor Susan McFadden, author of the new book *Dementia Friendly Communities: Why We Need Them and How We Can Create Them*. She adds: "We need to listen to [people living with dementia] and we need to talk to the folks who are shy and hesitant to find out what they want in their communities." The following are a few examples:

Dementia-Friendly Indiana

A standout in this effort, according to Karen Love, is Dementia Friendly Bloomington (Indiana). Its first workshop was in 2017 to brainstorm what a dementia-friendly community would look like. Today, committees work on expanding legal and financial services, safe driving, and making public spaces dementia-inclusive. This initiative offers employee training to businesses and, with the guidance of people living with dementia, suggests ways to make places more navigable and safer.

"My philosophy is that people living with dementia need a friend to help them walk through life," says Jan Bays who helped found DF Bloomington. "They have many, many abilities, and they see the world differently because their brains process things differently. The key to living successfully is having a safe environment that supports them."

Amanda Oporta, Dementia Friendly Liaison for the state of Indiana and a founding member of Dementia Friendly Bloomington, says: "From the beginning of the conversation with the Bloomington community, all the way to the gatherings and conferences, there has always been a supportive mindset for the community and people living with dementia. Through their

creative collaborations, they have really set the bar high! They have been a guiding light for the rest of the state with their passionate perseverance to make sure this isn't just another small movement, but a way of life for people in their community living with dementia. I have gained so much and feel honored just to be a part of something so much bigger than myself and to get to see how it has resulted in bringing joy."

Among Dementia Friendly Bloomington's many activities:

- In collaboration with a theater group, people living with dementia have acted in plays over Zoom. "It might be hard for them to remember lines, so they can have their scripts," explains Dayna Thompson, who heads up the Alzheimer's and Dementia Resource Service at Indiana University Health. "They are over the moon to be included in this," she says.
- Thompson's team also partnered with the Monroe County History Center and the Community Foundation to create Living with History. The History Center reserves times for people living with dementia. In a quieter environment, they can go on Memory Walks, hang out at a Memory Café, or borrow Memory Boxes to take home.
- Monroe County Public Library piloted an accessibility program to learn how to create more accessible spaces for those who have cognitive changes. They brought the perspective of the person living with dementia and their care partner to offer suggestions about how businesses and organizations can make small adjustments that make big impact for people living with dementia and care partners, so they feel more welcome and comfortable navigating spaces they want to continue to visit. The goals are to look at accessibility and stigma and reduce the chances of isolation.

Dementia Friendly Bloomington has inspired 16 counties and now there are conferences statewide to continue to inspire more. "I truly believe that if we're focusing on people living with dementia in our community, it will make life better for all of us — giving information, safely finding transportation in town, improving wayfinding, checking on our neighbors, having places where people can socially engage across generations," says Thompson. "We might call it dementia-friendly, but it's what we all would like."

Dementia Friendly Nevada

Jennifer Carson, a dementia researcher at University of Nevada, Reno, wanted to expand programs for people living with dementia beyond the usual orbit of aging services professionals.

"We want to transform the broader community, so how do we find those pathways to change?" she says. "We set as a standard to have diverse representation across many sectors and to include people living with dementia in leadership."

Today six communities, each representing a range of sectors, are active in Dementia Friendly Nevada. For example, Dementia Friendly Pahrump, on the edge of Death Valley, hosted a film series, complete with popcorn and post-film discussion. With no theater in town, they first used the local electric company for showing, Cracked: New Light on Dementia, a research-based drama that seeks to change the stigma around dementia and to promote inclusion.

Dementia Friendly Pyramid Lake Tribe-Pesa Sooname (interestingly, there is no word for dementia in the tribe's language) focused initially on education. They then organized a summit in 2019 which drew 114 people from 14 tribes.

"The whole summit was developed by our partners," says Carson. "There was a color guard from the tribe, traditional songs and a heart-healthy lunch prepared by tribal members."

One of the best programs, says Carson, is a support group, Dementia Conversations, now held biweekly over Zoom.

Chuck McClatchey, who is living with dementia, leads the Monday group. At a recent gathering, made up of people living with dementia and family members, one participant asked for advice on how to get her husband (who was not attending) to agree to counseling, to help him overcome denial and better accept the disease. Others shared their own positive experiences with counseling, which in turn led to a conversation about how they each dealt with learning their diagnosis and getting to a place of acceptance.

The conversation was sprinkled with humor (one participant living with Lewy body dementia personifies the disease as "that rascal Lewy" who disrupts his thinking) and with deep appreciation for the trust and openness in the group. At a closing sharing, McClatchey said, "What I took away is that it's okay to ask for help. Everyone handles stress and anxiety in different ways. All the stigma can go in the trash where it belongs."

Dementia Together in Northern Colorado

What began as a caregiver support group at Cyndy Luzinski's church in 2014 evolved into the nonprofit Dementia Together, based in Windsor, Colorado. Luzinski, an advanced practice nurse, is the full-time executive director, supported by three part-time staff.

In 2020, nearly 1,800 people went to 80 Memory Cafés (in-person and virtual) in Northern Colorado. "The agenda is joy, reminisce, sing, and play games," Luzinski says. "The main purpose is having fun and for the couples to realize they can still have fun together." More than 500 attended "virtual variety shows" including concerts, gardening, and cooking programs.

Luzinski saw the power of connection in 2015 when researchers at Colorado State University launched a collaborative to study how the arts could benefit people living with dementia.

Through the B Sharp Arts Engagement program, people living with dementia and their partners attended concerts of the Fort Collins Symphony and participated in post-concert receptions and in research studies.

The first study found not only improved alertness, mood, and engagement among participants, but increases in cognition over nine months of going to concerts. For their part, the caregivers found a sense of community and felt a sense of "normalcy."

The group also tackled a common problem they heard from newly diagnosed patients. "The doctors would say, 'You have dementia, see you in six months,'" says Luzinski. "That is such a trauma for them." Dementia Together developed a resource folder and distributed it to internists, family practitioners, and neurologists to give to their patients. The folder includes basic information about the disease, caregiver tips, and helpful local organizations.

"Our elevator pitch," says Luzinski, "is the dementia journey can be overwhelming, but no one has to walk alone."

These stories from Indiana, Nevada, and Colorado are a few great examples of inclusive engagement opportunities offered by dementia-friendly communities-- and there are many more. Dementia-friendly communities across the country are bringing joy and connection to people living with dementia and their care partners. From dementia-friendly choirs to community movie nights, and Memory Cafés to Dementia Friends sessions (https://dfamerica.org/state-programs/), communities stay creative and committed to fostering connection. Visit the Dementia Friendly America directory (https://dfamerica.org/community-directory/) to find a community in your area!

2.4G Memory Cafés



Beth Soltzberg MSW, MBA, Contributor

Memory Cafes are gatherings for people living with cognitive changes or dementia and the people who care about them. What are they all about? They are a place to have fun, laugh, feel joy, share a sense of community, and try something new. The idea is simple but meaningful; we all need a place and time to have fun together. Visit the national directory at *https://dfamerica.org/memory-cafe-directory* to find a Memory Café!

Memory Cafés have spread as a global social movement, because the people who attend and the people who run the Cafés love them and want to see more of them. I've been running the JF&CS Memory Café and the Percolator resource sharing network for Memory Cafés since 2014, and I'll describe the ingredients that make Memory Cafés special.

First, no one is asked if they have a diagnosis or what it is. We meet participants "where they are." People can talk about dementia if they would like to. No one is put on the spot. Some participants are not aware of their cognitive changes or don't really want to talk about them - and that's fine.

Most Memory Cafés have some social time and some kind of facilitated program. Creative arts programs are common; so are programs about sports, history, travel, and fitness. Programs are interactive, and they are designed to engage everyone, including people living with advanced dementia, people with mild symptoms, and care partners.

Cafés are held in accessible community spaces like libraries, community centers, art museums, and YMCAs. I've seen a Memory Café at a bowling alley and at a botanical garden. Most Cafés are free of charge, though donations are always welcome.

Naturally, Memory Cafés usually offer refreshments! Some coffee, tea and simple snacks are part of the hospitality.

When Memory Cafés started, there were very few offerings for people living with dementia and their care partners that weren't just about problems, but that were places where you could go and have fun.

Above all, Memory Cafés should feel like home. This means that each one will be different. They should fit the language(s), culture(s), and interests of those who attend.

The best Cafés, in-person or virtual, are really interactive. The people who come share a part of themselves in Cafés structured to allow for great conversation. For some people, conversation is hard, but there are other ways to share and connect. When we meet virtually rather than in person this can be harder, but a silver lining is you can share things in your own home. We take advantage of that. People do a little show and tell of what makes them smile in their own home. That is almost the best part; people feel so connected. That said, people do love music, dance, movement, and more. At our Café, we had two sessions about the Boston Red Sox — and we had all these people come who don't usually attend. A group called Memories International led this, and they showed great clips from history, and people argued about the best plays. More men came out for that one.

Each Café should be inclusive and try to identify barriers that might make it harder for some members of their community to participate. Also it helps to have specialized Cafés, for example in houses of worship. People connected with that faith may have something special, a prayer, or a setting that resonates. It's also good to have Cafés in specific languages.

Each café should be inclusive and try to identify barriers that might make it harder for some members of their community to participate.

People of different cultures may have different ideas about dementia — what it is, what causes it, do they turn to a faith leader, or keep it in the family, or talk to a medical person? What are their values around caring for an older relative — do they feel we all need to do it ourselves, is it okay to involve professionals? There is also historic discrimination and ruptures in trust that make people feel there isn't someone they could trust. It's important that they have a resource from their community.

A lot of communities might find it hard to connect with a professional, but they have a strong ethic of "we're in this together." The differences are complex. One community partner of ours works with Russian speakers who are Jewish immigrants from the former Soviet Union. Because of what they had gone through, there was a strong feeling that you keep any kind

of disability to yourself. Where they lived [in the USSR], it was really dangerous to show disability or weakness.

Some immigrant communities who came here from better circumstances may have a different feeling about sharing what's going on with professionals or other community members. It's very specific to what people's life experiences have been. It's about listening, finding out what the specific group is dealing with and interested in, and what they need. Including participants in planning and implementation is important with regard to Memory Cafes or any type of programming.

A little history - Bere Miesen started the first Cafe in Holland in 1997. They spread around the world, and in 2008 Dr. Jytte Lokvig and Lori La Bey started the first Cafes in the US. In 2012, the Fox Valley Memory Project began, followed in 2015 by the Library Memory Project, making Wisconsin a hub for Memory Cafes. In 2014, JF&CS of Greater Boston started the JF&CS Memory Cafe Percolator as a free resource-sharing network for people who wanted to start Cafes. There is an incredible spirit of sharing among the Cafes, and our Memory Cafe learning community has participation throughout the U.S. and a few other countries, including Brazil.

In 2023, a group of Cafe leaders in this country came together to see if we could equitably and sustainably grow the number of Memory Cafes in the US. This group created the Memory Cafe Alliance, and many resources to help launch Cafes, including the above-mentioned national Memory Cafe directory at https://dfamerica.org/memory-cafe-directory.



SA Amigos Memory Café

Sara Masoud, MPH, Contributor

Sara, with the University of Texas Health in San Antonio, Texas, spearheads the Café. Since the pandemic, the Café team has met over Zoom. She shares these reflections.

Our team founded the first memory café that we know of in San Antonio. We began meeting in person in 2018 and went through several iterations before we found our groove. In 2019, the memory café went through a process of deciding what to call ourselves. The attendees spent three months and voted to choose SA [San Antonio] Amigos.

We are cultivating ownership of the space by the attendees. We wanted them to name the memory café, to suggest ideas for activities, and we've built that into our model. This year [2022], we have implemented "12 New Things" as our theme. In January, we had our regular guests all talk about something they have always wanted to try. I'm excited. Out of the 12 things, I've only done two of them.

One is making parquet [wood] coasters. A lot of our older gentlemen living with dementia don't resonate with craft stuff, but they liked this idea.

We want the conversations to help us build real connections with each other that honor the personhood of our guests.

A lot of people said they always wanted to be in a band or play music. So we started the "SA Amigos Found Sound Band" at one of our gatherings with a music therapist. People made music with everyday objects they could find around their house. For example, some people tapped on empty jars, shook a can full of dried beans, or ran a pencil along their jacket zipper. We've never tried to write or perform a song together. We've recorded it so the guests could share with friends and family members.

We also have some outdoor activities planned for the summertime. For example, a lot of people wanted to try making mosaics so we planned a gathering in the park to make those together.

There are a lot of conversation-based activities themed around the month. We really take care to not make our activities cheesy or childish. We want the conversations to help us build real connections with each other that honor the personhood of our guests. In one of our most beautiful "Creative Conversations" activities, we asked things like, "If your childhood were a smell, what smell would it be?" It evoked tears in a good way — "the smell of my mom's baking," "my dad's work boots."

We have a pretty loyal base of 10 to 15 people who are regular attendees at our gatherings. Out of 12 months, they attend at least six to eight a year. Others join in and out. In any given café, attendance goes up and down, we will have maybe 15 to 20. Maybe 70 percent are caregivers who attend by themselves, the rest come alongside someone living with dementia. It's pretty rare that we have someone living with dementia attend by themselves, but we do have some attend on their own.

Zoom isn't the most friendly way for everyone to join. Before COVID-19 hit, we met in person and had a free transport service offered by our community partners. Being virtual brings its own challenges, but we try our best to make it work. We now host quarterly in-person gatherings to include those who don't like to, or can't, join online.

We had 70 households log on for a virtual game of Lotería [a Bingo-like game popular in Mexico]. It was a bilingual activity. We do sometimes have some people who join us who don't speak fluent English. To help them be included, we have a volunteer co-host who translates. I found an artist on Etsy of unique tablas [boards] that you put the beans on. We got the registration and we mailed people their individual playing cards, making sure everyone had something different so we wouldn't have double-winners. We had prizes mailed to the guests who won. In between calling out cards, we would read the traditional riddles that go with each card and would invite guests to stretch with us or take deep breaths to help them feel relaxed.

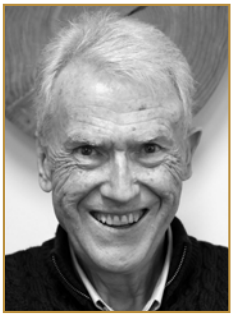
People went bananas for it — they just loved that activity. We try to do it every six months at our virtual Memory Cafés. We don't do it too often because when we are busy playing, there's not that inter-connection happening between the players and our goal is really to help people stay social and build connections. I want people to talk to each other.

There are also things that did not work for us. Starting in person, we were doing our memory café at a senior center. We thought this was a cool way to get into the older adult

community and provide an activity that is age-friendly. But people there were already connected in some ways. They didn't really need the memory café as much as those who weren't already attending senior centers. We moved into a community space with a local organization, Jefferson Outreach, who provides free transportation to homebound seniors and people living with disabilities. It was truly a great partnership and the transportation really helped people. One participant said, once a month, this is the only time I leave my house.

In terms of virtual cafés, we had to plan a lot harder. You can't put people in a Zoom room and expect conversations to just happen on their own. In real life, that happened organically, and same with being bilingual. I didn't realize how much planning had to go into a virtual café. We plan at least a month out. I have what I call our "secret ambassadors." I'll reach out to guests who are really committed to the Memory Cafés and ask their advice on planning, outreach, and more. We have members who share our goals to help families impacted by dementia stay socially connected to their communities. These guests are really the best partners. During the memory cafés they'll often try to help me engage quiet or reserved guests by saying, "Hey so-and-so, tell me about this." The ownership component [by attendees] is something I'm really proud of. This is their space to make connections, explore their creativity, get to know their partners, and cognitively engage in a judgment-free gathering.

2.5 Being a Dementia Advocate



Jim Mann, Manual Guide

It took me about a year to be more open about my diagnosis of dementia. I needed to feel comfortable with my new reality. I needed to know more about dementia and what it would mean for me in all facets of my life because I knew I would be asked questions. I needed information so I could adequately respond.

My early journal entries remind me how scary I found Alzheimer's in the early days. The disorientation. Understanding the sensory changes caused by dementia and my new feelings about crowds, all took a bit of time as did the constant adjustments to my activities of daily living. I understood the need to come to grips with this new life, adapt, and continue living sensibly.

A diagnosis shatters your self-confidence. Your self-esteem. Which I now realize is a factor in our withdrawal from activities. And for some, society. I'm glad I took the time to learn and understand as it gave me newfound confidence.

I realized too, I needed more than that: I needed a purpose. I needed a reason to get out of bed in the morning. What could I do? I was still driving but I wasn't able to continue consulting. Perhaps, I thought, I could volunteer using the same skills I had in business where I was an advocate, a communicator, and a marketer. Plus, I had the experience of seeing dementia through my mother's eyes.

I once read, 'If they don't give you a seat at the table, bring a folding chair.'

And there it was. I'd identified my purpose, I had confidence, and I knew some of the issues. The stigma surrounding dementia I'd seen when my wife and I were alongside my mother after my father's passing was eye-opening. I realized what a big issue stigma was. But what about opportunities to hear from the person living with a diagnosis? It was there I felt a vacuum, so I put my hand up. And then my world changed.

Being an advocate and speaking out whether one-on-one or in a meeting, we educate. We advocate to educate. We increase awareness because we live with dementia, which others need to hear. If we don't tell the story — our story — who will, and how will stigma be challenged and the stereotype of a person with dementia change?

- We can downplay the power of advocacy. But we shouldn't.
- We can diminish the strength of education. But we can't.
- We can ignore the significant power of the individual. To our peril.

Each and every one of us is a powerhouse. As a self-advocate, I have chosen to be active through committee and board work with dementia-related organizations. I have also focused my time and work in areas where I feel I may make a difference and in some of those areas the voice of a person with dementia has been absent.

I was diagnosed with Alzheimer's in 2007 at the age of 58. The experiences, the conversations I've had, and the reactions I've heard, have all added to the richness of my life. Some have been heart-warming and some have been jaw-droppingly surprising.

Like a well-educated person in medicine who assured me he knew, after seeing me on a panel, that I didn't have Alzheimer's. Look at the way you're dressed, he said. (I'm glad I had someone with me for that one!) I consider encounters like these to be teachable moments, my opportunity to nicely outline where our perspectives and experiences differ. Hopefully they will walk away and reflect on what they have heard.

- That's how we make a difference.
- That's how we can improve our environment.
- That's how we can move mountains.

And that's why it is important for us to be at the table. A policy table or a table alongside researchers as the preparatory work on their project's submission is being compiled. Where our perspective, our lived experience can and will contribute to better and more robust outcomes. I once read, "If they don't give you a seat at the table, bring a folding chair."[1]

I speak to university students periodically and after speaking to one class of master's students in health, I received a note from one of them saying in part:

> *Your talk was very insightful and gave me a completely new perspective of understanding dementia patients, their challenges and the problems faced by patients and relatives at care facilities. It would definitely help us in gaining a deeper understanding and help us do good work in future.*

That is how we will effect change. That is how you can effect change. Are you ready?

2.6 Living Alone with Dementia



Rev. Dr. Cynthia Huling Hummel, Manual Guide

Soon after I was diagnosed, I started to look into some of the programs and services in my area for those living with dementia. I figured since I was diagnosed with younger onset Alzheimer's, I should learn as much as I could about what was ahead.

I did some research and started making phone calls. One receptionist at an area agency on aging told me bluntly that their programs and services "were for dyads."

1 The quote is from Shirley Chisolm, the first African-American woman elected to the U.S. House of Representatives.

I asked her what she meant, and she gave me some examples. "Typically we will get a call from a husband or a wife who is caring for a spouse who has Alzheimer's, or we sometimes will get a call from an adult child who is caring for a parent with dementia. We don't have services for people who are living with dementia by themselves. If you want to use our services, you have to come with a care partner." I was fuming, but I explained as calmly as I could that I didn't have a care partner, that I was my own care partner and that I was living alone. The receptionist seemed annoyed and told me I wouldn't be eligible to attend their programs unless I came with a care partner. I hung up. I was so angry and humiliated.

Too often, single people living with dementia are singled out and excluded from supports and services because we do not have a care partner.

I've talked to other friends who are living alone and living with dementia — and my experiences are not unique. This happens all the time. It's hard enough to find the right supports and services for those living with dementia. But if you're looking for an additional challenge, try doing this on your own. It sometimes feels like I am running an obstacle course.

I remember a time when I tried to register for an upcoming conference and was told that I needed to have a care partner accompany me. I was really miffed and I shared this with my friend, Diane, who immediately offered to meet me at the conference and to be my "care partner" for the day. While I appreciated Diane's kind offer, I declined it. I ruminated on the agency's negative response. It was crazy because I could drive 100 miles (each way) to get to the conference, but I would not be able to attend the conference unless someone like Diane was there to "keep an eye on me." AARGH! Another time, I heard about an upcoming picnic for those living with dementia (and care partners) with the same requirement of having a care partner there to supervise. That gave me an idea. I called my friend, Neil, who also lived by himself with dementia, and we decided that we would be each other's care partners. I drove to Neil's house and we went together. The organizers weren't too happy with our showing up without care partners. Too damn bad!!

It's upsetting enough to be diagnosed with dementia. It is even more upsetting to be treated as incompetent. It is humiliating to be excluded from educational and social events simply because you do not have a care partner. Thankfully, there are allies out there. Over the years, I met a number of sympathetic people who were willing to "bend the rules" and look the other way and let me attend programs by myself, but I worried at times that they might lose their job for allowing me to attend events alone. I am well aware that I am considered

by some to be an insurance liability — and that if something should happen to me while I am at an event by myself, there could be repercussions.

I am very aware that, at some point, I will NOT be able to travel or attend events on my own — but right now, I am able. Shouldn't that fact be acknowledged and celebrated?

Some of us are single by choice and some are single by circumstance, such as death, divorce, and relocation. According to the Alzheimer's Association, there are approximately 800,000 of us living alone with dementia. Too often, single people living with dementia are singled out and excluded from supports and services because we do not have a care partner.

As a pastor, I have often comforted people who have found themselves suddenly single, such as a grieving spouse, who is just trying to figure out next steps as she tries to imagine her life without her husband of 20 years. Sometimes "singles" will move in with a family member rather than live alone, and this arrangement works well for many. Some may take in a roommate. Some like myself are content to live alone. We are all different. There are benefits to the single life! I can get up when I want. I can eat what I want and when I want. I can travel when I want. I have heard too many stories from those living with a dementia diagnosis of family members who have taken over and forbidden them to do the things they once loved to do.

Yes, for now I am quite content to live alone. I say "for now" because the time will come when that will be more difficult. It is sometimes tricky to balance autonomy versus heteronomy — that is having someone who makes decisions for me.

Sometimes people react with pity when they hear that I live by myself. "Oh you poor dear! Isn't there anyone who might live with you?" I believe these people are trying to be helpful as they offer ideas for companions. "Couldn't your daughter move in?" or "What about having a home health aide?" "You've got an extra room, how about getting a roommate?" This unsolicited advice is not terribly helpful and seems to say, "Doesn't anyone care about you?"

It's time for organizations to rethink their policies around requiring care partners for individuals with early symptoms of dementia in order for that individual to be able to attend a program. Dementia is not a cookie cutter condition. Symptoms may progress more quickly for some people and require the assistance of a care partner. Others seem to experience a slower rate of symptom progression. Some may have trouble with wayfinding — others may not have this problem. We are all different and some require more support than others.

If you are a single person living with dementia, you may find that there are extra obstacles in your way as you seek to find the services and supports that will allow you to live your best life. Please don't give up. Keep pushing the envelope. If you are not already a member of Dementia Action Alliance, please connect with us. We have a number of online discussion groups as well as educational, social, and art events online — and we are here for you.

— Blessings, Cynthia

2.7 Finding Silver Linings in Your Unexpected Journey



Rev. Dr. Cynthia Huling Hummel, Manual Guide

I was chatting with a friend, and she told me that she was waiting for a contractor to provide her with an estimate for a hole in her roof. A heavy branch had come down during a storm and she had a mess. She said, "Thankfully, no one was hurt — and, thankfully, insurance will cover the repairs!" As she looked up at the sky through the hole in her house, she said wistfully, "Well looks like, I've finally got the skylight I've been wanting."

Carol experienced a silver lining. What's a silver lining? A silver lining is a sliver of hope or a positive prospect about a negative situation, such as having a hole in your roof.

I was facilitating a dementia support group for men, and one man was sad because he wasn't able to take care of his yard the way he used to. His wife had to hire a kid from the neighborhood to mow the lawn and trim the shrubs. Another man in the group said, "Jerry, Jerry — that's not a problem because now you have more time for golf. Heck, tell the kid to mow you a putting green." Soon all the men in the group were jumping in the conversation: "Hey Jer! No more dealing with poison ivy, no more raking! No more having to put out the grass clippings." The men in the group were pointing out the silver linings, and soon Jerry was joining in the fun. His face brightened and so did his mood.

Having a sense of humor helps! If we can laugh at a situation, it can help diffuse the anger or frustration we may be feeling.

Looking for a silver lining can change our outlook on life. Finding a silver lining can change our tears of frustration to tears of relief or even happiness. Some people are able to find a silver lining right away. They seem to do it automatically. For others, finding the silver lining is next to impossible. They just can't see anything positive about THEIR negative situation.

Thankfully, we can get better at finding silver linings — by exercising our positivity muscles and asking ourselves this question, "Is there anything, at all, no matter how small, that gives me a sliver of hope in this difficult or bleak situation?" Or make "Finding Silver" a game and challenge yourself to find one small silver moment. One of my favorite silver

lining stories is when I attended a free art class for people living with dementia. The focus of the class that day was mask making and attendees were invited to make one mask. I enjoyed mask making so much, I went home and over the next few weeks, I created 35 more masks.

My masks illustrate what it feels like for me to live with early symptoms of Alzheimer's. I took photos of each of my masks, wrote about each one, and published a book called, "unMasking Alzheimer's: The Memories Behind the Masks." My masks have been on exhibit in various conferences around the U.S., and ten of my masks were exhibited at the National Gallery of Art in Stockholm, Sweden. Additionally, free copies of my book were given to all the attendees at an international conference in Stockholm. A silver lining, for sure!

One way to get better in detecting silver linings is to "rerun the tape" in our mind of an upsetting encounter, like getting in an accident. We can go ballistic, or we can try to calmly assess the situation. What happened? A man in another car ran the stop sign and ran straight into your car. It was a scary situation indeed. But if you stop and breathe, you might notice that no one was seriously hurt, that the police came right away, and there was no real damage to your car. Sometimes, when we revisit situations, we can better see things in a positive light.

What do these examples have to do with living with dementia? For many, it is easy to focus on the negatives of living with a diagnosis. It's easy to focus on the challenges and problems that we may encounter each and every day. But if we choose to shift our focus and look for the silver linings, or positives, in our daily lives, we may just find that we feel better about life and about our situation.

Having a sense of humor helps! If we can laugh at a situation, it can help diffuse the anger or frustration we may be feeling.

Another way that we can find a silver lining in a situation is to ask ourselves questions like these: Who helped me today? What did I learn today? What happened today that surprised me? Who or what made me laugh? Sometimes, I don't see the silver lining in the moment — but it appears later when I reflect or reminisce. Instead of focusing on things in our lives that went wrong or the decisions that we regret, why not focus on the silver linings? Life is full of these little blessings if we only take the time to look. Practice gratitude! Give thanks for those people in your life who care for you and about you and for those sweet silver lining moments the day brings.

— Blessings, Cynthia

2.8 By Us For Us Guides

The By Us For Us guides are a series of guides created by a group of talented and passionate people living with dementia and care partners. They were founded in 2004 by Brenda Hounam, who was diagnosed with dementia at 53 and recognized there was a clear gap in support for people living with dementia and care partners in Canada. What makes these guides unique is that they were created BY people living with dementia, FOR people living with dementia.

The guides were developed using the Authentic Partnership Approach, which values the contributions of people with lived experience and involves working collaboratively and equally with others. People living with dementia were actively included in all aspects of developing the guides, from identifying topics and gathering information, to making decisions on final content and cover artwork. Input was gathered from people of different ages and backgrounds, who were living with different types of dementia.

The project was later expanded and now includes three series:

- A series for people living with dementia
- A series for people living with dementia and care partners
- A series for care partners

There are currently 15 guides that provide people living with dementia and care partners with information, strategies, and tools to enhance their well-being and manage daily challenges. Free copies are available online and hard copies are available for purchase.

The guides are supported by the Murray Alzheimer Research and Education Program (MAREP) at the Schlegel-UW Research Institute for Aging (RIA). To learn more, and to download the guides *Enhancing Communication and Managing Triggers*, visit: *the-ria.ca/resources/by-us-for-us-guides/*

SUGGESTED RESOURCES

Articles

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Daly, L. Fahey-McCarthy, E. Timmins F. (2019). The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis. *Dementia* 18(2):448-470.

Books

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Devi, G. (2017). *The spectrum of hope: An optimistic and new approach to Alzheimer's Disease and other dementias.* Workman Publishing. [Note: also available in large print edition]

Furman, R. (2020). *A healthy brain for life: How to prevent Alzheimer's, dementia, and memory loss.* Revell Company.

McFadden, S. (2020). *Dementia-friendly communities: Why we need them and how we can create them.* Jessica Kingsley Publishers.

Lokvig, J. (2016). *The Alzheimer's and Memory Café: How to start and succeed with your own café.* Endless Circle Press.

Taylor, R. (2007). *Alzheimer's from the inside out.* Health Professions Press.

Documentary

"Alzheimer's: What You Can Do," 2021. Virginia Public Media (PBS, NPR)	vpm.org/dementia-documentary-series

Websites

The Alter program was created in 2019 at Georgia State University to address the lack of resources and awareness around dementia in African American and faith communities.	alterdementia.com/
American Heart Association diet focuses on foods that are beneficial for brain health.	www.heart.org
Dementia Alliance International is an independent self-advocacy organization of people living with dementia.	www.dementiaallianceinternational.org/

Dementia Friendly America offers a host of resources to help communities create better support for people living with dementia and their care partners, including education and training materials, community sector engagement guides, and a community toolkit to foster the adoption of dementia friendly practices.	*www.dfamerica.org/*
Dementia Friendly America Toolkit	*dfamerica.org/community-toolkit/*
Dementia Friends USA (administered by Dementia Friendly America) is part of a global movement that is changing the way people think, act, and talk about dementia. Information sessions delivered through volunteers and an online tool help raise awareness of what dementia is, how it affects people, and the actions we can each take to make a difference for people touched by dementia.	*https://dfamerica.org/state-programs/*
International Association of Indigenous Aging (IA2) works to identify and implement the most effective solutions to the most significant issues facing American Indians, Alaska Natives, and Indigenous people around the globe.	*iasquared.org/*
Memory Café Directory provides a list of Memory Cafés around the country.	*www.memorycafedirectory.com/what-is-a-memory-cafe/*
MIND diet focuses on foods that are beneficial for brain health.	*www.medicalnewstoday.com/articles/mind-diet-linked-to-lower-cognitive-decline-risk-especially-in-women#How-the-MIND-diet-affects-brain-aging*
National Institute on Aging provides articles, studies, and tips on exercise.	*www.nia.nih.gov/toolkits/exercise*
SilverSneakers is a health and fitness program designed for adults 65+.	*silversneakers.com*
Sleepfoundation.org provides educational, evidence-based information on sleep	*www.sleepfoundation.org*
The Vegan Diet provides a nutritional overview and information for incorporating vegan principles and practices into your diet.	*https://www.webmd.com/diet/vegan-diet-overview*

VISIT
Demetia Action Alliance
www.daanow.org

SECTION 3: Emotional, Psychological and Functional Health

I use the analogy of a Christmas tree to describe that my dementia symptoms affect some aspects of my abilities, but many other important abilities remain. "A Christmas tree may have many lights and ornaments. Imagine that some of the lights don't work and a few of the ornaments have been removed. The Christmas tree is still beautiful and serves a purpose."

Laurie Scherrer, Manual Guide



We are each of us a whole person—and our health and well-being are the sum of our emotional, psychological, and functional health. Health experts and people living with dementia share their expertise, experiences, and strategies here to build understanding and next steps.

Explore Section 3 and consider:

- The Seven Domains of Well-Being
- The Changing Nature of Intimacy
- Self-Confidence Through Therapeutic Care
- Strategies for Living Safely at Home
- Mind-Body and Creative Practices

3.1 Your Overall Well-Being

Before being diagnosed with dementia, you may not have given much thought to actively supporting your well-being. Generally, people think of well-being in terms of physical health, but well-being is broader and includes social, psychological/emotional, and spiritual dimensions as well.

All dimensions of well-being are vital, important, and interconnected. Think about a time when you were at odds with someone important in your life and how it made you feel. You may have felt fine physically but unsettled emotionally and this affected your overall state of well-being. There are many ways well-being can be disrupted, including not feeling personally safe or financially secure.

> The Preamble to the Constitution of the World Health Organization *notes that well-being includes "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."*

Discovering you have dementia can certainly be a blow to your sense of well-being. You will need to become intentional about maintaining your well-being. It will require active work on your part. For most of us, this does not occur naturally. The good news is the rewards are more than worth your effort.

A Holistic View

Throughout human history, people have recognized the connections between mind, body, and spirit. Ancient practices such as meditation and prayer not only calm our thoughts and emotions but have been shown to support our physical health, lowering blood pressure, reducing stress hormones, and boosting our immune systems.

Many of us have experienced these mind-body-spirit connections, whether it's having butterflies in our stomach or trembling hands when we're nervous or feeling a lack of energy or changes in appetite when we're depressed. Our mood or mental state can affect our bodies, and vice versa. Developing habits that nurture health in mind-body-spirit aids in our overall well-being. For example, exercise can help our mental outlook, and becoming absorbed in music or a good conversation can distract us from physical ailments and lift our spirits.

Unfortunately, when doctors deliver a diagnosis of dementia, they often say that there's no treatment and nothing you can do. "It would be good if instead they'd say, 'You'll have some challenges. Here's what we can do to manage symptoms and have a quality of life that you enjoy. Let's figure out what you enjoy now and what sparks joy for you, so we can build upon that,'" says Colin Milner, CEO of the International Council on Active Aging. His organization's members include 10,000 senior living communities.

Advocates for improving the quality of life for people living with dementia argue that too much focus has been placed on pharmacological "fixes," and not enough attention paid to enhancing well-being and quality of life. If you focus on cognitive losses and inabilities, you miss focusing on what you can do, how you can compensate for changing abilities, make accommodations, and have a positive attitude. Being proactive is transformative.

Dr. Jason Karlawish stresses that our well-being also depends on the world around us. In his book *The Problem of Alzheimer's*, he describes dementia as a "humanitarian problem," not just an individual challenge. "Imagine a world reconfigured to support changing cognitive abilities. Some of these innovations will be technological fixes to the environment, sort of sliding doors and voice recognition devices for the mind; others will be changes in the ways we interact with, look out for, and support each other. Imagine a revolution in technology, society, and our culture," he writes. In an interview, he notes that we need resources to "accommodate" our brains. These include everything from sidewalks and walkable communities, to social structures to support care partners, to access to brain-healthy food.

"Dementia is a challenge that engages many people across multiple disciplines. It's affecting society broadly," he says.

3.2 A Framework for Emotional and Psychological Well-Being

"It is important to let go of a deficit-based approach to supporting people living with changing cognitive abilities and move to a strengths-based, proactive approach," notes Allen Power, MD, in his ground-breaking book *Dementia Beyond Disease — Enhancing Well-Being*. Drawing on a framework developed by the nonprofit The Eden Alternative (*www.edenalt.org*), Dr. Power explores seven domains of well-being:

- **Identity** — personhood, which is both sacred in itself and a reflection of how others view us. Our identity emerges from our life history and all the unique experiences we have had
- **Connectedness** — a sense of belonging and involvement, being connected to those around us, to our home and belongings, and to nature, embracing creativity, spirituality, love, and hope
- **Autonomy** — choice and freedom, self-determination, not being coerced or constrained
- **Security** — freedom from anxiety or fear, safe (both physical safety and emotional security), living with privacy and respect
- **Meaning** — purpose, feeling needed and useful, making a difference
- **Growth** — changing, learning, developing, evolving, expanding
- **Joy** — happiness, delight, contentment, pleasure

The deep cultural stigma associated with dementia and the related fears and anxiety about what the future holds can undermine a sense of well-being. Stigma also contributes to self-isolation or to friends and family treating us differently. There can be frustration and sadness about not being able to perform activities in ways that once were routine. Changes in the brain may also contribute to depression and anxiety.

With intention and support, people living with dementia can help maintain their psychological and emotional well-being. "Improving people's experience of dementia means improving the support they get to process how they feel, and how they understand and think about the condition, their future, and their relationships. Maintaining a sense of control, identity, and connection is a key focus as dementia progresses," notes the British Psychological Society.

> *One of the issues that I have with my family is when they say "Oh, we can't do that because she'll get too confused or might not be safe. We can't go to the boardwalk because she might wander away" — instead of finding accommodations or ways we can do that safely. I say to them, you're looking at my inabilities instead of abilities.*
>
> **"Anne"**

Sherrie Dupuis of University of Waterloo in Canada notes that stigma, combined with a narrow biomedical view that sees the person as the disease, combine for a one-two punch to someone's psychological and emotional health. People living with dementia have told her research team that one of their frustrations is having dementia described as purely a cognitive issue. "Yes, dementia has cognitive components, but it's also experienced emotionally. We live in emotional ways. We all do as human beings. We need to reflect and teach about the experiences of dementia that can engage with emotions," she says.

One of the most important things in ensuring your emotional well-being is having a sense of purpose and making a contribution. (See *The Importance of Having Purpose and Goals* in Section 1.12, page 97.) "For all of us, well-being is impacted if we don't have a sense of purpose," says Angela Lunde of the Mayo Clinic. "Unfortunately, people living with dementia are especially susceptible to having their sense of purpose taken away."

"We have a sense of purpose in our younger years that changes as we age and even more so if we have a disease that causes dementia," adds Angela's colleague at the Mayo Clinic, Jodi Melius, RN. "That doesn't mean a person with dementia has to give up on a life with purpose, but they may need to think about it in a new or different way."

Maintaining Self-Confidence

Related to having a sense of purpose is self-confidence. "Often people living with dementia feel like they can no longer do certain things", says Angela Lunde. "This makes sense because if others don't believe in us; we lose confidence in ourselves."

Others — even those close to you — may make assumptions about what you can and cannot do. Try not to let that undermine your sense of self-worth. Be clear about your choices and preferences and let others know that you'd rather make a mistake than not try at all.

"Self-confidence can be optimized in persons with dementia when those around them stop making assumptions based solely on their dementia diagnosis, and when they focus on strengths rather than their deficits. If friends and family offer encouragement, persons living with dementia are much more likely to remain confident in their abilities, maintain activities, and even learn new things," she stressed.

At the same time, she adds, "Keep in mind that having dementia sometimes means letting go of things, such as driving. However, people living with dementia can continue to do many things especially with some adaptations and accommodations, or with a little assistance from others. Accepting assistance can be hard, but if it allows you to continue doing something you love, then assistance is a good thing."

Environment

Does Your Environment Support Your Well-Being?

You may find that you are much more sensitive to your environment than you were in the past. Don't be embarrassed or uncomfortable stating how you're feeling.

Consider:

- **Stimulation:** Too much stimulation may be disorienting and upsetting. Too little stimulation can be boring and unsettling.
- **Noise:** Choose your surroundings with intention. Environments with many loud voices and noises—parties, restaurants, outdoor festivals—may make it hard to concentrate and to have a good time. Visit community places and social gatherings that are more quiet or visit at off-peak times. Perhaps request a quieter table when you visit your favorite restaurant next time.
- **Sounds:** You may also find that sounds can become more confusing—with sounds on the television seeming to be coming from outside your door. Some people living with dementia may, because of changes in the brain, hallucinate footsteps (and also certain smells like perfume or smoke). Choose what comforts and soothes.
- **Smell and Taste:** Aging can affect our sense of smell and taste; some studies have also shown that losing a sense of smell is very common in most types of dementia and in Parkinson's disease. Some scents can evoke unpleasant memories, but some can bring back warm memories of bread baking and gardens in bloom.

Remember, whether it's physical or emotional comfort, ask for what you need.

When to Seek Professional Help

Sorting out manageable problems from mental illness that needs treatment, such as clinical depression, can be challenging. Many people living with dementia find that getting professional counseling or therapy is beneficial. Having a caring professional who can help you gain perspective or figure out strategies for managing problems is well worth the effort.

It may be difficult to find mental health professionals who are trained in supporting people living with dementia and their care partners. However, what is most important, says Angela Lunde, is to find someone who will listen, validate your experience, and whom you can connect with and trust.

If you are experiencing mental illness or psychological problems, going on medication may not be the first or best choice, says Allen Power, MD. "Antidepressants can be tried and may be helpful if clinical depression is present. However, some people living with dementia have a type of apathy in their demeanor that can look like depression but is not amenable to the drugs."

Be sure to check with your neurologist if another healthcare practitioner prescribes medication. If you have Lewy body dementia, for example, some prescription drugs, including anti-psychotics, could be dangerous. (See also *Medications and Medications to Avoid* in Section 5.4, page 287.)



When Thoughts Turn to Suicide

Susan Wehry, MD, Contributor

Depression can be treated, and suicide is preventable

Nearly 46,000 Americans died by suicide in 2020, according to the Centers for Disease Control and Prevention (CDC). Significant rate differences are found depending on age, gender, ethnicity, and race, but suicide occurs in all demographic groups. Specific suicide rates for people living with dementia are not known.

Thinking about suicide is common. One in 10 Americans say they have thought seriously about taking their own lives. What makes some people go on to die by suicide? The reasons are unique to each individual. Research shows that no one takes

their life for a single reason. Life stresses combined with certain risk factors, such as childhood trauma, substance use, chronic physical pain, bipolar illness, and depression are strongly linked to suicidal thinking, attempts, and completions.

Whatever the unique circumstances, a sense of hopelessness is common among people who seriously consider and die by suicide. The dominant doom-and-gloom narrative about dementia may make people living with dementia especially susceptible to a feeling of hopelessness. In addition, societal stigma over the "burden" of dementia and chronic illness on care partners may further instill hopelessness for people living with dementia. Research shows that when people living with dementia buy into these stigmas, they tend to avoid social interactions and become isolated. They are more likely to become anxious, depressed, and commit suicide. Fortunately, organizations such as the Dementia Action Alliance are effectively countering that stigma and supporting individuals with brain changes to thrive. This is not to minimize the real loss and challenges faced by people living with dementia, but only to say it is half the story.

Suicide is preventable. Asking someone directly if they're thinking about suicide won't "put the idea in their head" — most people are relieved when someone starts a conversation. Where depression is playing a role, getting treatment is critical: taking one's life is far too important a decision to make while depressed and depression is treatable. Getting someone through an intense moment of active suicidal crisis significantly reduces the risk they will die by suicide now and in the future. Most people who survive a suicide attempt go on to engage in life.

If you or someone you care about is talking about suicide, listen. Remind them they are not alone, and help is available. If they have a plan, find out if they have access to the means for carrying out that plan. Over half of suicide deaths in the United States are by firearms. Safely securing firearms can make the difference between life and premature death.

For more information, check out the American Federation for the Prevention of Suicide *afsp.org/* or call or text 988 (formerly the National Suicide Prevention Lifeline and now the 988 Suicide and Crisis Lifeline). You can also reach the lifeline at t 1-800-273-8255.

3.3 Intimacy and Sexuality



Emily Franke, LSW, MSW, Contributor

Living with dementia often alters sexuality and intimacy including those in long-time relationships. The following are some suggestions to help you discuss and handle issues that may arise around what can be sensitive topics.

Changes are Common

If you are living with dementia, you may worry that your spouse or significant other will not feel the same towards you. You may find that your own sexual desires have changed. Some people continue to experience an active sex life, while others have increased or decreased libido. Some people living with frontotemporal dementia, for example, because of changes in a particular part of their brain, experience an increase in sexual desire along with a lack of inhibition. (See *Frontotemporal Dementia*, Section 8.9, page 451.)

> *Intimacy, both emotional and physical, is a basic human need that does not go away simply because somebody has dementia. It is perfectly normal to still have desire — and it is perfectly normal to have desire fade.*
>
> **Angela Lunde, MA, Contributor**



Changes related to sex may be physical or emotional, which aligns with the different types of intimacy that all humans enjoy. Physical intimacy is about touch and closeness between bodies. In a romantic relationship, this closeness may include holding hands, cuddling, kissing, and sex. Your relationship doesn't have to be sexual or romantic to have physical intimacy — hugging friends and family is an example of non-romantic physical intimacy.

Psychological or emotional intimacy is the sense that you could be open and honest in talking with someone else about personal thoughts and feelings not usually expressed in other relationships. You may be psychologically intimate with friends or family in addition to your partner or spouse.

There may be several factors that are affecting the changes you notice related to sex and intimacy; this is normal. It may feel overwhelming trying to identify what is going on. But it's not always necessary to identify a specific cause to begin to address the overall issue of changes associated with sex. Approaching these changes with curiosity instead of judgment lends itself to finding solutions that work for you. When it feels overwhelming trying to figure out where to start, consider the **3 T's**:

- More **time**
- More **touch**
- More **talking**

Time: *Might mean initiating intimacy over a longer period including more foreplay both physical and emotional. Taking time to get comfortable and relaxed so that feelings of love and affection become the focus instead of focusing on performance (like achieving orgasm).*

Touch: *Refers not only to sexual touch (touching of genitalia) but also affectionate touch. Affectionate touch may include massage, kissing, light tickling, or touching other areas of the body such as the shoulders, back, or feet. It might also mean increasing time spent physically close to your partner, cuddling for instance, with no goal like having sex in mind.*

Talking: *Might be a wide variety of activities including discussing your concerns with your partner, your healthcare provider, or other supports in your life like friends or support group. We will dive into talking about it in the next section.*

Talking about "IT"

Discussing sexual matters can be uncomfortable. Very few people look forward to having the "birds and the bees" conversation at any point in their lives. In her book *Dementia Reimagined*, Dr. Tia Powell notes that our culture is uneasy about older people having sex. "But the problem is even broader. There are prejudicial ideas about people with any sort of disability engaging in sex," she writes.

For LGBTQ+ individuals living with dementia, there is an extra layer of prejudice. According to the Alzheimer's Association's 2018 *Issue Brief on LGBT*[1] *and Dementia*: "Gay, lesbian and bisexual older adults face the additional barrier of [healthcare] providers who do not recognize that many people are attracted to people of their same gender, or who harbor negative opinions about same-sex sexual contact. Healthcare providers need to examine their own beliefs and prejudices, as well as organizational policies. A same-sex sexual relationship may trigger the family's or care partner's biases toward or about the LGBT community."

Whatever your situation or identity, try to be open and honest about your feelings, even though sex can be uncomfortable to talk about, even — or especially — with your partner.

So, what can you do?

- Use "I" statements.
  - For example, "I feel worried that you might think my lack of desire is a lack of desire for you rather than a result of my diagnosis." Instead of "You make me feel guilty for not having a desire for sex."
- Try using "Ask, Tell, Ask" as a framework for starting conversations.
  - Ask for permission to talk about sex or intimacy.
  - Tell the other person what you are feeling or experiencing using "I" statements.
  - Ask what they think about that information or how they are feeling.

Frustration, guilt, anger, grief are all normal emotions when an intimate relationship changes. If you are feeling this way, your emotions are valid and worth discussing with your partner or support system.

[1] LGBTQ+ is currently the term preferred by the LGBTQ+ community. When the Alzheimer's Association's paper was written in 2018, the preferred term was LGBT.

"I feel more guilt than anything," says Jo (not her real name), who is living with dementia, about her lack of interest in having sex with her husband. "I feel guilty for more than one reason. I feel guilty because I have this stupid disease. Afterward, I feel awful because I've just been laying there. He's understanding, but I know he's frustrated. I don't know how to talk to him about it."

She is hardly alone. "People living with dementia have a sense of guilt and burden," says Jodi Melius, who facilitates many support groups at the Mayo Clinic. "Try to find intimacy in other ways if sexuality is not a place of comfort."

"My lack of interest started around the time of my cognitive problems, but years before I had a diagnosis," says Celeste (not her real name). She said her sex drive went from a "7 down to 2" on a scale of 10. "I now have very little interest in intercourse, but more interest in hand rubbing or that kind of intimacy. I have not had a conversation about it. I feel like he might take it personally and feel like it's him and not the dementia. I don't want to hurt his feelings."

People from the LGBTQ+ community who are living with dementia often experience these same challenges, though they can be heightened. A 2014 survey found that one in three LGBTQ+ older people are very or extremely concerned about "being lonely and growing old alone," as compared to 19 percent of non-LGBTQ+ people.

Seeking Medical Support

Many people as they age lose some of their sexual desire or function. Medication and medical problems, as well as age, can affect libido. But most people, both from the LGBTQ+ and heterosexual communities, continue to be sexually active, including those living with dementia. A 2018 study by researchers at the University of Chicago, for example, found that the majority of people living with dementia who are partnered and living at home are sexually active (59 percent of men and 51 percent of women).

Men living with dementia can experience changes in their sexual performance. "My issue is I cannot ejaculate when I am having sex with my wife. I get aroused but it is very hard to climax," says Tom (not his real name). Women may experience changes in vaginal lubrication, increased or decreased sensitivity, or vulva and vaginal wall thinning and shrinkage (vulvovaginal atrophy). While some changes are normal and age-related, others may be related to medication or medical diagnoses.

"More than one-third of men and one in 10 women in the study's dementia group reported bothersome sexual problems, but only 17 percent of men and one percent of women living with dementia talked to a physician about sex life changes that result from a medical

condition like dementia," according to study author Stacy Tessler-Lindau, MD. If a physical or mental change is affecting your satisfaction with your sex life or is resulting in pain, talk to your medical providers.

There are options for specialized counseling to discuss topics like intimacy and sex. Ask your doctor for a referral or recommendation. You may find that your medical provider is not well-versed in the topic of sex, due in part to societal stigma. If you encounter this, don't be discouraged. Raise the topic in a dementia support group where you've established a sense of trust and can hear what others are going through. "Being able to express myself freely made me feel very comfortable that I wasn't alone," said Jo of her experience discussing this with other women who live with dementia. "Maybe I won't be so hard on myself."

Tip: Using "Ask, Tell, Ask" is a good way to start conversations with a medical provider also!

Take Home Message

Whether or not you have a sexual relationship with anyone, maintaining physical and emotional intimacy with friends, family members, and others is critical to your well-being.

> *Our love has never been stronger.*
> *The "wild monkey sex" is gone.*
> *But the tenderness, the touching,*
> *the waking up in the middle of*
> *the night together is there.*
>
> **A care partner (who asked not to be named)**



Finding Intimacy if You're Single and Gay ... or Anyone Else

John-Richard Pagan, Manual Guide

Sex is a topic that comes up in support groups I lead. It's important to think about how sex and dementia relate to one another. What happens in Lewy body dementia, which I have, is that we have autonomic dysfunction. This can affect one's sexual drive. For some it's an overly active drive while for others we have a total disconnect from our physical sexual drive. This can be amplified by behavioral changes, which decrease emotional desire. How does that affect your sexual relationship — or does it?

When I was diagnosed originally with neurodegenerative disease and then with Lewy body dementia, I was with a partner who was half my age and who had a very strong sexual drive. My sexual drive completely dropped off — I had no sexual drive whatsoever. I felt like I had failed the relationship, and I couldn't provide what he needed. He would say, "It's okay and I'll work with it," but you could see it was really frustrating for him. I finally ended the relationship partly because of the lack of desire for sexual intimacy and because he was younger, and I questioned his ability to care for me if the time came. I believe in monogamy and I didn't believe in stepping out of the relationship [for sex], so that was not an option.

I got to a point where I thought a sexual relationship was impossible and, therefore, I would be by myself for the rest of my life. In talking with others about sex and relationships, I've found that for some it's true — it's all about the sexual drive, their libido. When that stops or decreases, that becomes a hindrance in the relationship. But for others, there's a recognition that there's something beyond the actual sexual connection for the intimacy of the relationship. Intimacy can include anything from cuddling to foreplay and just enjoying one another's company. I've become comfortable with that. And with thinking that a relationship is possible. I just need to be honest with the person I'm in a relationship with and let them know that I can only go as far as I can go.

I've talked to other people whose sexual drive was magnified after diagnosis. They wanted more sex than their partner did. I encourage them to be creative finding new ways to make it interesting for them and their partner, including seeing a sexual counselor to suggest new methods of enjoying the intimacy ever deeper.

Due to my spirituality, I've also come to a place where I trust my Creator that I will be exactly where I need to be regarding a relationship. My mother [my care partner] thinks I should not be in a relationship because of my dementia. I understand that. It's easy for children and parents of people living with dementia to think intimacy is over for that person. They want to take care of them, and they can't see that person being sexually active. In care communities, it's not uncommon to find that someone has crawled into another resident's bed for sexual intimacy.

Living with dementia doesn't mean that the drive for intimacy isn't there. I look forward to having another intimate relationship. I know it will probably be a lot more hugging, kissing, and holding hands and going for walks together or watching movies. I really feel the right person would be okay with that. I've gone from feeling hopeless to feeling hopeful.

As a former psychotherapist, I listened to people talk about their intimacy and sexual behaviors. It's nothing to be shameful of. Your physician may not be willing or comfortable talking about or asking about your sexual life. If that is the case, you could talk with a psychiatrist or therapist.

Intimacy and sexuality are natural parts of who we are — we're meant to be intimate beings and we're meant to be sexually active until we're not. There's no shame. We don't have to do something because we're submitting to our partner's needs. We can acknowledge where we're at and find new ways of being intimate. That was something I was really surprised at when I led the Lewy body dementia group — others who had lost their drive didn't know how to connect with their partner. Didn't you go to the beach or take long walks or hold hands when you were dating? Do the same things. Stimulate yourself in other ways. And go as far as you want to go comfortably when it comes to sex.

As a single gay man, my biggest challenge is how do I tell somebody that I have dementia — how do I date somebody and be completely honest? I can tell you that in the gay community, sex is a huge part. It is hard to find somebody who's willing to talk to you and doesn't want to immediately jump into sex. For me, some of it also has to do with, "Do I want to burden somebody else?" There is that word, burden. We try so hard not to use the word "burden," but it sits in the back of our minds, as people living with dementia. Do I have the right to burden someone else if my condition progresses over time? My dementia affects my ability to walk and my balance. I have a cane, and I have a walker I keep in my car. I'm not the guy you are going to take on long hikes! It leads me to pull back from social interactions, not taking a chance out of concerns of acceptance.

It's been challenging to be single. My spirituality is part of what keeps me sane. It gives me some peace and reminds me that if it's meant to happen it will happen. I work hard to accept that.

3.4 Functional Health





Angela Edney, MSA, OTR/L,
Alka Mehra OTR, CLT, RAC- CT and
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Aegis Therapies, Contributors

Your "functional health status" refers to your ability to perform daily activities to meet basic needs and fulfill your usual roles. Prioritizing your functional health will help you maintain independence and dignity, and enhance the quality of your life.

To maximize functional health, you may want to consult with therapists, including physical therapists, occupational therapists, and speech-language pathologists. A good therapist will assess your condition and needs and help you develop strategies for maintaining your capacity to participate in day-to-day activities. This in turn will give you confidence in your abilities.

Therapists can adjust your routines as needed. For example, Mr. Jones was worried about forgetting his daughter's birthday. By working with an occupational therapist, he was able to create a manageable reminder system. Your functional health status is an important factor not only in determining your overall health, but also for measuring your risk of having an adverse event, such as a fall. Therapists can identify risk factors to prevent or manage things like maintaining balance and strength and learning cognitive and word-finding strategies. They can help you learn about the connection between sensory changes that you may be experiencing (vision, hearing) and your body's ability to navigate spatially.

You can get help figuring out how to continue to pursue the activities that you enjoy and that give you meaning and purpose. An "occupational profile" is a summary of your history and experiences, patterns of daily living, interests, values, and needs, based on your cultural background. With your assistance, your therapist can create a comprehensive profile to provide you with individualized care.

Independence and Confidence in your Body

Having confidence in your abilities is a life-long effort for many of us and is made more challenging for people living with dementia. You may have concerns about losing independence and personal autonomy. Here are some steps you can take:

- Reflect on your fears and concerns and identify your goals for the future.
- Educate yourself about dementia using manuals like this one and reach out to trained professionals to gain a better understanding of how dementia can affect your body and life course.
- Have open discussions with family and friends about your fears of losing independence and personal autonomy. These discussions will help others know how to best support your goals.
- Find out what resources are available to help guide you and your family/friends through the course of your condition and to plan for ways to preserve quality of life.

To promote your independence and self-confidence you may want to participate in therapy and/or social groups that are geared toward promoting positive self-image. Continuing to acknowledge your strengths and abilities and prioritizing self-care are all important aspects of promoting a positive self-image, and especially important for people living with dementia. As abilities change with your symptoms, counseling and therapy can teach you coping mechanisms to deal with those changes. Some individuals opt to take a spiritual approach to their self-care and coping techniques, such as meditation, prayer, music, and mind-body centering.

As discussed earlier in this Manual, trying new activities and interests also boosts confidence. New experiences promote learning and can stimulate the brain to grow and form new connections. Just as the phrase "use it or lose it" promotes exercise to maintain muscle strength and stamina, the same applies to our brain functioning.

Develop Good Routines and Stick to Them

Routines play an important role in helping you maintain functional health and independence. Developing a good daily routine that works for you early on in your diagnosis of dementia, and sticking to that routine, will help later when attention and forgetfulness may make daily tasks more difficult to complete. Writing down your daily routines and schedules helps promote consistency. Consistent routines, such as getting up at the same time every day, completing weekly chores on set days and times, and following the same grooming routine each morning and evening help reduce the chances of "missing" an important task and

reduce the chances of a functional decline. This predictability will help reduce confusion related to time and events, as well as improve short-term memory of events.

Success can be enhanced further by ensuring your family and friends understand how consistent routines can promote your independence and functional health. Occupational and physical therapists, as well as speech-language pathologists, can assist with creating daily and weekly routines or schedules. Mental health therapists also play an important role in helping to adapt these routines as your symptoms advance, to help you continue to thrive in your desired environment.



Mix Up My Routine = Mix Me Up

Laurie Scherrer, Manual Guide

Her brother calls her every morning. For three days, he couldn't call.

This insignificant little change threw me into four days of "Dementia Daze" (some call it a fog). Suddenly the "routine tasks" I performed every day were a challenge. I couldn't remember what I had done and still needed to do. Since I couldn't accomplish the "routine" tasks, the other tasks on my list seemed extremely overwhelming. Unable to process how to rearrange my day, I walked around in circles, pacing the room, trying to think it all through. The feeling of being lost triggered more confusion and frustration.

What Types of Therapists Support Functional Health?



Angela Edney, MSA, OTR/L,
Alka Mehra OTR, CLT, RAC- CT and
Rachael Redman, MsED, CCC-SLP,
Aegis Therapies, Contributors

Physical Therapy

Physical therapy helps restore and maintain physical health. Among the treatments physical therapists provide:

- Gait training to improve walking abilities
- Physical exercise to improve strength, range of motion, and function
- Balance maintenance
- Wound care to improve skin integrity and promote wound healing
- Pain reduction
- Safety awareness and education
- Falls prevention strategies
- Activities to improve cardio-respiratory status

Physical therapists can help improve the lives of individuals living with dementia by finding strategies that focus on enhancing function, independence, and safety.

Occupational Therapy

With strong knowledge of a person's psychological, physical, emotional, and social makeup, occupational therapists can evaluate how your condition is affecting your body and mind using a holistic perspective.

They provide a person-centric approach to ensure an individual's ability to live independently, safely, and to the highest potential including learning principles of work

simplification/energy conservation strategies. Occupational therapists provide home safety assessments, recommending durable medical equipment like grab bars, bath bench, toilet safety devices, and other home modifications like ramps, railings, stair lifts, and more. Occupational therapists also help with other adaptations in your home to increase safety and independence, such as adaptive silverware and grooming and hygiene tools (e.g., toothbrush, comb, hairbrush). Additionally, occupational therapists can provide necessary family and care partner education. They will recommend additional support services if needed, such as a home health aide to assist with bathing or to assist with cooking, laundry, and grocery shopping. This can allow people living with dementia to remain in their home environment of choice for as long as possible.

Occupational therapy practitioners may also work as consultants in health information technology, addressing health of the communities, education, e.g., in schools, driving and community mobility, and many others.

Speech-Language Pathology

Speech-language pathologists (SLPs) assess, diagnose, and treat speech, language, and swallowing disorders (known as dysphagia). A speech-language pathologist can assist you with word-finding, organizing thoughts, paying attention, remembering, planning, and problem-solving. For example, when working with a speech-language pathologist you may work on how to use memory aids and strategies for remembering details of an event, situation, or a person's name.

One common, evidence-based approach used by speech-language pathologists is called "spaced-retrieval with errorless learning," which helps you recall pieces of information. When using this approach, you and your speech-language pathologist will together determine an important piece of information that you would like to remember with greater ease, and then choose a target question to evoke a desired physical or verbal response. Next, your speech-language pathologist will systematically increase the time intervals between the questions, to create opportunities for recalling and learning the desired information. Together, you and your speech-language pathologist may use spaced retrieval to help you remember a specific phone number or a step needed to complete a daily task safely. They also might train your care partners to understand the technique.

Other areas might involve training and counseling on effective communication approaches to use with your partner/spouse, children, and friends. These approaches can reduce instances of communication breakdown and frustration. Simple strategies include reducing environmental distractions, like turning off the TV or radio, or facing each other when speaking or making sure that everyone in the conversation knows

the topic and when it has changed. This may not always be easy for individuals having trouble with attention or hearing changes or if you're in a crowded room.

A speech-language pathologist can also assist with swallowing disorders, which occur in seven to 23 percent of older adults, and more so with people living with dementia.

Tips for Dealing with Swallowing and Speaking Concerns

Dehydration, malnutrition, unintended weight loss, and respiratory infections can contribute to difficulty in swallowing. This in turn reduces quality of life and functional health. Swallowing disorders are commonly the result of sensory or motor changes within the body's nervous system (or a combination of both). They may also be a result of a behavior, such as rapid eating or taking large bites that affect the control of chewing and swallowing.

A speech-language pathologist can work with you to address a swallowing disorder. They can help you compensate with strategies such as:

- Taking small bites or more frequent sips
- Learning exercises to restore and strengthen the muscles used with swallowing
- Changing your position when you eat or drink
- Modifying temperature, taste, or food texture and liquid consistency

As noted above, an occupational therapist can help you learn to use adaptive silverware, cups, and other equipment.

Another common problem caused by age and/or medications is dry mouth (xerostomia). The effects of dry mouth can result in difficulty chewing, as well as swallowing food, liquids, and medications. You may consult with your physician or SLP on using different natural and over-the-counter treatments to address dry mouth.

The ability to communicate our thoughts and ideas is something we take for granted every day. The ability to talk is an intricate process beginning with thoughts in the mind that we formulate into words to speak. Your brain creates patterns that it connects and sends to your mouth to communicate. The process of speaking occurs with the use of many muscles in our face, lips, tongue, and throat, as well as muscles for breathing.

Changes in speech can occur in different types of dementia, and may be a result of a breakdown in the brain's ability to create and send the patterns to create sounds from your mouth. Muscle weakness or a combination of both brain changes and muscle weakness

can also play a role. These changes may help in diagnosing what type of dementia you are experiencing.

As we get older and more sedentary, our breath becomes shallower, affecting our ability to project our voice and talk. Increasing your breath support may help you reduce fatigue when communicating, and enhance your ability to speak longer phrases and tell stories, by lessening excessive pressure on the muscles in your throat and mouth. In cases when speech becomes very difficult, a speech-language pathologist might recommend the use of technology to facilitate communication.

Enteral Nutrition (Tube Feeding)

Currently, there is little evidence that tube feeding improves survival, quality of life, or pain for individuals living with advanced dementia. It's important to talk to your healthcare provider about the risks and benefits of alternative ways of providing nutrition versus tube feeding, as well as making sure your family and support networks understand and respect your wishes in the later stages of dementia. Be sure to keep a written record of what you want and share it with your doctor, family, and care partners. (For more on advance directives, see *Getting Your Financial and Legal Affairs in Order*, Section 4.8, page 250.)

Maintaining Motor Control and Balance

Motor control refers both to your reflexes and to your ability to direct movements to complete tasks or stabilize your body in space. Balance (postural control) is the ability to maintain a center of gravity that allows you to stand upright and move around without falling. Good balance requires coordination of the brain, nerves (sensory and motor), bones, joints, muscles, ears (hearing), and eyes (vision). Another important part of balance is related to a term called "proprioception," which refers to the position of your body and how your body knows where it is in the world. Motor control and balance work together to help your body move and complete daily tasks.

As we get older, we tend to lose muscle mass and function. Physically inactive people can lose as much as 3 to 5 percent of their muscle mass each decade after age 30. This progressive muscle loss, as well as changes in the brain associated with dementia and aging, can affect your motor control, balance, strength, flexibility, and range of motion. This in turn increases the risk for falls.

To prevent muscle decline, incorporate physical activity into your daily routines. If you notice changes in motor control and balance, seek help from a physical or occupational therapist to

reduce the speed of functional health decline. There may be ways to adapt your environment to help ensure safety and security, as well as promote independence and functional health, as your symptoms change.

The Seattle Protocols are an example of a set of effective exercise programs that have been researched. Originally developed to treat depression in people living with dementia, they have also been found to increase physical function and to improve mood and slow the development of advanced cognitive symptoms. According to an article in the *Journal of Nutrition and Healthy Aging*, the Seattle Protocols make exercise a "pleasant activity" and teach people living with dementia and their care partners strategies for successfully establishing and maintaining exercise goals.

3.5 Living Safely in Your Home

People living with dementia are four to five times more likely to fall than older people who do not have dementia. For those who fall, the risk of sustaining a fracture is three times higher for people living with dementia. Changes that increase your risk of falling include:

- Perception that affects judgment and the ability to reason
- Recognition of sensory input, such as sight, sound, and touch
- The ability to understand and express needs
- The brain's inability to coordinate movement and to communicate with the muscles to carry out day-to-day functions despite having the physical ability
- Misinterpretation of the environment, causing illusions and misperceptions regarding depth, light intensity, color, pattern, and temperature
- Loss of memory and challenges with new learning
- Difficulty in initiating tasks, leading to immobility

If you fall, these are the kinds of questions a healthcare professional will consider:

- Is there a reversible cause or is it related to another medical condition?
- Are you taking multiple medications?
- Are you experiencing medication side effects or interactions?

- Are you taking your medications as prescribed?
- Do you have changes in your vision?
- Has your mobility changed?
- Are you restless?
- Are you fatigued?
- Are you experiencing pain that you have not been able to communicate?
- Do you have adequate nutrition and are you drinking enough liquids?

Things You Can Do

- Ensure adequate lighting (increase lighting, reduce glare, limit shadows)
- Keep pathways clear (declutter, keep floor surfaces level, dry, and non-slip)
- Remove area rugs
- Enhance accessibility (keep important items in consistent, visible, easy-to-reach places, lower bed height, use adaptive equipment)
- Increase bathroom safety (use a non-slip bathmat, a bath chair or bath bench, a handheld shower, and have an accessible emergency system close by such as Lifeline or cell phone)
- Grab bars (therapists can assist with appropriate location) by shower area and toilet
- Ensure safe footwear (buy shoes with Velcro closures, avoid walking indoors in socks or slippers, ensure outdoor footwear is appropriate for the weather)
- Reduce noise level (avoid sudden, loud noises)
- Use mobility devices correctly, if recommended (canes, walkers)

In addition, if you have a dog, have a routine for hanging up the leash. Or for a cat, consider moving the litter box to a higher surface to avoid tripping or excessive bending.

Be sure to ask your doctor if any of your medications might affect your balance and alertness.

Home Safety

Remaining at home safely with as much independence as possible is the goal of many individuals living with dementia. You may find success in maintaining your independence by making simple modifications to your environment and routines. The following ideas may help reduce the chances of life-threatening or other critical situations occurring throughout the course of dementia. (For more on home modifications and safety tips from those living with dementia, see *Supportive Home Modifications*, Section 4.7, page 245.)

- Installing automatic shut-off function for stove, microwave, electric kettle, or small convection/air fryer oven
- Keeping emergency phone numbers easily accessible (on the wall, back side of cell phone)
- Using your phone for safety (e.g., bringing it to the bathroom during shower, notifying family when you will be showering, buying a phone with a clip to keep it on you)
- Having an emergency alert button or smartwatch with falls impact detection
- Using a buddy system for safety checks (e.g., phone call check, set lunch date)
- Setting "location on" for smartphones
- Using medication tools such as an automatic pill dispenser or bubble-wrapped medications for each time of day (morning, noon, supper, and evening)

Adaptive and assistive equipment

At some point, assistive or adaptive equipment will likely be useful to maintain independence and safety. Determining the correct equipment for your needs depends on the skills of an occupational therapist who can assess what will work for you and your lifestyle. This may help you avoid unnecessary costs and plan for the future.

Adaptive and assistive equipment

- ☐ Digital or talking clock
- ☐ Grabber to help reach objects
- ☐ Smart devices with set reminders and checklists (Google Home, Alexa, iPad, tablet)
- ☐ Calendars and planners to promote organization and recall
- ☐ Sock aid or shoehorns
- ☐ Toilet risers
- ☐ Magnifying glasses or magnifying stands with light
- ☐ Seat cushions (promote positioning and comfort)
- ☐ Color contrast plates and dish ware
- ☐ Razor, brush, or comb extension handle

Gun Safety

As dementia impacts coordination, eyesight, memory, motor skills, judgement and decision-making, and more, gun safety is also impacted.

If you have firearms in your home, **make gun safety planning a part of your life planning.**

Be sure to:

- Consider how dementia symptoms have impacted your ability to access, load, and unload your gun, engage the safety, and clean your firearm in a consistently safe manner. Visit a shooting range with a trusted friend or loved one to have your firearm skills assessed.
- Consider how changes in your ability to manage strong emotions--depression, anxiety, anger, fear—might impact your judgement with a firearm present. Could impaired judgement in those moments lead to gun-related accidents or tragedy?
- Consider if you will always be able to communicate to others (loved ones, care providers, safety officers) that the firearm you may be holding is disabled. You may have taken steps to ensure that your gun is not operational, but will others know that in a moment of crisis?
- Craft a **firearms safety plan** *before* it is needed so that your care partners can include your knowledge and preferences. This is an opportunity to share your memories and experiences, and to also direct care partners to your firearm(s) and advise on their removal at designated points along your dementia journey.

Visit *firearmlifeplan.org/*
to get your Firearms Safety Plan started!

3.6 Mind-Body Practices



Julia Wood, OTR/L, Contributor

Mind-body practices are techniques designed to enhance the mind's positive impact on the body. These include behavioral, psychological, social, expressive, and spiritual practices such as yoga, meditation, tai chi, and biofield therapies. These approaches are becoming increasingly popular, with many having reported benefits for managing symptoms associated with various chronic diseases.

Reflective Exercise

Reflective exercise forms combine deep breathing, meditation, and any form of movement to obtain a state of deep relaxation. The most common forms are yoga and tai chi, which have been studied over the last decade to see if they can positively impact changes in cognitive, physical, or psychological outcomes in individuals living with dementia. More research is needed, but studies have shown positive results in a variety of outcomes including improved balance, improvements in various aspects of cognition, improved performance of activities of daily living, increased endurance, improved confidence and self-esteem, increased quality of life, and decreased care partner stress.

TAI CHI is a self-paced form of gentle physical exercise and stretching. It involves a series of movements performed in a slow, focused manner and accompanied by deep breathing. Each movement flows into the next without pause, ensuring that your body is in constant motion. Tai chi is low impact and puts minimal stress on joints and muscles, making it generally safe for all ages and fitness levels. Tai chi is inexpensive and requires no special equipment. You can practice tai chi anywhere, indoors or outside, alone or in a group class.

YOGA, which means union, is most commonly associated with the physical practice of postures woven together and coordinated with the breath. Yoga practice is generally intended to improve flexibility, coordination, and balance; build strength; calm the mind; and relax the body. Yoga can be adapted to a variety of abilities and ages, making it accessible for most people.

Mindfulness and Meditative Techniques

These age-old practices are based on Eastern traditions that focus on self-regulatory techniques to help one maintain attention and awareness. These interventions share a goal of working to "be in the moment" without judgment. Research over the last 25 years has shown a variety of positive effects from mindfulness-based interventions for people with dementia including improved sleep, better mood, cognitive improvements, structural brain changes suggesting neuroplasticity (the brain's ability to change and adapt), and increased quality of life.

Biofield Therapies

These therapies are based on the belief that human beings are fields of energy that are in constant interaction with others and the environment. These interventions involve modification of the human energy field by directing healing energy through the practitioner's hands. They include Reiki, Therapeutic Touch, and Healing Touch. They most likely impact well-being by promoting relaxation and reducing stress and anxiety. More research is needed, but studies have shown decreased agitation and improved mood, following participation in biofield therapies for people with dementia.

REIKI

Reiki is an energy healing technique that promotes relaxation and reduces stress and anxiety through gentle touch. Reiki practitioners use their hands to deliver energy to your body, improving the balance and flow of your energy to support healing. Studies suggest that Reiki may create feelings of peace, relaxation, and well-being. During a typical Reiki session, you lie on a massage table fully clothed as the Reiki practitioner gently places their hands on or slightly above your body in specific energy locations.

THERAPEUTIC TOUCH

This is where the practitioner hovers their hands over the body to correct or balance energy fields. Studies suggest that therapeutic touch may help reduce pain and lessen anxiety. Typical sessions are similar to Reiki.

HEALING TOUCH

Healing Touch uses gentle hand techniques thought to help re-pattern an individual's energy field, and accelerate healing of the body, mind, and spirit. The goal of Healing Touch is to purposefully use the energetic interaction between the practitioner and the individual to restore balance to the energy system. This non-invasive technique employs the hands to clear, energize, and balance the human and environmental energy fields, thus affecting physical, mental, emotional, and spiritual health.

When seeking activities to assist you in living well with dementia, mind-body therapies can provide a personalized, low-cost strategy with no documented side effects. More research is needed to understand how they may benefit individuals living with dementia but, given the scope of evidence, these mind-body approaches offer potential symptom management for those living with dementia, care partners, and healthcare providers to explore.

3.7 Creative Practices

Throughout this Manual you will find examples of how creative practices expand and deepen the well-being of people living with dementia. Cynthia Huling Hummel, for example, discovered mask making and painting, and finds great satisfaction in pursuing art. Her masks were displayed in the National Art Museum in Stockholm, Sweden.

> *Art is a way to communicate when words don't work. People's spirit really shines through. I've had powerful moments of connecting with people who were communicating and experiencing life differently. People living with dementia have helped me learn more and more about the enduring personhood and the whole rainbow of ways that people can connect, can share their spirit, their creativity, their memories, beyond one person alone with their database of memories.*
>
> **Beth Soltzberg, MSW, MBA, Contributor**



You can tap into creativity in boundless ways, from gardening to cooking, dancing, writing poetry, knitting, playing an instrument, singing, collage, and pottery. Here are some examples:

MOVEMENT-BASED GROUPS

Movement-based groups, including those that are designed specifically for people experiencing cognitive change, can be fun, challenging, and creative. These can be exercise or dance groups. There is some evidence that physical exercise and movement not only improve physical functioning but also mood. Exercise may also help slow the progression of cognitive changes. (See *Pillars of Well-Being*, Section 2.2F, page 128.)

DANCE

Dance can support expression if speaking becomes difficult. Dance uses gestures and rhythmic movements as a form of expression that can amplify or replace traditional ways of communicating. By engaging the body as a form of expression, dance can promote and extend a feeling of connection to self and others. In this way, dance can serve as a form of language.

Dance is both a good way to exercise and a creative outlet for people living with cognitive change. Many people become incredibly involved in the rhythmic activities that dance provides. Studies suggest that dance may benefit cognitive function, maintain motor function, and improve quality of life, although more research is needed. One 2021 "meta-analysis" of 14 studies in the journal *Frontiers in Aging Neuroscience* found that "dance interventions may positively affect cognitive function, rote memory, immediate recall, delayed recall, and attention in patients with [mild cognitive impairment]."

THEATER, DRAMA, AND STORYTELLING

These are beneficial for people living with cognitive change, according to several studies. These practices promote social interaction and emotional relief in a failure-free setting. Visual arts and storytelling are often combined.

CREATIVE WRITING and **POETRY**

These tap into different ways of communicating how we see the world. There are groups especially for individuals living with cognitive changes.

MUSIC

Whether singing with a choir, listening to recorded or live music, or playing a musical instrument, music is pleasurable and good for the brain. When playing

a musical instrument and singing, we utilize our procedural memory. This may be better preserved than short-term memory and is beneficial regardless of our abilities. Popular videos show individuals with advanced symptoms of dementia who continue to perform ballet or play the piano with amazing ability. These videos also illustrate the connection between music and muscle memory (movement).

LEISURE ACTIVITIES

Leisure activities also can be both fun and therapeutic. Examples include doing puzzles, reading, gardening, participating in sports, and joining organized group discussions. Whether you do these independently or with some assistance, they can be beneficial.

SENSORY STIMULATION

This is a way to engage in creative practices even if your symptoms advance. For example, one man had long been in a handbell choir. As his condition worsened, he moved very little. However, because of his long-term and procedural memory, when a white glove was put on his hand, he knew that it was time to play in the handbell choir. As the music played, he knew from a gestural cue (touch) to ring the handbell and play his part. This made him and his family happy, knowing that he was still able to participate in a favorite activity.

Another example of sensory stimulation involved using the scent of roses to bring pleasure to someone with advanced symptoms of dementia. A husband was sure

> *"On a Positive Note Chorus," based in Neenah, Wisconsin, has been singing and performing since 2014. The chorus is made up of people living with dementia and their care partners. It's an enormous gift to be with these folks. We want the community to see that folks living with dementia can bring joy to them.*
>
> **Susan McFadden, PhD, Contributor**



his wife was unable to respond to him. He mentioned to the occupational therapist that his wife had always loved roses. The therapist suggested he bring his wife a bouquet. She showed him how to bring the roses within his wife's field of vision and then close to her nose. His wife moved her head toward the rose, attempting to smell it. She smiled, held her husband's hand tight, and cried with happiness. So did he. Roses became an enjoyable part of their new routine.

TimeSlips is devoted to engaging people living with dementia and other elders in meaningful projects large and small. Using prompts and small-group connection, *TimeSlips* trainers help people living with dementia create stories and dramatic scripts, which they can then act out.

Its core values are:

- Saying, "Yes, and …"
- Asking beautiful questions
- Giving proof of listening
- Opening ourselves to wonder
- Committing to rigor and the value of all human beings
- Finding meaning by connecting our personal expressions to the larger world

"The arts and creativity are an emotional and symbolic language. They open up people's expressive and communicative potential." — *Anne Basting, PhD, founder TimeSlips, and a MacArthur Fellow*

> *I like having music on.*
> *I like to dance around*
> *the house — but not sing!*
>
> **Kim Reid, Manual Guide**





The Arts and Personhood

Daniel Potts, MD FAAN, Contributor

Painting connected my father to his story

"Art is an appeal against vanishing." — Lynn Casteel Harper, *On Vanishing*

I grew up musical. My mother was a voice and piano teacher. I became a neurologist, but I really didn't appreciate the usefulness of the arts in healthcare until my Dad was diagnosed with Alzheimer's. He attended adult day care, and was exposed to both expressive arts therapies and the use of arts and creativity. That exposure really gave Dad his life back and enabled us to have a relationship with him that we were struggling to have. I cannot emphasize enough how thankful we are for that.

The arts gave him an outlet to express himself better, to make himself known, to deal with these emotions, to take him back to parts that were healing to him.

We did not think he was an artsy person. He was not creative, not musical, he didn't sing. He was gifted with his hands but did not create art. When he started attending Caring Days Adult Day Care, he was struggling with language, dealing with his emotions, and communicating with family and friends. The arts gave him an outlet to express himself better, to make himself known, to deal with these emotions, to take him back to parts that were healing to him.

He met George Parker, who was a volunteer artist with an innate understanding of how to share his art with others and pull out their gifts and talents. George began by showing them pictures he had created. Once people got into it, he let them paint what they wanted.

Dad started out copying things, then he began painting things in his mind — his father, his father's shoes and hats. Dad grew up sawmilling. He painted logs, wood rings, trees, people he had relationships with early on, workers in the sawmill. It was just fabulous. It validated Dad, it gave him something to be proud of. It connected him with his story, and it seemed to satisfy and give him peace. We think it made him more communicative, more able to pay attention. It was just easier to be with Dad. It really was amazing.

It taught me so much. I had been looking at Dad from the point of view as a physician, seeing losses and inabilities. This showed me giftings, the freedom to express what was inside. That led me to a deeper appreciation of the concept of personhood. I realized it's still there, but we have to change the way we look for it. We have to change ourselves.

What does this mean — scientifically, neurologically, spiritually, philosophically? I've explored that for 15 years. I've met with people who know a lot about this. We went on to start a foundation, Cognitive Dynamics. When we developed our programs, we thought most of it was about art and creativity. But it's really not. The art has value of its own, but I see it primarily as a means of shoring up personhood and enabling relationships. By shoring up personhood, we allow that individual to continue to express what's inside of them and tap into that which makes each one of us a person and share that, and by means of that sharing to build relationships.

To see some of Lester Potts's art and to learn more about the arts and people living with dementia, visit Cognitive Dynamics Foundation: *cognitivedynamics.org*

SUGGESTED RESOURCES

Articles and Reports

Alzheimer Society of Canada, (2018). Dementia, intimacy and sexuality. *alzheimer.ca/bc/sites/bc/files/documents/intimacy-and-sexuality.pdf*

British Psychological Society. (2016). Psychological dimensions of dementia: putting the person at the centre of care. *www.bps.org.uk*

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Taking Charge of Your Health and Wellbeing website, Earl E. Bakken Center for Spirituality & Healing, University of Minnesota. *www.takingcharge.csh.umn.edu/mind-body-therapies*

Books

Basting, A. (2021). *Creative care: a revolutionary approach to dementia and elder care.* Harper One.

Jewell, A., editor. (2011). *Spirituality and personhood in dementia.* Jessica Kingsley Publishers.

Glazner. G. (2014) *Dementia arts*. Health Professions Press.

Websites

Online jigsaw puzzles and other games using art from around the world.	*https://artsandculture.google.com/play*
Social engagement calender managed by CaringKind in NYC. Several zoom art engagement opportunities are listed.	*https://www.caringkindnyc.org/socialengagement/*

From Cornell Lab, a great overall website to explore for bird-lovers.	*https://www.allaboutbirds.org/cams/*
Public domain artworks gathered into free downloadable coloring books. They also have "stories" which are scrollable slide shows on a wide variety of topics.	*https://www.europeana.eu/en/colouring-books*
For geography buffs--some of these are really challenging, some more easy, but the user gets to choose.	*https://www.geoguessr.com*
The Getty Museum has short videos, including videos of music performances. Some are meant for young audiences, some for adults.	*https://www.youtube.com/channel/UCwYxqqsGNMkiNZIdYyiC5sg*
Art therapist Elizabeth Gronke--and the American Folk Art Museum collection.	*https://www.youtube.com/watch?v=HjX6V3LlbKs*
For all kinds of free games, including word games and picture quizzes, just type in your subject of interest.	*https://www.jetpunk.com/*
The Metropolitan Museum of Art has many videos of musicians playing the instruments from their collection. (They also have free, downloadable coloring pages of artwork from their collection at *https://www.metmuseum.org/learn/learning-resources/coloring-pages*.)	*https://www.youtube.com/playlist?list=PLB73DA5433C3A8C95*
"Relish's mission is to help improve the overall wellbeing of people with dementia by providing fun, meaningful activities that help build their relationships with their family, friends, and caregivers."	*https://relish-life.com/en-us/blogs/activities/tagged/art-crafts*
For travel lovers, the photo galleries of amazing world traveler/photographer Darren McLean.	*https://www.taste2travel.com/*

SUPPORT
Demetia Action Alliance
www.daanow.org/donate

SECTION 4: Life Affairs

I took special care to get my affairs in order…I'm maintaining good communication with my friends and my daughter. I have a good plan in place.

David Baldridge, Manual Guide



You've received a dementia diagnosis. It's time to turn to practical matters related to the future and to craft next steps in your journey. Important information for bigger decision-making and helpful strategies for day-to-day living are shared here.

Explore Section 4 and consider:

- Employment Options
- Driving Assessment and Travel Tips
- Taking Care of Daily Tasks
- Making Supportive Home Modifications
- Managing Legal and Financial Affairs
- Avoiding Scams

4.1 Cognitive Changes and Your Job

Some people may be able to continue to work after being diagnosed with dementia. Just because you get a diagnosis does not automatically mean you must quit your job or retire immediately. Your job responsibilities and dementia symptoms will need to be evaluated and perhaps some adjustments made. Some accommodations can be made to allow individuals to continue to work. Working with your human resources department or your direct supervisor might be helpful. Perhaps cutting back hours or adjusting responsibilities can allow you to continue in your work position.

If you are still working, you are probably wondering how long you can continue to do so. Deciding when to stop and when to tell your employer can be challenging. Your doctor's evaluation, and your ability to drive, may be contributing factors. If you are in a high-stress position, your doctor may determine that the job is impacting your dementia symptoms, or if you work in a high security position it may be determined that your continued employment poses a security risk.

Giving up your job will affect your finances, and it may change who you regularly engage with, and how you fill your time. It may also affect your self-confidence and identity. Allen Power, MD writes in his book, *Dementia Beyond Disease*, our culture highly values a strong work ethic. "... our work ethic has elevated productivity to the extent that those who cannot produce as much ... are devalued, even if they have previously spent decades of their lives in highly productive work."

If you are just noticing cognitive changes, you might consider creating "an occupational living will." In his book, *The Problem of Alzheimer's*, Dr. Jason Karlawish tells the story of a colleague who created this novel tool. He wrote down how he wished to proceed if he developed cognitive impairment, and he shared this with his colleagues. He asked them "to make a fair and reasonable assessment of his work performance and to share their observations with him. If these observations trigger a concern, a plan is in place for a formal assessment with a physician," Dr. Karlawish writes. The colleague even made a video speaking to his future self, saying his wishes as far as work and his abilities to perform his job.

Whether it's concerns about working or driving, having a few trusted people in your circle who will be honest with you is invaluable. Cynthia Huling Hummel noted, "I have a 'circle of care' — that is, a few dear friends who have agreed to 'hold up the mirror' (so to speak) to help me to recognize that my abilities have changed. They will let me know when I may be lacking in capacity to make wise decisions."

Often one of the first places cognitive changes are noticed is in the workplace. Sometimes you will notice the change; other times it is coworkers or colleagues.

Common examples of activities in the workplace that you may have uncustomary difficulty with:

- Processing numbers if this had been a strength
- Remembering decisions made at meetings and who attended
- Understanding verbal instructions
- Managing multiple tasks simultaneously
- Remembering meetings or appointments
- Concentrating
- Losing confidence in making decisions

It is common for people to misidentify these signs as stress or due to a heavy workload. Being overworked, not getting restorative sleep (see restorative sleep, *Pillars of Well-Being*, Section 2.2E, page 123), and feeling distressed can certainly cause temporary lapses in cognitive abilities; however changes associated with dementia are different. If challenges persist, contact your primary healthcare provider to discuss your symptoms and concerns.

If it is determined that you are living with a form of dementia, you will have many decisions to make, including when you share this information with your employer. You may have concerns about sharing your diagnosis with others due to the stigma associated with dementia. As noted in *Tell People or Not* (see Section 1.15, page 105), Dr. Gayatri Devi warns that your employer and coworkers may begin to view you through "Alzheimer's-colored glasses," assuming that you are incapable of work, even if up until now you had been given strong evaluations.

As the late Richard Taylor, a renowned advocate and author of *Alzheimer's From the Inside Out*, said in an interview, "Ideally, an employee would be told: 'These are not the kinds of errors we generally see in you. But we're still committed to you as an employee — we have a lot of investment in you. This is a new problem for us to solve. You want to keep your job and we want to keep you. How can we partner with you?' "

Try to make a plan for financial security event if it may change as the disease progresses.

In truth, this may be unlikely to happen. Because of the stigma, many experts caution that employees diagnosed with dementia need to proceed carefully. Consider how losing your job or retiring may affect matters such as health insurance and your income. Try to make a plan for financial security even if it may change as the disease progresses. If you feel your continued work would endanger others, you must take measures to ensure safety.

Among other suggestions from Dementia Australia about next steps:

- Have a dress rehearsal with family or friends for how you will tell your employer.
- Discuss the possibility of adapting aspects of your job to make it possible for you to continue.
- Think about who needs — or doesn't need — to know at your workplace.
- Identify one or two trusted people who might be willing to help you with

specific parts of your job.

- Know how much medical leave you have, as well as any disability benefits.

Americans with Disabilities Act and Your Job

What about the Americans with Disabilities Act (ADA)? Does it offer protection to employees living with dementia? In theory, yes. In practice, far too many employers view a dementia diagnosis as a reason to force an employee into retirement.

The ADA prohibits discrimination against people living with disabilities in several areas, including employment, transportation, public accommodations, communications, and access to state and local government programs and services. The ADA was established to ensure that individuals living with disabilities are not discriminated against. The ADA defines disability as "a physical or mental impairment that substantially limits one or more major life activities."

Much depends on your symptoms and the nature of your work. The ADA does not go by diagnosis but by functional impairment. If an employee can complete their work requirements with reasonable accommodation, they should be protected under the ADA. For someone living with dementia, this could include a flexible schedule, desktop reminders, or some assistance from a co-worker. Richard Taylor continued teaching at the college level for a few years, with support from his teaching assistant.

The Job Accommodation Network (JAN), a service of the U.S. Department of Labor, cites some general examples of reasonable accommodations. These include restructuring jobs; making worksites and workstations accessible; modifying work schedules and

responsibilities; and providing specialized equipment. Employers are required to provide an accommodation unless it would cause undue hardship for the employer, which is assessed on a case-by-case basis.

If you are unable to work due to your dementia diagnosis, you may be eligible for Social Security Disability Insurance. This is for people who have paid into the Social Security system but who have not reached their full retirement age. (Social Security is gradually increasing the full retirement age. To see a calculator, go to *www.ssa.gov/benefits/disability/qualify.html*.) Once you have reached your full retirement age, then your benefits convert to regular Social Security. (For more on SSDI, see *Getting Your Financial and Legal Affairs in Order*, Section 4.8, page 260.)



She Loved Her Job, But 'Then Things Changed'

Laurie Scherrer, Manual Guide

Learning from others with disabilities

Laurie Scherrer had worked her way up the career ladder and enjoyed the challenges of the business world. Through her skills in computer programming, training, and management she rose to the position of Vice President and Director of Information Systems at a bank. "I had a knack for almost any computer programming and for bringing projects from conception to success," she says.

Eventually, she found she no longer enjoyed managing employees. She discovered a new career passion: sales. Her warm personality and financial skills made her an excellent sales person. She loved her work and earned good money.

Her final and favorite job was selling mobility vans for people living with physical disabilities. "I really loved that job," she says, "But then things changed."

She found she could no longer do basic arithmetic. "We were at a convenience store one day. I was picking up something small to buy, and I remember not knowing how to count the money." At the same time, she found that she was turning from a "people person" to someone easily agitated by others.

She lost her job selling mobility vans. But she learned something important that she carried forward. "I watched the way these people with physical disabilities found strategies to continue to live and to overcome their challenges. Many had such an 'I can do' attitude which focused on their abilities rather than their disabilities. After my diagnosis, that resonated with me. If they can find ways to adapt and find strategies to live positively, then so can I."

4.2 Dementia and Driving

Driving is a fundamental part of our culture. Driving is equated with independence. Our love affair with cars has been written into popular songs since the 1950s, from "Route 66" and "Little Nash Rambler" to "Truckin'" and "On the Road Again." For many, cars are a primary way to get groceries, go to doctor's appointments or church, commute to work, and travel on vacation.

Nearly 90 percent of adults in the U.S. have a driver's license. According to the American Public Transportation Association, 45 percent of Americans have no access to public transportation, so it's no small consideration to contemplate no longer being able to safely drive.

When someone is diagnosed with dementia, losing their ability to drive is one of the first concerns. Some people in the early stages can continue to drive safely, while others have visual-spatial problems early on or other cognitive symptoms that make driving a hazard.

Driving is a complicated process that uses several parts of the brain to control different aspects. Remembering how to operate a car is part of our procedural or implicit memory, much like riding a bike or tying our shoes. Navigating where to go is controlled by a different part of our brain where declarative or explicit memory is stored. Thus you might be able to brake and steer properly but get lost going to your daughter's house.

If you or your care partners have concerns, it's a good idea to get an independent driving evaluation. According to the American Automobile Association (AAA) there are two types: clinical driving assessments are conducted by occupational therapists and driving skills evaluators are licensed and certified by states.

If you are still able to drive safely, have your driving reevaluated every six months or so as your symptoms may change. Some doctors require that you have a partner, friend, or family member evaluate your driving skills once per month.

The Alzheimer's Association identifies the following signs of unsafe driving:

- Failing to observe traffic signs
- Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- Becoming angry or confused while driving
- Hitting curbs
- Using poor lane control
- Making errors at intersections
- Confusing the brake and gas pedals
- Returning from a routine drive later than usual
- Forgetting the destination you are driving to during the trip

You may be able to recognize some of these signs on your own or you may need to rely on others to share with you their experiences of your driving. Again, having a few trusted people in your circle can be very helpful. Listen to their judgment. While some care partners are overprotective when it comes to driving, they are likely thinking not only of your safety, but of other people's safety. It is best to err on the side of caution and be in control of making the decision to stop driving.

Regardless of when you stop driving, you need to make a plan. Think about what you use your car for and how you will continue to have access to those products, services, and activities when you can no longer drive. Even if you believe you can drive safely for the foreseeable future, it is a good idea to plan ahead.

Fortunately, we live in a time when there are many more options than in the past, although in rural communities some of these may not be available.

- Groceries and carryout meals can be delivered, either by the supermarket or restaurant, or by one of many delivery services such as Instacart, Doordash, UberEats, and GrubHub. You will typically need to order these on your computer or smartphone. Often, these delivery services can shop from your list at multiple stores, adding to the convenience and assistance of such services. Most delivery services charge extra, so be sure you are aware of any additional fees.
- Online shopping is now standard for basically anything you want or need. Whether through *amazon.com* or thousands of other retailers, nearly 76 percent of Americans have used online shopping, and 25 percent do so monthly.

- Taxis and driving services such as Lyft or Uber can transport you anywhere in your area, including to the airport. Generally these services are requested through a smartphone, although some taxi companies still use phones. (That said, some communities report that it's more difficult to get driving services in their neighborhood.) There are also private drivers that you can hire directly or through a company.
- Public transit may be an option, either bus or subway. In the early stages, you may be able to manage this on your own, or ask a friend or care partner to go with you at least a couple of times so you can be comfortable with the bus routine.
- Contact your local Area Agency on Aging or Eldercare Locator (*eldercare.acl.gov*) to find out what transportation options there are for you.
- See if your community has a Village, a neighbor-helping-neighbor organization aimed at allowing people to age in place. They usually have a pool of volunteers available to provide free rides. A map of Village locations can be found at the Village to Village Network, *vtvnetwork.org*.
- If you are part of a faith community, ask if any members of the congregation would be willing to pick you up for services and meetings you wish to attend.
- Ask friends and family if they'd be willing to help you out with rides from time to time. Offer to treat them to lunch or a movie in exchange for a ride.
- Research services — such as hairdressers/barbers or veterinarians — that will come to you. They may not be as expensive as you think.
- As your symptoms advance, your care partner could look into home medical and dental services. Many are covered by Medicare or other insurance, depending on your condition. Even hospital care is beginning to be provided at home in some areas.

"I voluntarily gave up driving in 2010 but I know how gut-wrenching it is for many people…," says Manual Guide Jim Mann. Having a plan and being proactive may help ease some of your sadness and worry about giving up your license.

Jim advises, "Be creative about getting out. If you are no longer able to drive, continue living. Start walking more in your community. Perhaps there is a small group of people who meet for coffee that would welcome you to join and offer to pick you up. Above all, know your world has not collapsed."

4.3 Making Air Travel Easier

A good example of how a disability frame can be helpful is the Dementia-Friendly Airport *www.dementiafriendlyairports.com/about-us.html* initiative. Launched in 2018, the Dementia-Friendly Airports Working Group is a collaboration of professionals, academics, and volunteers, including people living with dementia and care partners. Unlike some disabilities, such as those affecting mobility or vision, dementia may not have visible signs, such as a wheelchair or service dog, especially with early symptoms. The working group's efforts include training airport staff to understand "hidden disabilities" and to create policies and spaces that will support people living with dementia.

Among the recommendations for airports:

- Use signs, photos, and videos to make their processes and services clear to passengers.
- Provide quiet areas for travelers to wait for flights and calm routes through the airport, avoiding hectic retail shops and restaurants.
- Train staff to recognize a badge or lanyard indicating a passenger is living with dementia and allowing someone to accompany them to the gate.

As dementia becomes recognized as a disability, many other public places may be more open to measures such as setting aside quiet areas or having clearer signage. (For more on *dementia-friendly initiatives*, see *Community Supports*, Section 2.4F, page 166.)

Unfortunately, most airports are not yet dementia-friendly places. For people living with dementia, airports are at the top of the stress meter. Airports are very noisy places, often with competing overhead announcements about things that travelers need to pay attention to, such as a gate change or flight cancellation. Besides the noise overload, airports provide visual overload. There is a lot of signage to navigate — check-in, baggage drop-off, baggage claim, wide assortment of gates, TSA screening, travel advisories, advertisements, and much more. The auditory and visual overstimulation adds to the general level of stress experienced when needing to fly.

Manual Guides Laurie Scherrer, Barney Nelson, and Mark Timmons offer the following recommendations when you need to fly:

Preparation

Plan ahead for as much and as many things as possible! Get to an event, conference, or appointment one day early when possible!

Booking the Flight

1. When booking your airfare, opt-in for "Priority Boarding" when available.
    a. Passengers with Priority Boarding are allowed to board the plane as a separate group from most passengers, usually the first or second group called to board.
    b. This may cost a few dollars more when you book your flight but is totally worth it to help reduce crowd-related anxiety and stress.
2. Beginning **TWO weeks before your flight**, request Special Services from both the airline and TSA (the airline website may say one week – that doesn't always work out).
    a. This is the single, biggest step you can take to make the airport experience easier.
        i. There are multiple ways to make this request (online form, email, phone call); USE THEM ALL.
    b. Be specific and explain how your symptoms make the airport difficult.
        i. E.g., "My dementia affects the way I measure distances in such a way that attempting to use escalators is hazardous."
        ii. E.g., "The symptoms of my dementia can cause me to easily get overwhelmed, confused, and disproportionately anxious in loud, busy, unfamiliar places.
    c. The airline will make note of your request, and when you check your luggage, the employee will confirm what exact type of assistance you need.
        i. At some airports, if you have a friend or loved one helping you, that person can get a pass that allows them to accompany you through TSA and all the way to the gate (that person will need to show I.D.). Check with the airline when you book your ticket or call TSA at that airport.
        ii. If you are alone, it is STRONGLY ADVISABLE to request a wheelchair assist. A second airline employee will wheel you from the luggage check all the way to your gate, including assisting you through TSA checkpoint.
    d. Check into the Hidden Disabilities Sunflower Program (*hdsunflower.com/us/*). Available at over 280 airports, this program has designated airport personnel who have completed training to support people with hidden disabilities.

Packing

1. At least two weeks prior to travel:
    a. Start making a list of everything you will need (you will probably add things to this list up until the day of travel).
        i. Put the list in some order (i.e., clothes, medications, etc.) There are apps available that can help you make and organize lists (e.g., *https://www.AnyList.com*).
        ii. Highlight items to distinguish Check-In or Carry-On.
    b. Purchase Travel Bags:
        i. When packing there are two tips to help avoid confusion when in a strange place. Pack by outfit not by garment type – one outfit together rather than all pants together.
            1. Pack each outfit in a separate travel bag (include under garments, socks, etc.) – everything you need for that particular outfit. If you awake in the morning disoriented you will be thankful you don't have to think about what to wear.
            2. Place each complete outfit on a hanger that you can place directly in your closet. Include accessories if applicable.
        ii. Label the bag or hanger with when you are to wear it (i.e., Monday Day, Monday Night, etc.).
    c. Medical Assistive Devices (such as a CPAP machine or Nebulizer) are not to be packed in your checked luggage.
        i. They are given a special tag identifying it as a medical device.
        ii. Items with a medical device tag do not count toward your carry-on allowance.
    d. Medication is suggested to be added to your carry-on with a large enough supply to cover up to four days. If your luggage is lost, it could take some time to get medications filled.
    e. Ear plugs and/or headsets in your carry-on are extremely important to reduce noise and confusion.
2. Once you are sure all your wash is done, and you are ready to start packing:
    a. Checkmark items off your list as you put them in the luggage.

b. Keep your list, and on the return trip check off items as they go back into your suitcase to make sure you are not leaving anything behind.

c. Weigh your luggage and make sure you are within airline guidelines.

3. Identification, tickets, and *Please Be Patient With Me I Have Dementia* cards (available at daanow.org) should be kept where they are readily accessible. Consider a pouch that hangs around your neck and shoulder. It is easy to misplace this info when going through security.

   a. You will need to show your I.D. and ticket at least twice (at some airports three times)--once when checking in, then when going through TSA, and, at some airports, also at boarding.

   b. *Please Be Patient With Me I Have Dementia* cards can really help you through the airline process and even on the plane. Use them.

   c. Consider also keeping a care partner's phone number with your I.D. If you get confused this can help others know how to help you.

   d. KEEP ALL OF THESE HANDY UNTIL YOU ARE ON THE PLANE.

At the Airport

1. Plan to arrive early – this will help reduce your stress if everything does not fall into place.

2. Let them know at check-in that you requested and need wheelchair assistance (see Booking the Flight above).

3. Once you are at the gate:

   a. Let the gate attendant know that you will need early boarding (but perhaps not a wheelchair assist) and any special instructions (e.g., I can't do escalators, or I may need a reminder to get on the plane).

   b. Sit at the least crowded location near the gate that you can find so you can escape some of the noise and confusion. Sitting by a wall or corner can often reduce some of the over-stimulation.

4. If you need the restroom--it is extremely easy to get turned around in an airport:

   a. Try to use the restroom closest to your gate (when possible).

   b. Write down your gate number and keep it in the pouch with all your ID.

c. If possible, have someone wait for you outside the restroom and hold all your belongings except your I.D. Pouch.

At the Hotel

1. Write down the name of the hotel, and your floor and room number, on something that you will always keep with you. Room keys no longer list your room number. At the conference, consider writing your room number on the back of the name placard that you will keep around your neck.
2. Give the Hotel Manager your *Please Be Patient With Me I Have Dementia* card and explain that you may get disoriented and confused.
3. Keep the contact information for a care partner on you.
4. When you get to your room the first time, look for markers that can help you get back to your room (e.g., near the statue or picture of "X" I turn left, at the escalator I turn right).
5. Become familiar with the hotel. Practice how to get to and from your room, the lobby, the conference, or any other gathering place.
6. Become acquainted with lower traffic areas that may offer a quiet escape when needed.
7. Check for any potential safety concerns and try to avoid them. These may include over-busy wallpaper or carpet that causes balance distraction.
8. Keep your ear plugs handy. Sometimes the motor of an escalator or blowing of a fan can cause confusion. You need to be able to block those out.

RELAX AND HAVE FUN!



Airports through a Disability Lens

Chuck McClatchey, Manual Guide

What 'dementia-friendly' could mean for travelers

Manual Guide Chuck McClatchey has been on committees to help both the Las Vegas and Kansas City airports become dementia-friendly. He was part of Dementia Friendly Southern Nevada's Community Awareness program, which was the first in the country to be implemented at an airport. He worked with the Cleveland Clinic to develop a training program for airport employees. "We wrote the lesson plan from scratch," Chuck says.

"We had three in-person training sessions, and then COVID hit. We tried with virtual, but it was not the same as in-person training," he says. "I was amazed. Every person participating was involved in it. No one seemed to be sitting there because they had to be there. Surveys said it was really great."

In addition to learning about dementia, the training gave employees a chance to learn how stressful airports can be. Finding a family bathroom or simply a quiet place to sit is a challenge. "We talked about if they see somebody that looked lost, how to approach them, and how to communicate with care partners and people with dementia."

In Kansas City, a new airport was being built, and Chuck was on a committee to give them ideas about dementia-friendly design. Having a designated quiet place for families is ideal, whether it's for people living with dementia or parents with children who have autism. "One of the care partners flew with his wife, who was living with advanced symptoms of Alzheimer's. They were walking in the airport and she froze. The carpet color went from beige to black and she was afraid to step on it. We advised them not to have such a stark contrast in the carpet. Additionally, black flooring can be perceived as a hole. The Detroit airport has strobe lights — that doesn't help. Loud music when people are trying to concentrate on where they are going isn't good either."

More Travel Strategies

- **Your Travel Plans:** When planning ahead, decide which events on your trip are most important to you. Make a contingency plan for achieving these travel goals if the unexpected happens. Is there space on your itinerary for making changes when needed? Are dates and entry times for exhibits or excursions flexible? If a sightseeing destination is too crowded on a given day, can you visit again, at a quieter time, during your stay?

- **Your Packing List:** When making your packing list for car travel, distinguish where you will need certain items—In The Trunk/Luggage or In The Car. Discovering that snacks are locked away as you're heading down the road can be very disappointing.

- **Your Travel Bag:** You may want to include a travel bag just for beach or water activities and include your towel, sunglasses, and sunscreen. (Sunglasses can also be useful for reducing over-stimulation.) Consider other "special event" bags that would include needed accessories.

- **Your Hotel, Dining Spots, and Vacation Shopping Stops:** Be sure to share your *Please Be Patient With Me I Have Dementia* cards and explain that you may need more time making your selections, may become disoriented or confused, or may need some extra support. These cards, available from *www.daanow.org*, are a great way to advocate and inform while receiving good customer service.

SAFE TRAVELS—AND HAVE FUN!!!



Managing Your Schedule

Create strategies that work for you!

- **Create a daily routine** that you can stick to—even if you were a more sponstaneous person in the past. Consider the best time for waking, meals, activity, rest breaks, and bedtime. Keep in mind what times of the day you have the most energy.

  As symptoms advance, you might find it helpful if your care partner writes down a daily schedule that works for you. In consultation with her father, Jennifer Carson created binders of important information, one for direct care partners and one for family and friends. The **binders included a section on his daily schedule**, beginning with his regular wake-up time of 8 am, with a cup of coffee, through sleep at 10 pm. In between are times of activity and rest, meals, medications, and stress-free, quiet evenings.

> *I've learned to expect to be surprised. I never know what dementia is going to throw at me from one day to the next. I used to be surprised at how downhill my brain function gets late in the afternoon. Now I know to schedule as much as I can in the mornings and early afternoons.*
>
> **Mark Timmons, Manual Guide**



- **Use post-it notes as reminders** in places you will look, like the bathroom mirror. Take down the notes as you accomplish the tasks. Erasable whiteboards in high traffic places—the kitchen, main hallway—are helpful and can be updated throughout the day.

- Additional **visual cues** can support daily routines. Manual Guide Jim Mann has a simple way to keep his bedtime routine of taking three medications straight. "I would get confused because I would [take the medications] out of order, and it would cause great frustration. I finally developed a solution." He places on his nightstand the three items, each sitting on a small card marked 1, 2, and 3 to remind him of the order. The cards also have a city in moonlight, so he'll know that these are things to take at night.

- And don't hesitate to check in with your **tech-savvy friends and family members**. Your **computer or phone** can help you stay organized. Jim also advises, "Use your smartphone calendar and alarms. When I'm somewhere and a new appointment is made, I put it immediately in my phone. I also make use of the phone calendar's two warning times so I can be reminded of an appointment." For other ideas on tools to manage your time, see *Technology Supports*, Section 6, page 325.



A Simple Way to Organize Your Week

Rev. Dr. Cynthia Huling Hummel, Manual Guide

Planning ahead reduces stress

Cynthia Huling Hummel developed a clear, hands-on way to keep her week straight. "Living alone, I don't have someone who will remind me of my day-to-day activities," she says. "But I have a great system in place. To organize my week, I have my 'memory bench.' Several years ago, I purchased an inexpensive bench as a way to get organized and keep track of my different appointments and activities. You could also repurpose an old table or invest in a "cubby hole" system like kids have in school.
The point is to have an area to lay out your week.

"Having a visual reminder of my week on the bench helps me stay on track each day. I made signs for my bench for each day of the week. Every Sunday night, I lay out the coming week's activities. For example, if I plan to go to the pool on Monday, I put my pool bag in the Monday section of the bench. I also check to make sure that everything I need is in that bag. I learned that the hard way, by forgetting to pack a towel one day and having to put on my clothes over a wet bathing suit. If I have a dentist appointment on Friday, I put a note in the Friday pile with the time — and an extra toothbrush. Having an object there is a GREAT cue for me.



"I try and visualize (literally!) what I will need each day. That way, I am not searching for my swim goggles in my swim bag on Monday at 6:30 a.m. If I am speaking at an event on Thursday, I will put my presentation in the Thursday pile. Every night, I will write out a reminder for the next day that I will see while I have my coffee — Today, is MONDAY — get going. This system works great for me, but if it's too much for you to lay out the entire week, you might try it on a day-to-day basis — that is to say, before you go to bed at night, think about what you will need for the next day and lay it out in a place where you will see it."

4.5 Managing Your Stuff

People living with dementia often find that a well-ordered, decluttered home environment works best for them. It can help reduce confusion and stress, and you don't waste your time trying to find things that are not in easy view. As you declutter, you want to keep treasured items and not get rid of things you still enjoy.

You might want to enlist the help of a friend, family member, or professional organizer/declutterer to help you gradually sort through your belongings. Do a little at a time. One tried-and-true technique is to have three boxes to put things in: one for trash; one for items that you want to keep; and one for clothes, objects, or books to donate to charity or give to someone you know. This can be a satisfying way to revisit your things and focus on what you truly appreciate having. It's also satisfying to give away items that you no longer need but will be useful or enjoyable for someone else.

LAURIE SCHERRER'S



TIP **STORE CHRISTMAS THINGS** — decorations, scrapbooks, and other storable things — in clear plastic bins that are labeled with an image of the item, making them easy to find

TIP **USE SMALLER CLEAR BINS** in the kitchen pantry, labeled with images of the contents (Laurie came up with this trick, after adding flour to a dessert when she meant to use confectioner's sugar.)

TIP **PLACE CANNED FOODS** facing front on the shelf

TIP **ARRANGE SPICES** in alphabetical order

TIP **KNOW THE SIZE OF YOUR SHEETS** by sewing or safety-pinning a large tag off the middle of the bottom end of the sheet, noting what size the sheet is (king, queen, full, twin) (The tag at the bottom lets you know easily which direction to spread the sheet.)

4.6 What About Pets?

A beloved pet is good for our well-being. Pets offer mutual affection and a reason to get out of bed. Their care can give our life purpose. They also make us smile or even laugh out loud. And petting them can be soothing.

More than two-thirds of U.S. households have pets. According to the U.S. Department of Health and Human Services, "Interacting

with animals has been shown to decrease levels of cortisol (a stress-related hormone) and lower blood pressure. Other studies have found that animals can reduce loneliness, increase feelings of social support, and boost your mood."

People with advanced symptoms of dementia frequently respond positively when dogs or cats are present. A number of clinical trials of pet therapy for people living with dementia have shown benefit, although more research is needed.

Manual Guide Laurie Scherrer has a service dog named Lil Dawg. Lil Dawg is Laurie's close companion and brings her much joy. As a service dog, she also looks out for Laurie's well-being. "Lil Dawg knows some sign language. She is trained to go get Roy [Laurie's husband] if she feels I am in distress, if I fall, or if I give her the command. She knows I have a difficult time in the shower sometimes, so she sits outside the shower and tells Roy when I am ready to get out. A couple times she came into the shower when she sensed I needed help."

It's good to make a plan
for who will care for your pet
if you are no longer able to.
Perhaps an animal-loving friend, relative,
or neighbor would be willing to
make the commitment to care for your pet.

Manual Guide Dave Baldridge says he and his two dogs are "radically bonded." Like other canine search-and-rescue dog handlers, "We tend to develop close relationships with our animals with sophisticated levels of understanding."

His 8-year-old border collie, Duer, (Gaelic for "hero") is from a top herding line in Scotland. "He's changed from a wild and crazy young guy to being my constant caregiver. He follows me everywhere. Border collies are far smarter than me," he says.

Dave has serious balance problems as one of his dementia symptoms. To exercise the dogs, he takes his electric wheelchair to a park. "Their daily care is critical," he says. "Sometimes it's hard for me to remember if I fed them or not. But they remind me!"

Caring for his dogs is his "reason for staying alive. I don't want them to find new homes, although I know they may have to," he says.

As Dave suggests, you may find that you need to make adjustments in order to continue to care for your pet. For instance, Terry Berry lives alone with her dog but close by her two daughters. Her daughters noticed the dog was losing weight and realized their mother was forgetting to feed the dog. Their ingenious strategy was to use an empty mayonnaise jar and mark the outside with permanent ink to show "full" and "half" levels. Every morning Terry fills the jar to the "full" level with dog food and gives the dog half of the jar of food. She leaves the jar on the kitchen counter to serve as a reminder and in the evening gives the other half of the food in the jar to her dog for dinner. She leaves the empty jar on the counter so the next morning she'll see the empty jar and be reminded to fill it up and start the cycle again.

In her book *The Spectrum of Hope*, Dr. Gayatri Devi writes, "I believe very strongly in the therapeutic power of animals." She brings her two dogs to her office daily and she has found her patients living with dementia love seeing them. "Lola and Huck are a memorable and treasured part of my office team."

She also supports her patients adopting a cat or an older rescue dog, "because animals can both keep their owners more active and offer a sense of connection and intimacy."

As with other aspects of life, it's good to make a plan for who will care for your pet if you are no longer able to. If your pet has accidents in the house, or experiences unusual weight loss or gain, it may be a sign that you are not able to keep up with their care. Perhaps an animal-loving friend, relative, or neighbor would be willing to make the commitment to care for your pet. If you are able to set aside some funds to go towards its care, that may help you to find someone.

4.7 Supportive Home Modifications

If your plan is to stay in your own home for the time being or for the long haul, you may need to consider some home adaptations to make sure that your residence still works well for you. It's a good idea to ask an occupational therapist to conduct an assessment to make sure that your home is safe and not an obstacle course. Some symptoms of dementia, such as visual and spatial changes, may make it more difficult for you to navigate around your home. One particular concern is falls, as discussed below.

"Fortunately I live in a house that's very user-friendly with ledges and walls I can lean on," says Dave Baldridge, who does not have a care partner. "Keeping my balance is a matter of constant focus. So far, so good."

Making Your Home Falls-Proof



Jill Bjerke, BS, DC, CAPS, Founder, Home Transition Solutions Group, Contributor

We all want to live in a safe home. You may find that your vision, balance, and spatial awareness change as a result of dementia. Falls are a particular concern. Each year three million older people are treated in emergency rooms because of fall injuries, according to the Centers for Disease Control and Prevention. What can you do to ensure your home continues to be a safe environment for you?

Below are some tips that apply to all types of homes, whether a house, condominium, apartment, mobile home, or senior living residence. They are the basic, most critical steps to help prevent falls as you grow older or your symptoms advance.

- Wherever possible, have at least one zero entrance (flat threshold) to your home. Likewise, within a home, install a mini-ramp for thresholds over one inch (13 mm) to reduce trips and to allow continuous movement of walkers and wheelchairs. Note: If a threshold is a trip/fall hazard, apply fluorescent tape to it for quick identification.
- Bathroom, kitchen, door, and furniture should have "C" or "D"–style knobs. Round hardware can be difficult to grip.
- Pathways throughout the home should always be clutter-free and furniture should be arranged for easy passage.
- Remove common trip and falls hazards from the floors: throw/area rugs, extension cords, shoes, clothing, pet toys, magazines, etc.
- Furniture, beds, and toilets, as well as any other item that you sit on, should have arms and should be at an appropriate height for stability for sitting and rising. Leather or vinyl fabric is preferred for furniture as it is easier to push yourself on and off of. Furniture should be well-anchored.
- Install motion sensor nightlights in every room and hall, if possible, especially in your bedroom and bathroom.
- Install grab bars in appropriate places in the bathroom, including around the toilet and in the shower area.
- Post emergency numbers and addresses in critical areas for quick access in emergencies.

- Install smoke/carbon monoxide detectors near the kitchen, furnace, and sleeping areas per local zoning codes. Batteries should be checked a minimum of every three months. In addition, it is vital that ALL residents of the home can hear the alarm in all portions of a home, including when someone removes hearing aids at night. You may also want to invest in a weather radio to receive notification of an imminent weather hazard so that you can take appropriate safety action.
- Three sources of lighting are recommended in every room: natural, ambient (i.e. wall-mounted), and task, such as a reading light.
- All stairs should have stable, continuous handrails on both sides and non-slip tread surfaces. Treads should be no more than 7-3/4" high and, if interior, have a light switch at both the top and bottom of the staircase. Fluorescent tape should be used on tread edge for those with vision or stability difficulties.

Home safety is an ongoing process. Having a home assessment done on a regular basis can help you identify changes or alterations that need to be made.

If modifications or changes are required, there are many professionals who can perform what is needed, such as Certified Aging in Place Specialists, handymen, remodelers, and contractors. There are also a variety of funding sources for assistance in paying for such services.

Home safety is the first step to a healthy home!

Home Safety Tips — From People Living with Dementia

We asked the experts — people living with dementia — what they have learned about living safely and well in their homes. Here are their ideas:

General Home Safety — Throughout the Entire Dwelling

- Make sure carbon monoxide, smoke detectors, and fire extinguishers are easily available, visible, and up-to-date. Check manufacturer-suggested replacement and expiration date, as well as fire safety suggestions. Although most systems require batteries to be replaced every two years, they should be checked every three months to ensure that they're still working. Most manufacturers require systems to be replaced every 10 years.
- Ensure a Quick Dial 911 or alarm is visible and accessible with a large display in all main rooms

- Eliminate all possible tripping hazards. Specifically watch for:
  - Throw rugs
  - Wires or cords
  - Clutter (books, papers, small furniture, or knickknacks)
- Anchor or secure furniture as much as possible. If I start to lose my balance I will grab for the closest object. It is important that most objects will support me.
- Provide chairs with arms for support and to help me get in and out easily.
- Keep all passageways and walkways well lit.
- Place nightlights in every room.
- Install timers for lights to automatically turn on at dusk. Shadows and darkness can cause a distraction or confusion — especially during the change from day to night. Proper lighting is essential to avoid shadows and falls.
- Keep all cleaning products (potential hazard) in one location and labeled. Important: these products should NOT be placed in the bathroom where I may also keep my mouthwash or other areas where I may keep products that are placed in my mouth.
- Store medications away from food. Pills should not be placed next to my stash of treats — if I am confused the colorful pills may look like my M&Ms.
- Eliminate clutter as much as possible — clutter can cause confusion.
- Ensure all shelves and storage are at an easily accessible height to avoid the need to climb.
- Stairs are less of a hazard when fully carpeted (not throw rugs).
- Install railings on all step-down areas including porch and step-down rooms — when possible hang a plant or other object at eye level to draw attention to the height.
- *Smart911.com* is a good safety website to sign up for.

Bathroom:



- Ensure proper lighting.
- Only use electric heat items with automatic shut-off (for example, a curling iron).
- Place large color-coded (red for hot, blue for cold) stickers to mark hot or cold faucets.
- Mark the water knob positions (nail polish works well) for comfortable temperatures.
- Install grab bars/guard rails throughout the room (toilet, shower, bath) to provide extra stabilization.
- Provide textured mats or stickers on slippery surfaces.
- Raised toilet seats may be appropriate to help with sitting and standing.
- Post a hygiene checklist by the sink and in bathing area with appropriate steps for grooming in each area. This encourages following the same routine daily.
- Provide unique color and shape bottles to differentiate the content (i.e. shampoo and conditioner should be a different shape and color) or large labels. (See photo above)

Kitchen:

- Avoid flat-top stoves, which can be a hazard especially when the adjustment is finger motion rather than knobs.
- Stove knobs should match the pattern of the heating element and not go straight across. (Knobs placed in a moon shape are often more accurate to the location of the burners.)
- Be prepared to remove stove knobs if needed for safety.
- Use appliances with automatic shut-off when possible.
- Have good lighting for food preparation.
- Mark refrigerated items with the date they should be disposed of; marking leftovers is especially important.
- Keep medications and vitamins away from eating and food areas.

Bedroom:

- Install a nightlight. Some prefer a light that shines continuously, while others prefer motion sensor night lights.
- Ensure that the passage to bathroom facilities is well lit.
- Proper height bed should be verified to ensure easy access, neither too high nor too low to comfortably get in and out.
- Verify proper size and fit of blankets and sheets — too long can cause legs to get tangled and create a fall hazard.
- Avoid heated blankets unless they have an automatic shut-off timer and are closely monitored for heat accuracy, electric failure, and cords/wire placement.
- Eliminate clutter from floors and tabletops.
- Provide a chair with arms near bed for dressing ease.

4.8 Getting Your Financial and Legal Affairs in Order

When people receive a diagnosis of dementia they often are told by their doctor to "get your affairs in order." The following six pages are the ABCs of what that means, courtesy of the National Institute on Aging, National Institutes of Health.

National Institute on Aging

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NATIONAL INSTITUTE ON AGING

Getting Your Affairs in Order Checklist: Documents to Prepare for the Future

No one ever plans to be sick or disabled. Yet, planning for the future can make all the difference in an emergency and at the end-of-life. Being prepared and having important documents in a single place can give you peace of mind, help ensure your wishes are honored, and ease the burden on your loved ones.

Checklist for getting your affairs in order

This list provides common steps to consider when getting your affairs in order.

1. **Plan for your estate and finances.** Depending on your situation, you may choose to prepare different types of legal documents to outline how your estate and finances will be handled in the future. Common documents include a will, durable power of attorney for finances, and a living trust.

    - A **will** specifies how your estate — your property, money, and other assets — will be distributed and managed when you die. A will can also address care for children under age 18, adult dependents, and pets, as well as gifts and end-of-life arrangements, such as a funeral or memorial service and burial or cremation. If you do not have a will, your estate will be distributed according to the laws in your state.

    - A **durable power of attorney** for finances names someone who will make financial decisions for you when you are unable to.

    - A **living trust** names and instructs a person, called the trustee, to hold and distribute property and funds on your behalf when you are no longer able to manage your affairs.

2. **Plan for your future health care.** Many people choose to prepare advance directives, which are legal documents that provide instructions for medical care and only go into effect if you cannot communicate your own wishes due to disease or severe injury. The most common advance directives include a living will and a durable power of attorney for health care.

- A **living will** tells doctors how you want to be treated if you cannot make your own decisions about emergency treatment. You can say which common medical treatments or care you would want, which ones you would want to avoid, and under which conditions each of your choices applies. Learn how to *prepare a living will*.
- A **durable power of attorney for health care** names your health care proxy, a person who can make health care decisions for you if you are unable to communicate these yourself. Your proxy — also known as a representative, surrogate, or agent — should be familiar with your values and wishes. A proxy can be chosen in addition to or instead of a living will. Having a health care proxy helps you plan for situations that cannot be foreseen, such as a serious auto accident or stroke. Learn how to *choose a health care proxy*.

These documents are part of *advance care planning*, which involves preparing for future decisions about your medical care and discussing your wishes with your loved ones.

3. **Put your important papers and copies of legal documents in one place.** You can set up a file, put everything in a desk or dresser drawer, or list the information and location of papers in a notebook. For added security, you might consider getting a fireproof and waterproof safe to store your documents. If your papers are in a bank safe deposit box, keep copies in a file at home. *View a list of important papers*.

4. **Tell someone you know and trust or a lawyer where to find your important papers.** You don't need to discuss your personal affairs, but someone you trust should know where to find your papers in case of an emergency. If you don't have a relative or friend you trust, ask a lawyer to help.

5. **Talk to your loved ones and a doctor about advance care planning.** A doctor can help you understand future health decisions you may face and plan the kinds of care or treatment you may want. Discussing *advance care planning* with your doctor is free through Medicare during your annual wellness visit. Private health insurance may also cover these discussions. Share your decisions with your loved ones to help avoid any surprises or misunderstandings about your wishes.

6. **Give permission in advance for a doctor or lawyer to talk with your caregiver as needed.** If you need help managing your care, you can give your caregiver permission to talk with your doctors, your lawyer, your insurance provider, a credit card company, or your bank. You may need to sign and return

a form. Giving permission for your doctor or lawyer to talk with your caregiver is different from naming a health care proxy. A health care proxy can only make decisions if you are unable to communicate them yourself.

7. **Review your plans regularly.** It's important to review your plans at least once each year and when any major life event occurs, like a divorce, move, or major change in your health.

Which documents do you need to have in place?

When you're getting your affairs in order, it's important to prepare and organize important records and files all in one place. Typically, you will want to include personal, financial, and health information. Remember, this is a starting place. You may have other information to add. For example, if you have a pet, you will want to include the name and address of your veterinarian.



Personal information

- Full legal name
- Social Security number
- Legal residence
- Date and place of birth
- Names and addresses of spouse and children
- Location of birth and death certificates and certificates of marriage, divorce, citizenship, and adoption
- Employers and dates of employment
- Education and military records
- Names and phone numbers of religious contacts
- Memberships in groups and awards received
- Names and phone numbers of close friends, relatives, doctors, lawyers, and financial advisors

Financial information

- Sources of income and assets (pension from your employer, IRAs, 401(k)s, interest, etc.)
- Social Security information
- Insurance information (life, long-term care, home, car) with policy numbers and agents' names and phone numbers
- Names of your banks and account numbers (checking, savings, credit union)
- Investment income (stocks, bonds, property) and stockbrokers' names and phone numbers
- Copy of most recent income tax return
- Location of most up-to-date will with an original signature
- Liabilities, including property tax — what is owed, to whom, and when payments are due
- Mortgages and debts — how and when they are paid
- Location of original deed of trust for home
- Car title and registration
- Credit and debit card names and numbers
- Location of safe deposit box and key

Health information

- Current prescriptions (be sure to update this regularly)
- Living will
- Durable power of attorney for health care
- Copies of any *medical orders or forms* you have (for example, a do-not-resuscitate order)
- Health insurance information with policy and phone numbers

Who can help with getting your affairs in order?

You may want to talk with a lawyer about setting up a general power of attorney, durable power of attorney, joint account, or trust. Be sure to ask about the lawyer's fees before you make an appointment.

You do not have to involve a lawyer in creating your advance directives for health care. Most states provide the forms for free, and you can complete them yourself. Learn more about *completing an advance directive*.

You should be able to find a directory of local lawyers on the internet or contact your local library, your local bar association for lawyers, or the Eldercare Locator. Your local bar association can also help you find what free legal aid options your state has to offer. An informed family member may be able to help you manage some of these issues.

What other decisions can you prepare for in advance?

Getting your affairs in order can also mean making decisions about organ donation and funeral arrangements, or what you want to happen to your body after you die. Deciding and sharing your decisions can help your loved ones during a stressful time and best ensure your wishes are understood and respected.

Organ donation and brain donation. When someone dies, their healthy organs and tissues may be donated to help someone else. You can register to be an organ donor when you renew your driver's license or state ID at your local department of motor vehicles. You can also register online. Some people also choose to donate their brain to advance scientific research. It may be possible to donate organs for transplant as well as the brain for scientific research. Learn more about *organ donation* and *brain donation*.

Funeral arrangements. You can decide ahead of time what kind of funeral or memorial service you would like and where it will be held. You can also decide whether you would like to be buried or cremated and whether you want your body's ashes kept by loved ones or scattered in a favorite place. Be sure and specify certain religious, spiritual, or cultural traditions that you would like to have during your visitation, funeral, or memorial service. You can make arrangements directly with a funeral home or crematory. Read these *tips on planning a funeral*. If you choose not to be embalmed or cremated, most states allow families to take care of transportation, preparation of the body, and other needed arrangements. Learn more about the *burial options available in your state*. Put your preferences in writing and give copies to your loved ones and, if you have one, your lawyer.

For more information about getting your affairs in order

American Bar Association
800-285-2221
www.americanbar.org

CaringInfo
National Hospice and Palliative Care Organization
800-658-8898
caringinfo@nhpco.org
www.caringinfo.org

The Conversation Project
866-787-0831
https://theconversationproject.org

Eldercare Locator
800-677-1116
eldercarelocator@USAging.org
https://eldercare.acl.gov

National Academy of Elder Law Attorneys
703-942-5711
naela@naela.org
www.naela.org

National Elder Law Foundation
520-881-1076
info@nelf.org
www.nelf.org

PREPARE for Your Care
info@prepareforyourcare.org
https://prepareforyourcare.org

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

Content reviewed: February 1, 2023

Dementia Health Care Directive

Many people have clear ideas about the medical care they would want if they were to develop dementia, but standard advance directives (living wills) do not cover dementia. Dementia is the most common reason people lose the ability to guide their own care, so expressing and documenting these wishes while you can is important. A Dementia Directive is a simple way to communicate your wishes if you are later incapacitated. Families often face difficult medical decisions if their loved one is living with dementia. Having a Dementia Directive or similar document to refer to can help them feel clearer that the decisions they make reflect what their loved one would have wanted. One common issue that arises is artificial feeding and whether you would want tube feeding if you can no longer feed yourself and appear uninterested in eating. (For more on *tube feeding*, see *Functional Health*, Section 3.4, page 209.)

The Dementia Directive is a simple tool developed by a physician to help you plan for your end-of-life care, depending on whether you are experiencing mild, moderate, or advanced symptoms of dementia. (For more information, visit *dementia-directive.org*)

A Dementia Provision, created by the nonprofit Compassion and Choices, is another tool that can be used as an addendum to your Advance Directive. (For more information, visit *compassionandchoices.org/*)

Another document is called a Do Not Resuscitate order (DNR) or POLST (Physician's Orders for Life-Sustaining Treatment - currently referred to as a "MOLST" (Medical Orders for Life Sustaining Treatment form in Massachusetts). If your heart stops beating or you stop breathing, you may not want intervention but instead would prefer a natural death. Without one of these orders, healthcare providers, including emergency rescue squads, will likely try to resuscitate you. Talk to your physician if you wish to have a DNR/POLST.

It is important that you give copies of your Health Care Directive and DNR/ POLST (or MOLST form in Massachusetts) to your care partners, your healthcare power of attorney, your physicians, and your attorney. Keep a card in your wallet that has the contact of whomever has your healthcare power of attorney. If you go to a hospital or a long-term care facility, the Directive should accompany you and be attached to your chart.

For more about advanced care planning, visit *Advance Care Planning: A Conversation Guide from the National Institute of Aging*.

Ways to Simplify Your Finances

CREDIT CARDS

If you have a number of credit cards, you may want to close all cards except two. One primary credit card is easier to keep track of than multiple credit cards. Keep the other credit card in a safe place, in case your primary card is lost and you need to charge something. Consider lowering the credit amount on the card as a measure of protection. You also may want to have a trusted family member or friend as the credit card company's contact in case they need to get in touch with you.

AUTOMATIC PAYMENTS

It can be beneficial to set up automatic payments through your bank for important bills, such as mortgage payments, insurance, utilities, and credit cards to ensure the bills are paid timely.

ACCOUNT ALERTS

Check with your bank to see if they can set up an alert notice to let you know when a bank balance drops below a predetermined amount. The alert can be a good heads up that a deposit has not been made, if there is an overpayment, or some other irregularity.

How to Choose a Financial Adviser

When selecting a financial adviser, consider:

- Professional credentials
- Work experience
- Educational background
- Membership in professional associations
- Areas of specialty

Make sure to ask the financial adviser if he or she is familiar with elder care or long-term care planning.

Qualities of a good financial adviser:

- **They ask the right questions** — A good advisor knows how and when to ask the important questions that encourage clients to open up so that they can gather all the information they need to create a financial plan.
- **They pay attention to and act on the information you provide** — A financial advisor should always listen to what clients have to say, prioritize their objectives, respect the chosen level of risk they are comfortable with, and tailor recommendations to suit these factors.
- **They treat clients with courtesy and respect** — If you feel as though you or your loved one are not being heard, understood, or treated with respect, seek financial advice elsewhere.
- **They explain things until you understand** — A good financial advisor will take as much time as necessary to explain a proposed plan or transaction and make sure their clients understand exactly what is going to happen and what risks and benefits are involved.

> *I was a ways down this path,*
> *and I knew things were happening.*
> *I took special care to get my affairs in order —*
> *my advance directives, my house payments,*
> *all the financial stuff I got in order.*
> *I'm maintaining communication*
> *with my friends and my daughter.*
> *I have a good plan in place.*

David Baldridge, Manual Guide



Financial Planning

The Alzheimer's Association offers current information, and more, regarding financial planning, including:

- Common costs of care, including medical and home safety equipment;
- *A Financial and Legal Document Worksheet*;
- Information about sources of financial support for care:
  - Medicare
  - Medicare Advantage
  - Medigap insurance
  - Medicaid
- Social Security Disability Insurance (which may provide coverage on a fast-tracked basis through the Compassionate Allowance Initiative for those individuals with younger-onset/early-onset Alzheimer's disease who meet other eligibility requirements)
- Veterans Benefits
- Supplemental Security Income
  - Information about the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA);
  - Additional information about disability, long-term care, and life insurance plans. (Note: Some life insurance plans have accelerated death benefits and/or waiver of premiums if the insured becomes disabled)
  - Helpful supplemental information about community support services, such as Meals on Wheels, respite care, and transportation services, including a free Community Resource Finder (Carelike - Provider Search).

Visit *Financial Planning | Alzheimer's Association*

One Family's Story



Manual Guide Kim Reid was among those who was able to receive SSDI without too much hassle. Her husband Robert shares their experience in an email:

"Honestly our experience was not as bad as most I have heard. Fortunately I had documented Kim's journey through the healthcare system very well, which made the application process easier.

My notes and copies of our after-visit summaries and diagnosis allowed me to provide more than enough detailed information for the several page application and supplemental documentation. The SSI web page and some Google research also helped.

Upon submission of the application for a lengthy review, we were only once asked to provide additional duplicate information and were Blessed with a first try approval. It was all done via mail with no in-person meeting for review and/or approval."

You may not have as smooth a time as the Reids. The coronavirus pandemic led to delays in many government services. Local offices are again open and hopefully delays will ease over time.



How to Get Help When You Can't Afford It

Pat McHenry Sullivan, Contributor

Many free offerings will help reduce expenses

My husband and I are among the vast majority of people who make too much for government health, housing, and other benefits, and way too little to afford market-rate dementia care or even personal care such as regular cleaning help. Some ways we thrive anyhow are:

- Networking, which led us to all the free programs we mentioned in our essay *Transforming the Narrative From Tragedy to Thriving* (see Section 7.2, page 366), including Moving Together, the GoldMind weekly arts lessons that come in the mail, and the free, thorough diagnosis and follow-up from University of California, Davis.
- Daring to ask for scholarships (for my husband John's improv training) and for medical financial assistance. Many, especially those from Kaiser Permanente, are very generous. Ours has eliminated most co-pays, starting when I got breast cancer, and he was diagnosed with mild cognitive impairment (MCI).
- Using the sharing economy through local and national list-servs to give and receive walkers and other medical equipment, exchange produce, give and receive household goods in top quality.
- Checking the many nearby senior centers where we can see free movies, attend free programs, go to the thrift shop, and connect with great resources.
- Living ecologically in a way that cuts expenses while helping to save the environment.
- Making the most of fix-it fairs (when COVID isn't preventing that).
- Making big pots of soup and other meals, then freezing portions for later use.
- Hanging out with other creative, ecology, and sharing-minded people who love helping each other and the earth thrive.

- Making the most of a superb city bus system and cheap taxi service for seniors. Several of the taxi drivers are so dependable they can take John to monthly medical services where my input isn't needed and return him safely. Meanwhile, I can get other important work done.
- Haunting Amazon and yard sales to create a library of DVDs John loves and can play on a portable player both to entertain and engage him and to increase my ability to work on non-care-partner tasks.

Another creative initiative is Co-op Day Care, an ancient and innovative concept that helps save money while increasing engagement. Inspired by parent-run cooperative schooling or after-school programs, the Institute on Aging in San Francisco opened a co-op day care program for people living with dementia, giving their care partners respite and connection to others in their situation. There's no charge, because care partners take turns helping to run the program. The program at the Presidio in San Francisco has been thriving for over a year. A new one is opening soon in West Oakland through the Institute on Aging.

House sharing is another option to consider. My husband and I are moving from California to Virginia, to share a home with my sister. She'll get my help to finish and publish a book — something I've done successfully for about a dozen people! She will provide backup and respite care for me. Sharing shopping and other chores will save us much time and energy. Thankfully, both of us are clear about what we want and need and are expert at setting boundaries. We are blessed with a creative, ethical approach to life that we got from our parents, then nurtured by ourselves and with the support of many others.

The Top 5 Financial Scams Targeting Older Adults

Reprinted with permission from: NATIONAL COUNCIL ON AGING
https://www.ncoa.org/article/top-5-financial-scams-targeting-older-adults/

Financial scams are everywhere these days and no one is immune. And sometimes it leaves older adults with no way to recoup their losses. Worldwide, people age 60 and over lost a combined $3.4 billion to fraud in 2023 alone.1 Behind that shocking figure? More than 100,000 very real people who have been robbed of their savings and financial security.[1]

"We all need to work together to make sure our seniors, their caregivers, families, and friends know the signs to look for that a criminal is after your money," said FBI Criminal Investigative Division Assistant Director Michael Nordwall in a Facebook post.

NCOA is here to help. When it comes to stopping online scammers, knowledge is power. Below, we cover the most common scams targeting older adults. We'll also tell you what to do if you or someone you know encounters one.

Why do financial scammers target seniors?

Fraudsters and con artists tend to go after older adults because they believe this population has plenty of money in the bank. But it's not just wealthy older Americans who are targeted. Older adults with low income are also at risk for fraud.

Plus, many people are embarrassed to report financial scams. And they can be tough to prosecute. Criminals therefore consider them "low-risk." However, these scams can be especially devastating for older adults whose ability to recover their losses is limited.

How common are financial scams targeting older adults?

In 2023, 536 people filed complaints with the U.S. Senate Special Committee on Aging Fraud Hotline. That brings the total number of registered complaints to nearly 12,300 since 2013.

The five scams that top the list of complaints for seniors:[2]

1. **The grandparent scam.** The grandparent scam is so effective because it exploits people's emotions. First, a caller gains trust by tricking their target into volunteering information, like a grandchild's name. They may say something like, "Hi Gram, do

you know who this is?" Then, with that name at the ready, they impersonate the grandchild.

In this scam, fake grandchildren ask for help with car repairs, late rent, a medical emergency, or even to post bond. They pretend to be in distress. *They may even beg the grandparent not to tell anyone*.

In other versions of this scam, a caller claims to be an arresting police officer, doctor, or lawyer trying to help the grandchild. They prey upon emotions to pressure victims into sending money as quickly as possible. And who among us wouldn't readily help a cherished relative in desperate financial need? These scams are even harder to identify and resist thanks to artificial intelligence (AI). Today, con artists can clone real voices of real relatives and use them to commit fraud.

People who run grandparent scams often ask to be paid through gift cards or wire transfers. These don't always require identification to collect, which means victims have no way ever to recover their money. Some victims report that scammers showed up at their homes, posing as "couriers" to pick up the money.

2. **Financial services scam.** These cons work because they appear to come from a legitimate source: a bank, a mortgage company, or a debt collection agency. Scammers call, text, or send email messages that look and sound perfectly legitimate. They may claim that a checking or savings account has been compromised and ask for personal information, such as a password or Social Security number, to "secure" it. They may promise better rates or terms on a home loan. Or they may threaten arrest for unpaid medical bills—which may or may not exist.

   Each of these types of claims is a lie. But scammers know how to be convincing. They can easily fake the information on Caller ID. They know how to make email addresses and links look real. And they often will use threatening language to scare their victims into volunteering sensitive information or sending money. Usually, the people committing this type of fraud will demand immediate payment through a *peer-to-peer (P2P) platform*.

3. **Tech support scams.** These scams prey upon the doubts and discomforts that many people have around computers. In fact, when it comes to fraud committed against older adults, tech support scams top the list.[2] *How do they work?* Typically, a person's computer or phone screen will freeze or go blank. A pop-up message will appear with a phone number to dial for help. When the user calls it, the scammer on the other end will ask for permission to log on to the device remotely. This fake "tech support" representative also may demand a fee to repair the "issue."

4. **Government impersonation scams.** In *government impersonation scams* (also known as *government imposter scams*), callers pretend to be from the Internal Revenue Service (IRS), *Social Security Administration*, or Medicare. They threaten to arrest or deport the person who picks up the phone if they don't pay their "unpaid taxes". Or, they may threaten to cut off Social Security or Medicare benefits unless the person provides personal details. This information can then be used to commit identity theft.

   Government imposters may demand prepaid debit cards, cash, or wire transfers as payment. Using special technology, they often "spoof" the actual phone number of a government agency or call from the same ZIP code (202 for Washington, D.C., for example). This can trick some people into thinking the caller is from a valid source.

5. **Romance scams.** As more people turn to online dating, con artists are seizing the opportunity. Romance scammers create fake social media profiles and use them to gain trust and steal money. In some cases, these scammers may be (or pretend to be) overseas. They may ask their victims to pay for visas, medical emergencies, and travel expenses to come to the U.S. Romance scams (also called sweetheart scams) can drag out for a long time. As a result, victims often lose a lot of money. The FTC found that in 2023 alone, more than 64,000 people reported a *romance scam*, with losses totaling $1.1 billion.[2] *Get tips for avoiding sweetheart scams*.

Other popular scams targeting older adults

- **Sweepstakes and lottery scams.** The sweepstakes scam is familiar to many of us. Here, bad actors call with good news: the person answering the phone has won the lottery or a prize of some kind. In order to claim their winnings, that person must send money, cash, or gift cards up front—sometimes amounting to thousands of dollars. Supposedly, this money covers "taxes" and "processing fees". Scammers may impersonate well-known sweepstakes organizations (like Publishers Clearing House) to build trust among their targets. Of course, no prize is ever delivered. Sometimes, fraudsters convince people to send even more money by telling them their winnings will arrive soon. Many continue to call people for months and even years after defrauding them out of an initial sum of money.

- **Robocalls and phone scams.** One common robocall is the "Can you hear me?" call. When the person who answers says "yes," the scammer records their voice and hangs up. The criminal then has a voice signature to authorize unwanted charges on items like stolen credit cards. Robocalls use automated technology to dial large numbers of households from anywhere in the world. While there are legal uses for

this technology, robocalls can also be used to carry out a variety of phone scams. These include false claims about expiring car or electronics warranties. Just like government impersonation calls, scammers often spoof the number they're calling from to make it seem like they're from a trusted organization. Yet another popular phone scam is the "impending lawsuit" scam. In this case, someone receives an urgent, frightening call from a person pretending to be from a government or law enforcement agency (like the IRS or the police). They are told if they don't pay a fine by a certain deadline, they will be sued or arrested for some made-up offense.

- **Business imposter scams.** The Federal Trade Commission (FTC) has found that at a *business imposter scam* takes a heavy financial toll on consumers age 60 and older.3 These criminals pretend to be from a business or charity, which makes them seem trustworthy. Like government imposters, business imposter scammers can fake their caller ID to make it seem like a legitimate communication. These fraudsters will try to convince someone to send money or a gift card or share personal information.
- **Investment scams.** This type of scam involves the illegal or alleged sale of financial instruments that typically offer low risk and guaranteed returns. The use of cryptocurrency (digital assets, such as Bitcoin) is common in investment scams. Cryptocurrency-related investment fraud cost adults age 60 and over $716 million in reported losses in 2023.1
- **Medicare and health insurance scams.** Every U.S. citizen or permanent resident age 65 and over qualifies for *Medicare*. This makes the program a prime tool for fraud. In *Medicare scams*, con artists pose as Medicare representatives in order to convince older adults to share their personal information. Scammers might also provide bogus services at makeshift mobile clinics, then bill Medicare and pocket the money. Medicare scams often follow the latest trends in medical research, such as *genetic testing*.
- **Internet and email fraud.** Some older adults come to technology late, and their learning curve is therefore steep. That makes them easier targets for internet and email scams. These scams include pop-up windows that look like anti-virus software; in reality, these windows install computer viruses when clicked on. These viruses can expose personal information or even disable the computer until a person pays a lot of money to have it fixed. (Sometimes this is called "ransomware.") Internet firewalls, built-in virus protection, and other safety precautions can help prevent this type of fraud. However, users must know about these tools—and it can be hard to keep up with the latest ones. Another scam, called a *"phishing" scam*, uses emails and text messages that seem legitimate. They appear to come from a well-known bank, credit card company, or online store. These messages may request personal

data, such as a log-in or Social Security number, to verify an account; or they may ask the recipient to update their credit card info. Scammers use this information to steal money or additional personal details. *Find out how to protect yourself against phishing scams*.

What to do if you think you've been scammed

Scams are specifically designed to catch us off guard, and they can happen to anyone. There's nothing to be ashamed of if you think it's happened to you. Keep important phone numbers handy, including the local police, your bank, and *Adult Protective Services*.

"It's a heartbreaking fact that scams have wiped out people's retirement savings," said Lois Greisman, Associate Director, Division of Marketing Practices at the FTC. "If a business, government agency, or even a grandchild in need contacts you, it's critical to check who you're really dealing with. Never panic or react quickly. Contact them at a number you know is real to verify."

To obtain the contact information for Adult Protective Services in your area, call the Eldercare Locator, a government sponsored national resource line, at 1-800-677-1116 or *visit their website*.

You can also *report scams online to the FTC*. Sharing your experience can help prevent it from happening to someone else.

SOURCES: [1] Federal Bureau of Investigation. Internet Crime Report 2023. Found on the internet at *https://www.ic3.gov/AnnualReport/Reports/2023_IC3Report.pdf*

[2] U.S. Senate Special Committee on Aging. Fighting Fraud: Scams to Watch Out For. September 2024. Found on the internet at *https://www.aging.senate.gov/imo/media/doc/2024_fraud_book_english.pdf*

3 Federal Trade Commission. Age and Fraud. Found on the internet at *https://public.tableau.com/app/profile/federal.trade.commission/viz/AgeandFraud/Infographic*

Beware of Financial Scams: One Family's Story

Janet first realized her husband James (not their real names) was having some cognitive problems when he fell for a complex financial scam over the phone. It began with a "computer technician," who identified himself as being with Microsoft, saying he had to conduct an online inspection of James's computer. That led to more calls from men convincing James that they needed his help to apprehend two high-placed security executives, one with Capitol One (his bank) and one with Microsoft. They told him if he told anyone, it would ruin their chances of catching the bad guy.

As luck would have it, Janet was out of town then, as was the regular bank manager who knew James. When he went to his branch bank to set up a wire transfer of $50,000 to a bank in Kathmandu, Nepal, no one questioned it. He had been instructed to say he was taking his family on vacation there.

When Janet returned home she was immediately suspicious, and got on the other line when the thieves call again. It was clear to her that something was amiss when "Daniel Smith" and "John Morgan" spoke in heavily accented English with many grammatical mistakes.

By then it was too late. The bank opened an investigation, but the $50,000 was gone forever. "The scammers made James feel as if he was helping the 'good guys' apprehend a 'bad guy,' and he wanted to be a good citizen," Janet says. She adds that he would have never fallen for it in the past, as he was a savvy communications specialist with his own consulting firm. That was when she first became aware of his cognitive problems.

The U.S. Department of Justice's Equal Justice Initiative "supports and coordinates the Department's enforcement and programmatic efforts to combat elder abuse, neglect and financial fraud and scams that target our nation's older adults." The EJI focuses on federal law enforcement activities, providing support to older victims, supporting the "efforts of state and local law enforcement, and other elder justice professionals, through the development of training, resources, and tools," promoting public awareness, and offering public awareness resources about elder abuse and "trending schemes."

Visit: *https://www.justice.gov/civil/consumer-protection-branch/transnational-elder-fraud-strike-force*.

SUGGESTED RESOURCES

Articles

Sabatino, C. (2016). Can my advance directives travel across state lines? An essay on portability. Bifocal (38)1. American Bar Association, americanbar.org.

Books

Devi, G. (2017). *The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias*. Workman Publishing Company.

Karlawish, J. (2021). *The Problem of Alzheimer's: How Science, Culture, and Politics Turned a Rare Disease into a Crisis and What We Can Do About It*. St. Martin's Press.

Landsverk, E., MD. (2022). *Living in the Moment: A Guide to Overcoming Challenges and Finding Moments of Joy in Alzheimer's Disease and Other Dementias.* Citadel Press/ Kensington Publishing Corp.

Power, G.A. (2014). *Dementia Beyond Disease: Enhancing Well-Being*, Health Professions Press.

Prosch, T. (2013). *AARP The Other Talk: A Guide to Talking with Your Adult Children about the Rest of Your Life*, McGraw Hill.

Sawatsky, J. (2017). *Dancing with Elephants: Mindfulness Training For Those Living With Dementia, Chronic Illness or an Aging Brain.* Red Canoe Press/Winnipeg.

Taylor, R. (2007). *Alzheimer's from the Inside Out*, Health Professions Press.

Websites, Publications, and a Play

Dementia Provision, created by the nonprofit Compassion and Choices, is another tool that can be used as an addendum to your Advance Directive	*compassionandchoices.org/*
Americans with Disabilities Act, U.S. Department of Labor	*www.ada.gov/topics/intro-to-ada/*
Aging Life Care Association (also called geriatric care managers) is made up of professionals who practice a holistic, client-centered approach to caring for older adults or others facing ongoing health challenges	*www.aginglifecare.org*

"At the Crossroads: Family Conversations About Alzheimer's Disease, Dementia & Driving," The Hartford Center for Mature Market Excellence	*s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf*
"Compassionate Allowances", U.S. Social Security Administration	*www.ssa.gov/compassionateallowances/*
"Disability Benefits," U.S. Social Security Administration	*www.ssa.gov/disability*
Elder Locator a public service of the U.S. Administration on Aging connecting you to services for older adults and their families	*eldercare.acl.gov/Public/Index.aspx*
"Employment and Dementia," Dementia Australia	*www.dementia.org.au/living-dementia/what-next-after-your-diagnosis/planning-ahead/work-and-dementia*
Geriatrics and Extended Care, Department of Veterans Affairs (VA) — Veterans with dementia may be eligible for certain benefits and services	*veteran.com/geriatrics-extended-care/#:~:text=The%20Department%20of%20Veterans%20Affairs%20has%20a%20set,diagnosed%20with%20chronic%20health%20issues%20and%2For%20%E2%80%9Clife-limiting%20illness.%E2%80%9D*
State Veterans Affairs Offices	*https://discover.va.gov/external-resources/?_resource_type=state-veterans-affairs-office*
Home Modification Information Network," University of Southern California Leonard Davis School of Gerontology	*homemods.org/acl/hmin/*
Home Transitions Solution Group provides home assessment, remote home care, and medical data integration and other services	*hometransitionsolutions.org/*
Job Accommodation Network (JAN) is a source of free, expert, and confidential guidance on job accommodations and disability employment issues	*askjan.org/*
National Council on Aging, "What Are The Top Online Scams Targeting Older Adults?"	*www.ncoa.org/article/what-are-the-top-online-scams-targeting-older-adults/*

Smart911.com is a national service meaning your Smart911 Safety Profile travels with you and is visible to any participating 9-1-1 center nationwide	*www.smart911.com/*
The American Automobile Association (AAA) — To learn more about clinical driving assessments, which can be conducted by occupational therapists or driving skills evaluators who are licensed and certified by states	*exchange.aaa.com/safety/senior-driver-safety-mobility/evaluate-your-driving-ability/*
AARP provides dementia-related resources to individuals and their loved ones. AARP has offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.	*https://www.aarp.org/health/brain-health/dementia-resource-guide-digital-edition.html*
AARP, "Help Your Family Plan Your Funeral in Advance"	*https://www.aarp.org/home-family/friends-family/info-2020/planning-your-own-funeral.html*
Alzheimers.gov provides resources and information on Alzheimer's and other forms of dementia across the federal government in one convenient location.	*http://www.alzheimers.gov/*
Alzheimer's Association provides free information, resources, workshops, and more for people living with Alzheimer's disease.	*https://www.alz.org/help-support/i-have-alz/plan-for-your-future/legal_planning*
The Conversation Project, a public engagement initiative with a goal to have every person's wishes for end-of-life care expressed and respected	*theconversationproject.org/*
The Dementia Directive is a simple tool developed by a physician to help you plan for your end-of-life care, depending on whether you are experiencing mild, moderate or advanced symptoms of dementia	*dementia-directive.org*
Five Wishes—An advance care planning resource from Aging with Dignity	*https://agingwithdignity.org/five-wishes/*

The ADEAR Center is a service of the National Institute on Aging (NIA), one of the Federal Government's National Institutes of Health and part of the U.S. Department of Health and Human Services. The ADEAR Center has a staff of Information Specialists available who can assist people living with dementia, their care partners and loved ones, and health professionals, in a variety of ways, including support referrals, free publications, news updates, and more.	*adear@nia.nih.gov*
CaringInfo	*www.caringinfo.org*
Centers for Medicare & Medicaid Services	*www.medicare.gov* For Medicare, call us at 1-800-MEDICARE (1-800-633-4227). TTY: 1-877-486-2048
National Academy of Elder Law Attorneys	*www.naela.org* 1-703-942-5711
National Elder Law Foundation	*www.nelf.org* 1-520-881-1076
Programs, tools, research, news, and more.	*https://www.usagainstalzheimers.org/*

VISIT
Demetia Action Alliance
www.daanow.org

SECTION 5: Medical Affairs

Remember to trust your instincts and don't be afraid to speak up if you're concerned.

Susan Wehry, MD, Contributor



Navigating our complex healthcare system can be difficult. Your individual needs and goals must be at the center of your medical next steps. Here you'll find information and resources you can use to chart your course through the medical challenges and opportunities ahead.

Explore Section 4 and consider:

- Crafting Health Goals
- Assembling Your Healthcare Team
- Making the Most of Doctor Visits
- Understanding Medication Options
- Managing The Hospital Experience
- Palliative Care, Hospice, and End-Of-Life Planning

Note: This Manual does not provide medical advice. **You should always speak with your physician and other healthcare professionals regarding your health.** No information within this Section is intended to be a substitute for professional medical advice, diagnosis, or treatment.

5.1 Health Goals

If you have Medicare, your physician may have asked about your health goals or goals of care during your annual wellness visit. You may not have given this much thought before. Or you may have thought about it like making a New Year's resolution: "Lose a few pounds." "Exercise more."

When diagnosed with a chronic health condition, such as dementia, it's a good time to give this more thought to determine what your health goals are. Think about your health goals broadly, not just medically. In "Discussing Goals of Care," in the online medical reference *UpToDate*, the authors suggest considering goals like "self-sufficiency, life enjoyment, connectedness and legacy, balancing quality and length of life, and a desire to be engaged in care decisions."

Some examples of goals:

- Have a healthcare team you trust.
- Limit exposure to things that cause you stress.
- Walk at least 30 minutes daily.
- Connect with people who matter to you.
- Do something that makes another person smile.
- Volunteer at something you find meaningful and interesting.
- Spend time in nature at least once a week.
- Take naps.
- Learn meditation and deep breathing exercises for relaxation.
- Have an evening routine to wind down.

Some people may be more comfortable conveying their goals verbally, others in writing. Barney Nelson, a Manual Contributor, for example, is conveying his goals in a video recording.

Allen Power, MD, adds that medical tests are not the only meaningful measure of health. "Those yardsticks are not the only yardsticks," he says. "There are so many things the tests don't measure. There's no mental status test that asks can you play a song on the piano — and there are people with very advanced dementia who can play beautifully. We have to ask what makes life worthwhile for each person?"

For example, Terrie Montgomery wants to walk regularly and listen to the birds. Dave Baldridge wants to keep caring for his beloved dogs in his own home. Jim Mann wants to ride the city bus and go downtown by himself. These goals are not medical, but they are related to health. "That's what keeps you going," says Jim. "That's what helps in your brain health."

> *I have returned to school to get a second bachelor's in religious studies. I take one class as I feel able.*
>
> **John-Richard Pagan, Manual Guide**



Being as self-sufficient as possible is a goal many people have. "We want people to try to take charge and step up and self-advocate and do what they can," says Dr. Power. "Taking charge of your overall health is one way you can do that. By saying, 'I do believe if I exercise, engage, keep going out and socializing, this can help me do better.'" That said, he added, sometimes a disease progresses more rapidly despite your best efforts. "If that happens, it doesn't mean you failed."

Health goals also encompass end-of-life decisions. Be intentional about your desires, write them down, and convey them to others.



From "Why Me?" to "What's Next?": Considering Dementia Research Trials

Cynthia Huling Hummel

From an interview conducted by Lauren Keeley, Indiana University

Cynthia's life journey has taken her from the Peace Corps in Jamaica, to the world of corporate America, and, finally, to a call to ministry. As she has been throughout her life journey, Cynthia remains committed to making a difference.

Lauren: Let's start with the basics. Where do you live and what do you do for your career?

Cynthia: I live in Owego, NY. I was invited to live in a community for retired Presbyterian pastors. Even though I'm technically retired, I'm not ready to stop fully living my life. I continue to preach on Sunday mornings and to volunteer my time to serve churches that don't have pastors.

I've had a very interesting life. I joined the Peace Corps after college. I was a teacher in Jamaica and my job was to start a school for special needs kids. When I left Jamaica after two years I went into corporate America and I worked for Dun & Bradstreet; I was a technology geek, so to speak. It was the very beginning of computers—I took care of computers that were five feet tall and had to be kept in refrigerated rooms. Then I felt a call to ministry, so I enrolled in seminary. It took me 5 years, going part-time to get my master's in divinity (101 credits!) and I was invited to be pastor in a church in upstate NY. I've been a pastor for 28 years and I love it.

Things changed when I started having symptoms of dementia; it was hard to be a pastor when I couldn't remember my parishioners' names or what they had shared with me. People tell their pastors all kinds of things—they talk about their personal life, if their son's involved in drugs, or their husband's having an affair, and so on. So not to remember somebody's name or to not be able to pick up a conversation because you don't remember what you even spoke with them about was hard.

I focus on what I can do and how I can still make a difference. I can still preach. I just need to use my finger so I don't lose my place in the sermon. I still provide pastoral care to those going through difficult times, lead memorial services, officiate at

weddings, visit with people in the hospital, and more. I have asked the members of the church to raise their hands if I accidentally skip over something during the service, e.g., the offering. I feel very blessed to be able to continue providing pastoral leadership, especially to congregations that don't have a pastor.

Lauren: That's great. Could you talk a little about your diagnosis experience?

Cynthia: It took me 8 years to get a diagnosis. I went from doctor to doctor seeking answers. When I was finally diagnosed with amnestic mild cognitive impairment due to Alzheimer's disease, it wasn't a surprise, but it was a sadness. My mom died with Alzheimer's, her only brother died with Alzheimer's, and my grandmother had some sort of dementia.

Dementia is an umbrella term (like cancer) and, just as there are many forms of cancer, there are different types of dementia and they have different symptoms and trajectories. So an accurate diagnosis is critical to providing care and support to the individual regarding their brain health. Researchers are now at the place where they can diagnose with much greater accuracy. I started having problems when I was 49 in 2003, and back then we didn't have PET scans that were easily available or blood-based biomarkers. Now we can diagnose Alzheimer's dementia much earlier and we know much more about the trajectory of the disease, and we have some treatments available and others in the pipeline.

Lauren: That's wonderful. I don't think a lot of people know about all the distinct types. I feel like it's very common to just say "dementia" or "Alzheimer's" and there's one image that comes to mind.

Cynthia: When someone has cancer, what's the first thing someone asks?

Lauren: What kind?

Cynthia: YES! And then even within those cancers there are different treatment options depending on the person and what they're trying to accomplish. Does that person need radiation? Does that person need infusions? Does that person need medication? And that's where we're going with dementia research—it's going to be precision-based medicine in the not-too-distant future. I always tell people it's an exciting time to be in research and it's a hopeful time to have Alzheimer's or another dementia.

Cynthia participates in long-term research studies, serves on national and international advisory councils and committees, and advocates for clinical trial participation by members of diverse communities.

Cynthia: There's so much that has happened just in the past few years. I'm passionate about research.

Lauren: I can tell!

Cynthia: Well, part of [my interest in research] is to honor my family members who died with Alzheimer's. And the only way we're going to get improved treatments, cures, and prevention is if people volunteer to be in research studies. I myself am in my 15th year of an observational study, where researchers are just watching my brain change with yearly cognitive testing, PET scans, and MRIs, and every other year I get a spinal tap so they can see how the disease progresses. This observational study is called the *Alzheimer's Disease Neuroimaging Initiative (ADNI)*, and it just celebrated its 20th anniversary. The data ADNI collects is available without cost to researchers all over the world. And there are also interventional studies (trials), which entail taking a drug (or placebo) and tracking the results.

To me, it's all so fascinating. I was appointed by the Secretary of Health and Human Services to the *National Advisory Council on Aging (NACA)* as the first person with a lived experience of a [dementia] diagnosis. It's a funding committee that oversees what research projects are coming down the pike and what researchers want to study more of.

Lauren: Do you get a say since you're on that committee?

Cynthia: Yes, I get to vote and I get to present my recommendations to my colleagues. I'm also serving on a committee for the World Health Organization, and I'm presenting next week on how and when to use blood-based biomarker testing to rule out or confirm Alzheimer's disease in clinical settings.

Lauren: That's incredible. How else do you advocate for Alzheimer's research?

Cynthia: I go out and I talk to people! I invite people to think about if they want to be in a trial, or in research generally. And the other thing I try to emphasize is we need to have diverse groups involved in research—everybody needs to be represented at the table. We need people of color. We need people who are from different communities. They need to be part of the research, because we don't know how the drug or treatment would impact differently because we've never looked at those factors.

Lauren: That's a good point. Thank you for explaining that because, as I said, I was unfamiliar with exactly what the research advocacy entailed. It sounds like you have found fulfillment in your life in all these different avenues, be it research or your work

as a pastor. What would you recommend for others who are living with dementia or Alzheimer's to do to find fulfillment in their lives?

For Cynthia, helping others and helping ourselves go hand-in-hand. Engagement instead of isolation is the key to living well with dementia.

Cynthia: I tell people we have to move from "Why me?" to "What next?" because we can't sit around and feel sorry for ourselves. I'm not saying we shouldn't grieve, we surely should, but we must move beyond that. For me, the best medicine to stop us from isolating ourselves is volunteering. When we help others, we help ourselves. There are so many ways to volunteer our time—working at a library or at a pet shop, reading to somebody who's blind, teaching English as a second language. There's so much we can do with the gifts and talents we have.

I've shed many tears, but I can't stay stuck there, right? Reach out and help other people! Get involved. Volunteer at a church or a synagogue or mosque. Volunteer in the community. Help at a senior citizen meal center to clear the plates. It doesn't have to be a huge or monumental task but finding a place where we can make a difference in somebody's life can bring joy to everyone involved.

5.2 Who Should Be on Your Healthcare Team?

As described elsewhere in this Manual, many different professions and practices can help you maintain your health and well-being. Most of these should be covered by insurance,but some may not be. If they are not covered, you may need to pay out of pocket or identify local resources that support your choices. For example, many Area Agencies on Aging offer brain health and exercise classes. You can find your Area Agency on Aging online at the Eldercare Locator: *eldercare.acl.gov/Public/Index.aspx*, and can contact Eldercare Locator for other questions at 1-800-677-1116 or *eldercarelocator@n4a.org*.

Your healthcare team members can include:

- **Primary care physician**, whose office may include a nurse practitioner or physician assistant who will sometimes see you. It is important to know that not all physicians have expertise in assessing, diagnosing, and supporting people living with dementia. Ideally your physician will be a geriatrician or have experience with older patients and be aware of special concerns like polypharmacy (too many medications). It is OK to ask if anyone in the practice has expertise with dementia.
- **Dementia specialist**, such as a neurologist, geriatrician, neuropsychiatrist, geriatric psychiatrist, or neuropsychologist, who will be up to date on research and who has a holistic view of treating dementia.
- **Other medical specialists**, such as a cardiologist or rheumatologist, depending on your medical diagnoses. Be sure that any medications or treatments from specialists are coordinated and approved by your primary care physician.
- **Pharmacist**, as another set of eyes on how multiple drugs might interact, and who should be familiar with medication side effects such as dizziness, confusion, or insomnia.
- **Dentist**, to help prevent gum disease and tooth decay which are much higher in older people than the general population. Some medications cause dry mouth which can increase the risk of cavities. Maintaining oral care can be difficult especially in advanced dementia phases.
- **Physical, occupational, and speech therapists**, who can each play an important role in promoting your functional health. (For more information, see *Functional Health*, Section 3.4, page 206.)
- **Cognitive therapist**, who has expertise in cognitive skills training and other strategies for people living with cognitive impairment or dementia. Some people find cognitive therapy helpful. Speech therapists may also provide cognitive therapy.

- **Mental health practitioners**, such as a psychologist, licensed clinical social worker, marriage or family counselor, or pastoral counselor, for depression and anxiety, and to help you process grief or other complicated feelings about your disease.
- **Creative arts therapists**, including visual arts, drama, poetry and creative writing, music, and dance, who combine creative expression and counseling.
- **Creative artists**, who are not trained in counseling but who can guide and open up your creativity to promote personhood, communication, and well-being.
- **Complementary therapy practitioners**, whose training might include reiki, massage, compassionate touch, or aromatherapy, and who may be able to help address stress and pain and promote well-being. (For more information on complementary therapies and practices, see *Mind-Body Practices*, Section 3.6, page 215.)

5.3 You and Your Doctor

> *You have to be your own advocate. You have to speak up. You have to say 'Look, I'm a person. I feel like you became a doctor, you took an oath, so help me.' If we feel we're not being treated fairly, we need to speak up.*
>
> **Terrie Montgomery, Manual Guide**



Going to the doctor can be stressful for anyone, but may be more so for people living with dementia. Sitting in a crowded, often noisy waiting room; having blood drawn; and wondering about test results can produce anxiety. Doctors and care partners who feel rushed or are impatient may add to this anxiety. Preparing for a doctor's visit can help things go more smoothly.

Making The Most of a Doctor's Visit

Make your doctor's visit go more smoothly:

- **Schedule your appointment** during *your* best time of day. Consider telehealth if it is available and if you are more comfortable being in your own home.
- If **paperwork** is required for the visit, ask the office to send it ahead of time via mail or e-mail. If you are comfortable using a computer, ask if you can fill out the information online. Be sure to let the office know of any change in your contact information or insurance.
- **Keep a notebook** handy at home to record questions, concerns, and new and changing symptoms to share at your next visit. Bring the notebook with you, but before leaving for the doctor review your notes, add anything that's missing, and prioritize what you would like to talk about.
- Maintain an **up-to-date list of your medications**, including over-the-counter drugs, herbal supplements, and vitamins. Keep that with you so that you have it for your next visit.
- Keep and share a **list of the names and phone numbers of any specialists** you've seen since your last visit.
- **Bring someone with you** to listen and take notes. This lets you focus on the doctor and what they are saying.
- Allow **plenty of time** to travel to your appointment and to park.
- Bring a **quiet activity**—newspaper, magazine, puzzle book, writing pad—to pass the time while waiting. Earbuds and music can also help pass the time and lift your spirits.
- Ask the doctor to **repeat or explain** anything you do not understand.
- End the visit with a **shared understanding** of goals of care and next steps. This could include new medication, new appointments, or new strategies like improved nutrition, deep breathing, and being outside more.



Tracking Dementia Symptoms Along the Journey

William "Barney" Nelson

From an interview conducted by Jamie Lett, Indiana University

When Barney Nelson received his diagnosis, he was not surprised. Based on his own research, he knew his symptoms already pointed toward Lewy Body Dementia. He rejected the tragedy narrative and looked forward to a life of trying new things and doing things in a different way.

Jamie: Why don't we talk about the diagnostic journey?

Barney: It's one of my favorite things to talk about.

Jamie: When did you receive your diagnosis, if you don't mind me asking?

Barney: January 2019, but frankly, six or seven months before then, I already had pretty well figured out what I had, because my symptoms just lined up very well with Lewy Body. I was starting to have hallucinations at night. My tremors were getting worse, my cognitive capability was getting worse. I'd had REM sleep disorder for many years, which has increasingly become a key indicator from a diagnostic standpoint, sort of a precursor to dementia.

Jamie: How did you feel after receiving the diagnosis?

Barney: I wasn't surprised, obviously, and I wasn't really scared. One of the first things out of my mouth was, "I'm not afraid to die." You know, dementias are fatal: there is no cure and there's really not a lot you can do, medicine-wise or whatever, to change the trajectory. I don't believe it to be a tragedy narrative, so to speak. You may have to pivot, you may have to do some things differently, you may no longer be able to do things you used to do, you may want to try new things. I knew what the end game was going to be, but I felt like I still could live a lot of my life.

Barney's diagnosis journey was smoother than many living with dementia. The log of symptoms that he had kept for many months had been a very useful tool for his health care team. To help others along their journey, Barney created Dementia Symptoms Tracking Tools. *www.dementiasymptomstrackingtools.com*.

Barney: When we talk about the diagnostic process, I very much got into that, understanding the process, because it worked so well for me. I'd hear so many stories from other people who would go four or five years with doctors, trying to get a diagnosis—a really horrible scenario. I mentioned I kept a log of my symptoms. By the time I saw the dementia specialist doctor, showed her my log and described what I'd been experiencing, we were well down the diagnostic road. She actually told me the log helped her understand in an empirical way what was going on with me. It made a big difference, you know?

I went ahead and put together a couple of log sheets and built a website and put them on there. It's called *Dementia Symptoms Tracking Tools*. There are PDF documents, you can download them for free, and you'll see the log and a list of all these different symptoms. You just keep track of what your symptoms are, the time frame they started, frequency, and all that. It's helpful information you can share with your doctor or just keep for yourself, as you track how things are going for you, how symptoms are progressing.

Jamie: When did you set that up?

Barney: Shortly after I was diagnosed, because I saw a real need for something like that. I saw the whole diagnostic process was a mess. Dementia is a very difficult disease to diagnose accurately, particularly Lewy Body. I saw a real need there, as I heard horror stories about people who, again, were going four or five years talking to three or four different doctors, getting three or four or five different diagnoses and not making any progress, living with fear and uncertainty. It was creating a really difficult burden for them and their families. I wanted to help; I put it together, it didn't take me all that long.

5.4 Medications and Medications to Avoid

Managing Dementia Symptoms: Medications

Medications are typically prescribed to treat the symptoms or the cause of an illness. The decision to prescribe a medication is based on an assessment of the likely benefits (efficacy) and the likely side effects or adverse reactions (risk). This is referred to as the risk/benefit ratio. More simply, the questions to ask about taking any medication are — Is it more likely to help than to harm me? Are the side effects worth it? It is important to have shared decision-making between you and your healthcare providers to determine the risk vs. benefit of any prescribed medications, and to consider medication interaction if you are managing other conditions or chronic diseases, such as diabetes, restless leg, Parkinson's, urinary incontinence, insomnia, or COPD.

Medications prescribed for people living with dementia target symptoms rather than causes So far, scientists have not found a drug or drugs that will prevent, reverse, modify, or cure dementia. Dementia is complex with many causes (see *Learning About MCI and Dementia*, Section 8, page 405), and it is unlikely there will be a single approach.

Medications that address the cognitive symptoms of dementia "are palliative in nature," explains Tia Powell, MD. "They can give some people some relief for some period of time but they are generally pretty modest. They are not disease-modifying therapies."

The following are the medications approved by the U.S. Food and Drug Administration for dementia:

CHOLINESTERASE INHIBITORS

Donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne) work by boosting levels of a chemical (acetylcholine) involved in memory and judgment. Although primarily used to treat Alzheimer's disease, cholinesterase inhibitors might also be prescribed for other dementias, including vascular dementia, Parkinson's disease dementia, and Lewy body dementia. Cholinesterase inhibitors are approved for all stages of of Alzheimer's disease. Side effects can include nausea, vomiting and diarrhea, loss of appetite, weight loss, insomnia, headache, and depression.

MEMANTINE (NAMENDA)

Memantine works by regulating the activity of a neurochemical, glutamate, that is also involved in learning and memory. Memantine is approved for moderate to advanced symptoms of Alzheimer's and in some cases is prescribed with

a cholinesterase inhibitor. Common side effects of memantine are dizziness, confusion, headache, constipation, and hypertension.

MONOCLONAL ANTIBODIES

Lecanemab and Donanemab

These drugs are approved for MCI and mild Alzheimer's and require IV administration. They are extremely expensive, and their serious side effects–brain edema and microhemorrhage–and unknown clinical benefit are also concerning.

Medications are sometimes used to treat symptoms other than cognitive symptoms, such as treatments for insomnia, anxiety, depression, and agitation. Remember the general rule — ask how likely a drug is to work and if the benefits outweigh the risks and side effects. Ask about alternatives. Non-pharmaceutical treatments for all of these symptoms are available. (See *Supporting Your Well-Being*, Section 2.1, page 112.)

It's important to keep in mind that polypharmacy (simultaneous use of multiple drugs) is a serious problem for many older people, whether or not they are living with dementia. According to the Centers for Disease Control and Prevention (CDC), seven out of 10 adults aged 40 to 79 take at least one prescription drug, and one out of five take five or more drugs. The potential for drug interactions and side effects is quite high.

"Medications might be good, but every single medicine has potential side effects," says Anne Ellett, RN, MSN. "I ask people to look at the whole spectrum of what they're taking.

In general, my approach is less is more. If you're on more than five things, you do have adverse events. It's not unusual for older people to be on 10, 15 things a day, a combination of prescription and supplements — no wonder they're dizzy or don't have an appetite or have bowel problems. Ask your healthcare provider to look at the risks and benefits of all your medications."

Periodically review your medications with your doctor. With each new medication or dose increase, closely monitor side effects because these may indicate adverse drug interactions and/or the dose adjustment. Don't assume you need to stay on a drug forever. If your doctor reports that kidney (renal) function has declined, dose reductions of some medications may be needed. Be sure to ask your doctor to check if you need changes in the amount of each medication you take. Your retail pharmacist will not have adequate information to alert you of the need for a lower dose.

A high pill burden or complex medication regimen can make it difficult to take medications correctly, and this can also lead to adverse effects. Concern especially exists if prescribed insulin (for diabetes) or warfarin (to prevent blood clots). Care partners should make themselves aware of how difficult it is to follow medication directions correctly and ask for medical professional help to determine best strategies. Ask to reduce to as few times a day to take medications as possible. Report what time of day has the most missed doses. Whenever possible, use only one pharmacy, enable automatic refills, enquire about pill-packing services at the pharmacy that can help with management, and/or use laminated charts, phone alarms, or text reminders from family and friends to keep you and your medications on track. Timed and alarmed pill dispensers are available for someone living alone.

Constipation or diarrhea are common problems and may be difficult to self-regulate. Care partners may be reluctant to assist out of respect for dignity. Many factors can change bowel frequency including activity level, hydration, diet, and medications. Too often unrecognized constipation may be the cause of agitation. Care partners should attempt to determine if constipation is a problem. Seek health care professionals to assist in finding the best treatment

Medications to Avoid if Possible

- **Sleep aids** are used to help people get to sleep and stay asleep. People living with dementia should NOT use these drugs regularly because they make the person more confused and more likely to fall. Avoid products containing diphenhydramine. Continuous use can lead to symptoms that resemble dementia, but are actually side effects.There are lifestyle changes people can make to improve their sleep. (See *Get Restorative Sleep*, Section 2.2E, page 123.)
- **Anti-anxiety drugs** are often prescribed for agitation. These drugs can cause sleepiness, dizziness, falls, and confusion. A better strategy is to address the trigger or unmet need that is causing the agitation. If an anti-anxiety medication is used, it should only be used for short periods of time.
- **Anti-convulsants** are drugs sometimes used to treat severe aggression. Side effects may cause sleepiness, dizziness, mood swings, and confusion.
- **Antipsychotics** are often prescribed for paranoia, hallucinations, agitation, and aggression. Side effects of using these drugs can be serious, including increased risk of death in some older people living with dementia. In some instances, antipsychotics may be given for severe aggression if no other intervention has helped. There is no evidence antipsychotics are useful after about 12 weeks.

Dr. Allen Power pioneered efforts to treat people living with dementia, especially those in care homes, without the use of psychotropic drugs that affect mood and behavior. Too often, he argued, people who express distress are drugged into lethargy. Instead, he advises care partners and staff to try to identify the trigger or unmet need the person living with dementia is struggling with that may be causing agitation or anger. (See *Coping with Expressions of Distress*, Section 7.6, page 388.) Centers for Medicare and Medicaid Services (CMS) tracks the use of antipsychotic drugs in nursing homes and has set a goal for their significant reduction.

What about Supplements or Alternative "Cures"?

It seems almost every week there is a new claim for "how to prevent or cure Alzheimer's disease" or some other form of dementia. We can't cover them all so you will want to have a trusted source of information about these claims. We recommend The National Center for Complementary and Integrative Medicine (*https://nccih.nih.gov*).

To date there is no convincing evidence from a large body of research that any dietary supplement can prevent worsening of cognitive impairment associated with dementia. This includes studies of ginkgo, omega-3 fatty acids/fish oil, vitamins B and E, Asian ginseng, grape seed extract, and curcumin. Additional research on some of these supplements is underway.

Be suspicious of any product or therapy that claims to prevent or cure dementia. That said, a healthy lifestyle, having a sense of purpose, and staying connected to others may help reduce your risk of further cognitive impairment or slow its progression

5.5 Prescription Assistance Programs

Prescription drugs can be very expensive. Even if you have signed up for Medicare Part D or other drug insurance, it may not adequately cover what your doctor prescribes. If you need help paying for prescription drugs, you might want to look into Patient (also called Prescription Assistance Programs (PAPs).

According to the website *Needymeds.org*, more than 375 PAPs operate in the U.S., helping more than 36 million people obtain pharmaceuticals. Some $13 billion worth of prescription drugs are provided to low-income people at no cost. Some PAPs do not pay the full cost but will sell it to eligible patients at a discount. The programs are usually paid for by drug manufacturers, and, to a lesser extent, government and nonprofits. Generally, a PAP covers one particular drug; it is not an overall drug insurance plan.

PAPs do have their critics. Many manufacturers have a confusing application process. They may not be open about what criteria they use to determine eligibility. Critics caution that manufacturers also have their own agenda with a PAP, hoping to turn you into a loyal customer for their other drugs.

A fact sheet by *Consumer Reports* and *Consumer Reports Best Buy Drugs* offers these tips:

- Ask your doctor to prescribe a generic drug, rather than brand name, if the generic is equally effective and available.
- Ask your doctor, clinic, or pharmacist to recommend a PAP.
- Visit the website of the manufacturer of the drug to see if they have a PAP.
- Find out — if you can — what the income requirements are for a particular PAP. Income limits generally range from $20,000 to $40,000, depending on the size of your family. In addition, your assets may not exceed $15,000 to $20,000, not counting your home and one car.
- If your income or assets are too high and if you do not have drug insurance, you may still be able to get help from some programs.

Be wary of online companies that offer to help you with the application process — for a fee. There should not be a charge to apply for a PAP. Ask your healthcare provider to help you if the process is too confusing.

Consumer Reports Recommends:

WEBSITES TO FIND A PAP

- RxAssist, *www.rxassist.org*
- Partnership for Prescription Assistance, *www.pparx.org*
- Needy Meds, *www.needymeds.org*
- Medicare, *www.medicare.gov* and search for Prescription Assistance Programs
- Medicare Rights Center, *www.medicarerights.org*

5.6 Cannabis and CBD

Cannabis

Does cannabis (marijuana) hold promise for treating dementia? Scientists at Johns Hopkins University, Harvard University, and other major research centers are studying that question.

According to Harvard Health (*The effects of marijuana on your memory - Harvard Health*), "Cannabis contains varying amounts of the potentially therapeutic compound cannabidiol (CBD), which may help quell anxiety. However, there's no question that marijuana (the dried flowers and leaves of the cannabis plant) can produce short-term problems with thinking, working memory, executive function, and psychomotor function (physical actions that require conscious thought, such as driving a car or playing a musical instrument). This is because marijuana's main psychoactive chemical, THC, causes its effect by attaching to receptors in brain regions that are vital for memory formation, including the hippocampus, amygdala, and cerebral cortex. The extent to which long-term use of marijuana (either for medical or recreational purposes) produces persistent cognitive problems is not known."

As of February 2024, 47 states, the District of Columbia, and 3 territories (Guam, Puerto Rico, U.S. Virgin Islands) allow for the use of cannabis for medical purposes. Thirty-eight states, the District of Columbia, and 3 territories allow for the use of cannabis for medical purposes through comprehensive programs.

As of February 2024, 24 states, the District of Columbia, and 2 territories (Guam and North Mariana Islands) allow for the use of cannabis for non-medical adult purposes.

CBD (Cannabidiol)

CBD is a chemical found in marijuana. CBD does not contain tetrahydrocannabinol (THC), the psychoactive ingredient found in marijuana that produces a high. CBD often comes as an oil, but it can also be formulated as an extract, a vaporized liquid, and an oil-based capsule. Food, drinks, and cosmetics are among the many CBD-infused products available.

Though CBD is often well-tolerated, it carries some risks. Side effects include dry mouth, diarrhea, reduced appetite, drowsiness, and fatigue. The U.S. Food and Drug Administration (FDA) warns that CBD can cause liver injury (as shown in some animal experiments in very high doses) and affect metabolism of other drugs you are taking, such as blood thinners.

The FDA has not approved CBD for treating dementia symptoms.

Harvard Health cautions that there is some unreliability about the purity and dosage of CBD in products. A recent study of 84 CBD products bought online showed that more than a quarter of the products contained less CBD than labeled. In addition, THC was found in 18 products. If you plan to use products containing CBD, talk to your doctor.

CBD has been found to help ease symptoms experienced by some people living with dementia, including:

- Anxiety
- Depression
- Agitation
- Insomnia
- Motor function problems

"For associated problems with dementia like anxiety, cannabis can help," says Dr. Allen Power. It has also been found to ease pain and nausea associated with cancer and chemotherapy.

Research is ongoing as to the potential benefits of cannabis for dementia.

5.7 Transcranial Magnetic Stimulation

A treatment being studied for dementia is called transcranial magnetic stimulation (TMS). It is a noninvasive medical device that uses magnetic fields to stimulate nerve cells in the brain.

There are two types of TMS, the original type that gives repetitive magnetic pulses, and a newer version called Deep TMS. Both have been approved by the FDA to treat major depression that has not responded to medication, obsessive-compulsive disorder, and migraine headache pain. In some European countries, Deep TMS is also approved for a wide variety of other conditions, among them Parkinson's disease and Alzheimer's. Side effects are said to be mild, with the most common being headache.

In the U.S., TMS for dementia is considered "off-label" because it has not been approved by the FDA for this purpose. Some neurologists do use it, including Dr. Gayarti Devi, who writes in *The Spectrum of Hope*: "I have spent a decade investigating the effects of TMS in patients living with dementia ... TMS increases cognitive reserve by increasing connections in targeted neural circuits." She believes it can also help with dementia-related language problems.

Others say that it is too soon to know if TMS is safe and effective for treating dementia symptoms. A review in the journal *eNeuro* in 2020, "Transcranial Magnetic Stimulation in Alzheimer's Disease: Are We Ready?" concluded: "Although small clinical trials in [Alzheimer's disease] have reported positive effects on cognitive outcome measures, significant knowledge gaps remain, and little attention has been directed at examining the potential influence of TMS on AD pathogenesis ... we caution that TMS therapeutic protocols established in young adults may have unexpected detrimental effects in older individuals or in the brain compromised by AD pathology."

Neurologist Daniel Potts and others recommend that people living with dementia interested in trying TMS look for a clinical trial in which they can enroll.

5.8 Telehealth Visits

Telehealth has been around for decades, and really took off during the COVID pandemic. A 2021 report by McKinsey found that the use of telehealth multiplied by 38 times from pre-pandemic figures. Some 40 percent of consumers said they would like to continue using telehealth, compared to just 11 percent pre-pandemic.

Among medical specialties, telehealth was used most widely in psychiatry. Since COVID, many doctors and therapists are using telehealth as insurance permits.

With telehealth you can be seen virtually by a healthcare provider, either online or over the phone, from the comfort of your home. It can also include using monitors to track things remotely, like blood pressure. The readings are sent automatically to your healthcare provider. As technology continues to improve, costs come down, and people grow more comfortable being in front of a video camera, telehealth will likely become increasingly common. Telehealth can be especially valuable in rural areas, where people often travel long distances to be seen by specialists.

"Telehealth for people with early symptoms of dementia works as well as for anybody," says Dr. Allen Power. "With certain symptoms, you need to be examined in person. Also, you might need some of the cues you get from a live conversation. Telehealth can be helpful to get an overall sense of how the person is doing and what they're experiencing. With more advanced symptoms, telehealth becomes more challenging as some people living with dementia become confused with the telehealth online process. During the pandemic, some nursing homes tried to connect residents with their families using video. Some could do it, some could not."

The National Institute on Aging is funding research on telehealth as a promising way to deliver healthcare to people living with dementia and their care partners, especially in underserved areas. According to NIA, "By making dementia care and education more accessible, telehealth can help manage dementia issues at home before a crisis happens. This, in turn, can lessen caregiver burden and stress and improve quality of life for people living with dementia. Promising evidence suggests that telehealth dementia services may also reduce emergency department visits, which may help reduce the costs of dementia care."

NIA cautions that insurance providers vary widely on their policies for covering telehealth, depending in part on state regulations. Be sure to check with your insurance provider before making a telehealth appointment.

5.9 Healthcare at Home

There is a growing movement to offer people a range of in-person medical services in their own homes — everything from house calls and dentistry to acute hospital-level care. This kind of delivery can be especially valuable for people living with dementia.

Much like telehealth, in-person healthcare at home was given a boost during the COVID pandemic, including for acute care. This was to reduce the spread of infection, a significant problem in hospitals, even before the pandemic. According to the CDC it is estimated that 99,000 deaths in the United States occur each year related to healthcare-associated infections (HAIs). As of November 2024, there have been approximately 1.7 million healthcare-associated infections. During COVID, the federal government gave a temporary waiver for acute-level hospital care to be delivered at home and still be covered by Medicare and Medicaid. Please note: Medicaid waiver programs can help pay for standard medical and non-medical care, personal care services, respite care and adult day care. However, each state can develop its own waiver programs so some rules, eligibility criteria and, as a result, coverage may vary.

A 2020 clinical trial in the *Annals of Internal Medicine* found that costs for treating acutely-ill patients at home were 38 percent lower compared to a hospitalized group. The in-home patients received fewer lab tests, radiology exams, and specialist consultations, and they were less sedentary. Their readmission rates were also lower.

In addition to hospital-at-home, there is a move to go back to the future with traditional physician house calls. The American Academy of Home Care Medicine trains physicians and other members of the health care team to provide home-based primary care. Technology,

including portable devices, makes this type of medicine more affordable, with high-quality results and high patient satisfaction. It also saves money. Over the first four years, the Independence at Home Demonstration project saved Medicare approximately $63 million and delivered high-quality care. Most of the savings came from reduced hospitalizations and skilled nursing facility services. Visit *www.aahcm.org* to find out if this type of home care is available in your area.

Other types of home health care, including services by nurses, occupational/physical/speech therapists, social workers, and spiritual care counselors, are available in some areas for people living with chronic conditions. Medicare will cover some of this care, including for people with advanced dementia and those who are homebound. (This coverage generally does not include long-term care by home-health aides, which is usually paid for out-of-pocket or with long-term care insurance.)

One company, DispatchHealth, operates in nearly 50 markets across 30 states, as of November 2024. Its model is to send a two-person team (a physician assistant or nurse practitioner and a medical technician) to your home when you call with a concern that might otherwise take you to an urgent care clinic or the emergency room. They will assess if you can be treated at home, or if you need to go to a hospital. The team can administer IVs, run lab work, change catheters, and many other procedures. The care is covered by Medicare, Medicaid, and many private insurers. DispatchHealth will bill your insurance company directly for services rendered. For more information, visit: *dispatchhealth.com*

The Veterans Administration has long offered a home-health care option to many veterans. The VA also pioneered programs to help compensate care partners. To learn more about these services, visit: *va.gov/geriatrics*.

When evaluating in-home living assistance, it's crucial to understand the payer source eligibility and ensure the provider employs care partners who are highly-skilled, undergo continuous training with a focus on compassionate dementia care, and pass through background checks. Look for a company that leverages technology and offers a wide range of services, including wellness-companionship, personal care, advanced personal care, and skilled nursing services. Visit *www.homewatchcaregivers.com* for more information.

Selecting Home Care Services
Interview Questions

Nicole Brackett, Contributor

These questions should help you gather important information and make an informed decision when considering home care services. Be sure to personalize them to fit your needs and interests.

For the Person Living with Dementia

Daily Routine:

- How will you help me maintain my current daily routine?
- What activities do you offer that I might enjoy?

Comfort and Safety:

- How will you ensure my comfort and safety at home?
- Can you assist with tasks I find challenging, like bathing, dressing, or cooking?
- How do you address safety concerns in the home?

Independence and Preferences:

- How will you support my independence in daily activities?
- Can I choose which tasks I want help with and which I prefer to do on my own?
- How do you accommodate personal preferences in the living environment?

Social and Emotional Support:

- How do you ensure a good match between me and the caregiver?
- What steps do you take to make sure I feel comfortable with the caregivers?

For the Family or Care Partner

Care Needs and Responsibilities:

- What specific types of assistance can you provide for my loved one?
- How often can you provide support throughout the day?
- How do you address the expressions of unmet needs related to dementia if my loved one cannot communicate the need?

Care Preferences and Priorities:

- What qualities do your caregivers have, especially in terms of experience with dementia?

- How many hours of annual skills training do caregivers receive?
- How do you support the activities and routines that my loved one enjoys?

Communication and Collaboration:

- How do you keep families informed about the care provided?
- How can we be involved in decision-making regarding my loved one's care, if needed?

Safety and Well-Being:

- What measures do you take to address safety concerns in the home?
- How do you ensure my loved one's well-being when care partners are not present?
- How often are caregivers screened using national background checks? Only at initial employment? Annually?
- Are caregivers insured by your organization?

Flexibility and Adaptation:

- How do you adapt care as my loved one's condition progresses?
- What level of flexibility do you offer in terms of care schedules and services?



Staying Connected with Home Care: Jennifer Carson

From an interview conducted by Liz Thomae, Indiana University

Jennifer Carson's life-long commitment to person- and relationship-centered dementia care was fostered by her mother's impactful nursing career.

Jennifer: I've been supporting people living with dementia professionally since 1987 in a variety of different positions and settings. I got my start because my mother was a nurse in a nursing home. When I was 12, I started volunteering in nursing homes and when I was 15, I went to work under my mother's direction.

Back in the 1980s, they used to call my mom "Doris Day of the Dementia Ward." She was this incredible ray of sunshine in an institution that was otherwise quite dark. She had a humanistic approach to nursing – before we even had words to describe it, like "person-centered." I knew at a young age there was something very special about the way my mom worked, and so I feel incredibly grateful to have been the beneficiary of her beautiful humanistic, person-centered approach. I remember thinking, "Wow! My mom can light these dark spaces with love and life. How does she do that?" And so, at a young age, I became curious about what made her approach so transformative. I wanted to change long-term care, just like my mom.

I kept learning on my own, trying to understand and enhance emerging approaches to dementia care. Over time, my perspective evolved beyond person-centered care to relationship-centered approaches that support active citizenship. I try to help people see that individuals living with dementia are not objects of care and support – they are full human beings. I know that people can live well with dementia when they receive support that honors their agency and contributions. I know it's achievable because I've seen it. I've done it.

Lived experience as a care partner and professional growth in her field have informed Jennifer's understanding of, and access to, quality home care. Jennifer advises starting the selection process early, researching the best agencies, and including the person living with dementia in the interview process.

Liz: Let's switch gears and talk specifically about home health care. What exactly is home health care? What's your relationship to it?

Jennifer: There are two different types of care that people receive at home. One is home health care, which is medical care provided by licensed professionals. The other is home care, which involves non-medical support. My dad was diagnosed with Lewy body and vascular dementia, and in my family we've had experiences with both types of care.

The first thing my brother and I did when considering home care with our dad was research the best agencies – because not all agencies are created equal. We wanted to ensure we could achieve continuity of care with full-time care partners. We wanted to make sure they were educated and well-compensated – sometimes you get what you pay for. Education really matters. If the home care agency doesn't train their care partners well, they could do more harm than good. If their approach isn't person– and relationship-centered, they might treat the person living with dementia like an object of care, or like a child, and things are not going to go well.

Another thing we did was start early. When people are proactive and seek home care before they truly need it, they have many more options. We were able to choose the agency we wanted, Home Instead. My dad even got to interview and select his own care partners, which allowed him to form relationships that lasted for six or seven years! Don't wait too long to do it. People decline faster when they withdraw from meaningful engagement in life, and care partners play such an important role in keeping people active. If you wait too long, you may find yourself stuck with whatever is available. And right now, that could mean slim pickings. So, get on it before you need it. Investing in home care is an investment in your loved one's well-being—and your own.

Liz: Since it's not medical care, what kind of things do home care staff do?

Jennifer: They help with activities of daily living (ADLs) and anything that helps my dad maintain his home and his life. But beyond that? Companionship. Too often, people think of home care only as assistance with ADLs, rather than recognizing the full range of ways it can help someone stay connected to what matters most. I see home care as an opportunity to stay meaningfully engaged in life and community. It's not just about what happens inside the home – it's about staying connected to the world outside of it.

Liz: What kind of challenges did you have to overcome?

Jennifer: Teaching care partners how to reframe their thinking about so-called "behaviors." A lot of what people label as "behaviors" is communication. Often, a person is trying to express an unmet need. Instead of pathologizing these responses as "behaviors," we should ask: What's really going on here? It could be an expression of distress, a response to an unmet need. A lot of home care agencies train care partners on "redirection." Well, I think redirection is a code word for distracting, manipulating, or charming someone living with dementia into doing what you want them to do. Instead, we should always respond supportively and seek to understand the world from the other person's perspective. Engage in empathetic curiosity, ask supportive questions, seek to understand, and most importantly, meet the unmet need.

Guiding An Improved Dementia Experience (GUIDE)

Matt Neal, MBA, CEO, Brigade Health, and Dr. John Geiss, DO, President, Brigade Health

From an interview conducted by Elise Baker, Indiana University

The* Guiding An Improved Dementia Experience (GUIDE) *model is the first Medicare program specifically designed to assist those currently living with dementia and their care partners. The lack of accessible healthcare resources and assistance results in significant physical, emotional, and financial strains for people living with dementia and their care partners. Medicare coverage is extremely limited for those living with dementia, often only covering annual wellness checks and partial coverage for prescription medications.

GUIDE was designed to reduce the strain on participants by connecting them with support services, respite care, and additional resources to mitigate those stressors.

Elise: Tell me about how your involvement with GUIDE began.

Dr. Geiss: I started doing geriatric primary care about 11 years ago in senior housing and in individuals' homes, and the majority had some form of cognitive impairment or dementia. The largest challenge for people living with dementia and their care partners is how to navigate through the challenges of: Where they are going to live? What levels of care do they need? Are they safe at home? How are we going to financially address these concerns? Also, how will they learn more about dementia and become familiar with the disease process?

So when the Centers on Innovation for Medicare announced the GUIDE program, we started analyzing as a medical care delivery system how to not only fulfill the requirements, but also excel and make a difference. I think that's why we've been so enthusiastic and so focused on growing this over the last year.

GUIDE provides a care navigator, educational support, respite care—with the person living with dementia centered in all that's made possible through this new initiative.

Elise: One of the things you mention is looking at the resources available for dementia care in the U.S. What are some of the things that GUIDE focuses on that aren't covered by Medicare?

Dr Geiss: I think the number one thing is care partner ("caregiver" in GUIDE and Medicare materials) support and guidance. With the program, they're able to get educational services, support, and a care navigator—a full-time person who is available to talk and guide them. The person living with dementia is obviously at the epicenter of why we're doing this, and must be included in decision-making, but they are not always solely navigating their own care.

This gives loved ones a temporary period of relief where a paid caregiver can come into the community in which they live and sit with them, support them, and allow the family member to perform other important and necessary tasks in their life, if they need to address something else. Many of these care partners are so overwhelmed because they don't want to leave their loved ones alone. Now there's a program that gives them a little reprieve when it comes to caring for their loved ones living with dementia.

Elise: That's an important aspect of GUIDE: it's person-centered, the person who is living with dementia and their support system. What are GUIDE's main goals?

Matt: The GUIDE program is intended to improve quality of life for people living with dementia and reduce the heavy burden on care partners. The program uses assessment surveys of the person living with dementia and their care partner(s), as well as claims data, to understand metrics such as the usage of high-risk medication.

In addition, GUIDE aims to improve care while helping to avoid unnecessary emergency department visits and hospitalizations.

GUIDE recognizes that care partnering can take many forms, and that partnering health care teams and care navigators with people living with dementia and their care partners can result in better outcomes—preferred living arrangements, fewer hospital visits, and more.

Elise: What services are available to care partners and people living with dementia?

Dr. Geiss: We do a lot of education, telling them that in order to identify as the care partner you don't necessarily have to be doing all the day-to-day services. If you are the closest person to the person living with dementia and you are doing anything to assist them, even if it's checking in on them once a week or once a month, you would qualify as a care partner. People living with dementia with identified care partners are provided emergent respite care, which equates to about 80 hours annually.

Matt: An example [is] where we helped an adult daughter whose mother had been in the hospital. They were trying to figure out, as she's coming out of the hospital, what is that going to look like for them? This care partner had children of her own, while also taking care of her mom. We were able to arrange for a professional caregiver to come in. That was the difference of being able to bring her home versus having her go into a skilled nursing facility, and they really wanted to be able to bring mom home.

Another example is a care partner who is supporting her father who is living with severe dementia. One of the things that they've been struggling with was incontinence. With their care navigator, they were able to work through getting a new type of catheter for her father. They were able to work with the primary care physician to get the right catheter in, which was for both the quality of life for the person living with dementia and the care partner. Fixing that issue was important, and it took establishing a relationship between the care navigator and the care team.

For a list of GUIDE providers: *guide-participant-list.xlsx*

To connect with Brigade Health: Visit their website at *www.brigadehealth.com* or call (855) 434-7763

5.10 Avoiding the Emergency Department

A visit to the emergency department (ED) can be stressful for all, but can be especially for people living with dementia. The crowds, loud beeping, bright lights, and long waits can lead to increased agitation and stress.

Emergency department personnel may not be trained in dementia care. They are there to respond to a particular urgent problem. They may not be able to take the time to carefully listen to someone who has trouble communicating. Add to that the risk of infection, hospitalization, and hospital-related delirium. In short, avoid going to the emergency department if you can. The American College of Emergency Physicians now offers a Geriatric Emergency Department Accreditation process. Accredited EDs have demonstrated care unique to older adults, often including increased education and knowledge on working with people living with dementia. Visit *acep.org/geda*

Studies have found that people living with dementia go to the ED often. According to a 2016 study by researchers at the University of Indiana School of Medicine, "... we found that older adults living with dementia who were frequent visitors to EDs and had higher numbers of comorbidities, received more costly care, were admitted to hospitals at higher rates, and had higher return rates than patients without dementia. Survival and ED return rates differed also according to the patients' dementia status" (meaning these rates were worse for people living with dementia).

The study continues: "To date, patients with dementia and other cognitive impairments have been recognized as more difficult for ED providers to assess and treat. We, however, know comparatively little about the decision-making of emergency providers when treating this vulnerable population, the care preferences of patients with dementia and their caregivers who seek care in this environment, or alternatives that might be readily offered to patients with dementia who wish to avoid admission to the hospital from the ED."

Of course, there are cases that are true emergencies, such as chest pain, signs of stroke, or excessive bleeding. Many problems can be handled in an urgent care clinic. These are smaller, less crowded and noisy, and lower cost than EDs. They can handle many non-life-threatening problems, such as:

- Allergic reactions and asthma
- Cuts and burns
- Falls, sprains, strains, and broken bones
- Colds and flus
- Sinus pressure and sinus infections (sinusitis)

- Strep throat
- Urinary tract infection

One of the best ways to avoid going to an ED is having a strong relationship with your healthcare provider. Being regularly seen can help nip problems in the bud. This can be made easier through telehealth or home visits, as discussed above. Discuss local alternatives to the ED in advance of a need with your healthcare provider.

It's also a good idea to find out ahead of time if there are non-emergency services you can call in case you fall. Many fire departments, for example, will send help to safely lift someone who has fallen and get them settled. Call your fire department and ask if they have "non-emergency lift" or "lift service" help. Often this is given at no charge. In some areas, you can also access this help by dialing 311.

In an article in *Annals of Long-Term Care*, "Dementia and the ER", the author concluded: "Perhaps we need to reconsider whether the ED is an appropriate site of care for patients living with dementia. The expansion of house-call practices that bring both providers and technology to the patient, rather than the patient to the provider, may be an alternative to ER care. Providers should also consider earlier initiation of palliative care for patients living with dementia. These approaches might better serve patients living with dementia, their families, and the healthcare system."

5.11 If You Have to Go to the Hospital

Sometimes going to the hospital is unavoidable. Whether it's through the ED or a planned hospital admission, there are many things you can do to prepare. Hospital staff and care partners offer the following tips to help things go as smoothly as possible:

- **Prepare a kit or folder ahead of time with key documents** including an up-to-date medications list, list of medical problems and surgeries, your primary care and specialists' phone numbers (including after-hours), advance directives (including a do-not-resuscitate order if you have one), healthcare power of attorney, and care partner contact information.
- **Create a document that lets the staff know** about the person living with dementia, including what is calming, what their bedtime routine is, what they prefer to be called, some basic biographical information, ways to communicate, and so on. Have it in a handy place where staff and visitors can view it. The Dementia Action Alliance, in collaboration with people living with dementia, care partners, and dementia specialists, created a tool, "What Matters To Me," that is simple and easy to complete

that provides the helpful information noted above. (See *Additional Resources*, page 406.)

- **Ask your healthcare provider which hospitals they practice in**, and which have access to your medical records electronically. Plan to go to one of these.
- **When going to the hospital, have two people along,** if possible, in addition to the person living with dementia. One is responsible for driving and letting the other two off at the door. This person can also be there to help during the waiting time. If the care partner needs to deal with insurance forms and other details, the other friend or relative can focus on the person living with dementia.
- **Inform the staff that the person has dementia.** Let them know of any communication strategies that may help.
- **Consider bringing** eyeglasses and hearing aids, if used, eye mask for sleeping, ear plugs to soften hospital noises, and favorite calming activities, such as knitting, puzzles, adult coloring books, or a headset with music.
- **Don't forget to make it clear** if the person needs to keep taking their medications while in the hospital.
- **If the person is on a regular diet** and not scheduled for any tests that must be performed on an empty stomach, have snacks and drinks that they would enjoy. Bring favorite dishes if they are not enjoying the hospital food.
- **Have the person choose one or two family photos** or scenic pictures to display.
- **Pack pajamas, slippers, and extra clothes**, so they don't have to wear a hospital gown.
- **Be aware that hospital staff likely have limited training in dementia**, so make them aware of any contraindicated medications, such as haloperidol (Haldol) for people living with Lewy body dementia.
- **Encourage hospital staff to see the person as an individual** and not just a patient living with dementia who is confused and disoriented from the disease.
- **Ask the doctor to write an order** that says the person's vital signs do not have to be taken in the middle of the night unless there is an important medical reason to do so. Often these are done routinely. Sleep interruptions will increase the likelihood of agitation or delirium.
- **Have a friend or relative there around the clock**, if possible. This can help keep the person calm and well-hydrated. It also may prevent mistakes in medication or other problems from arising, to have an extra set of eyes there. If you are the only

one available, take care of yourself. Take some time away from the hospital to get fresh air or go home for a nap. Be mindful of your own health.

- **Request the hospital chaplain visit** if you think the person living with dementia would find it comforting. You can also request other nonmedical volunteers, such as a book or art cart or a visit from a service dog, which some hospitals offer.

Being a calm and steady presence is the most important thing a care partner can do.

Being a calm and steady presence is the most important thing a care partner can do. That may go a long way towards helping your loved one weather a hospital stay.



Delirium

Susan Wehry, MD

Even seasoned physicians can miss signs of delirium

Delirium is a serious, life-threatening condition that can affect people living with dementia. It is often missed by care partners and the health care team because it mimics some of the same symptoms of dementia. But delirium is different from dementia. Dementia can get worse slowly and steadily over time; delirium happens suddenly and can change quickly. Care partners may need to advocate to make sure the health care team understands. Trust your instincts if something seems off. Here's what everyone needs to know.

Delirium is a *sudden* change in how a person thinks, acts, and perceives the world around them. It can happen to anyone, but people living with dementia are more susceptible to it [1]. Some signs of delirium include:

- Trouble paying attention.
- Confusion that comes on quickly and fluctuates over the day.

[1] National Library of Medicine. Medline Plus: Delirium. https://medlineplus.gov/delirium.html

- Seeing or hearing things that aren't there (hallucinations).
- Feeling very sleepy or very agitated.
- Not knowing where one is (disorientation).
- Big changes in sleep patterns.

Why is delirium more dangerous for people living with dementia?

For people who already have dementia, delirium can be very harmful. It can:

- Worsen their dementia symptoms.
- Lead to falls or injuries.
- Lengthen their hospital stays.
- Increase the risk of needing to live less independently, including the need for long-term care.

That is why it is so important to prevent delirium when possible, and to catch it early if it does happen.

Treating delirium is a matter of identifying and addressing the underlying cause.

Delirium has many causes but the most common are:

- **Adverse drug reactions.** This could be related to drug-to-drug interactions, incorrect doses or drug misuse, or being prescribed a drug considered a high-risk drug for an older adult. Always let the health care team know if there has been any change in medication in the days or weeks before the sudden increase in confusion.
- **Infections.** Infections of the urinary tract are usually the first to be checked. Make sure respiratory infections (like pneumonia) and skin lesions are also considered.
- **Electrolyte imbalance or change in blood chemistries.** A common cause of this might be dehydration or blood sugar levels that are too high or too low in a person living with diabetes.
- **Head trauma** from a fall.

Preventing Delirium at Home

- Encourage, but don't force, drinking water throughout the day
- Manage medications carefully. Always make sure to ask anyone who prescribes medications to tell you what the risks and the benefits are and what to look for if the person is developing an adverse reaction. Make sure the prescriber knows all the medication a person takes, both prescribed and over the counter, so that interactions can be avoided,
- Treat infections. Even a small infection can lead to delirium, so get medical help early.
- Check hearing and vision. Make sure glasses and hearing aids are working well and being used.

Preventing Delirium in the Hospital

Hospitals can be confusing places for everyone but especially for people living with dementia. Hospitals know this and many have implemented a program called HELP (Hospital Elder Life Program) that was designed by Dr. Sharon Inouye to prevent delirium. Always ask if your hospital has this program and ask them to initiate it.

In the hospital, nurses and doctors will check for delirium, and you can help, too. Tell the medical team right away if you notice:

- The person seems more confused than usual.
- They're seeing things that aren't there.
- They're much sleepier or much more agitated than normal.
- They don't seem to know where they are.

Here are other ways you can help:

- Bring familiar items to the hospital, like photos or a favorite blanket.
- Stay calm and reassure the person. Delirium can be very scary.
- Stay with them. Try to have a family member or friend there as much as possible.
- Provide orientation. Remind them often where they are.
- Encourage movement. Ask the nurses if it's okay for the person to walk around or do gentle exercises in bed.

- Make sure they can see and hear. Bring their glasses and hearing aids to the hospital.
- Tell the doctors about any new medications or changes in doses.

Conclusion

Delirium is serious—and there's a lot we can do to prevent it and catch it early. By knowing the signs and taking steps to prevent it, we can help keep people living with dementia safer and healthier. Remember to trust your instincts and don't be afraid to speak up if you're concerned. Your attention and care can make a big difference in preventing and managing delirium.

5.12 End-of-Life Planning

Dr. Jenny Randolph, in her research tracking 1,500 families living with Alzheimer's over a period of five years, found that less than 25 percent had a conversation about death. Talking about death and planning for it is generally considered morbid. Unfortunately, that is the influence of societal stigma. In actuality, death is one of the most intimate and personal life experiences.

Within hospice circles, it is often said that a person had a beautiful death. "A beautiful death" is unique for each person. For some, it is having people you are close to surround you with favorite music playing. For another, it may be having a spiritual guide present, or someone saying prayers, or reading treasured poetry, or simply sitting quietly by your side holding your hand.

If you have conversations about your ideal end-of-life scenario in advance and do some planning, others will know what you want and can help make it possible. Having end-of-life conversations does not need to be a depressing experience. Barney Nelson let his family know that he is videorecording his end-of-life thoughts and wishes. Once he is finished, he will gather his family so they can watch the video together and talk about it. Barney has a close and open relationship with his family and is comfortable talking about end-of-life issues.

Not everyone has a close family dynamic. In that case, it is better to limit the conversation to one or two family members with whom you have a close relationship. You may want to write a letter to other family members to caringly and kindly let them know your end-of- life wishes.

In 2010, a Pulitzer Prize-winning writer, Ellen Goodman, and colleagues launched a public initiative, the Conversation Project, to help people talk comfortably about their end-of-life wishes. There are many excellent resources on the Conversation Project website including a guide titled, "For Caregivers of People with Alzheimer's or Other Forms of Dementia." Visit: *theconversationproject.org.*

Living with dementia adds a layer of complexity to end-of-life planning. Dementia can progress unpredictably, so when is a good time to plan? You should do this as soon as you feel comfortable and ready. What if you never feel comfortable or ready? If that is the case, you can enlist someone you feel comfortable with and ask for their help. This person could be a close friend, family member, clergy member, or a therapist, among others. Be upfront with the person that this is something you are struggling with. The resources from the Conversation Project can be a good way to start the process and discussion.

End-of-Life Care for People Living with Dementia

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https://www.infosenior.care/alzheimers-and-dementia/www.nia.nih.gov/health/end-life/end-life-care-people-dementia.html

People often live for years with dementia. While it can be difficult to think of these diseases as terminal, they do eventually lead to death. Care partners often experience special challenges surrounding the end of life of someone living with dementia, in part because the disease progression is so unpredictable. Below are some considerations for end-of-life care for people with dementia.

Making medical decisions for people living with dementia

With dementia, a person's body may continue to be physically healthy. However, dementia causes the gradual loss of thinking, remembering, and reasoning abilities, which means that people living with dementia at the end of life may no longer be able to make or communicate choices about their healthcare. If there are no advance care planning documents in place and the family does not know the person's wishes, care

partners may need to make difficult decisions on behalf of their loved one about care and treatment approaches.

Questions to ask about end-of-life care for a person living with dementia

[If you are] a caregiver, you will want to understand how the available medical options presented by the healthcare team fit with the needs of both the family and the person living with dementia. You might ask the healthcare team questions such as:

- Who can help me with end-of-life care for my loved one living with dementia?
- How will your suggested approaches affect their quality of life?
- What are my options if I can no longer manage the care of my loved one at home?
- How can I best decide when a visit to the doctor or hospital is necessary?
- Should I consider hospice at home and, if so, does the hospice team have experience working with people living with dementia?

Being there for a person living with dementia at the end of life

As dementia progresses, caregivers may find it hard to provide emotional or spiritual comfort to a person who has advanced memory loss. However, even in advanced stages of dementia, a person may benefit from such connections. Sensory connections — targeting someone's senses, including hearing, touch, or sight — may also bring comfort. Being touched or massaged can be soothing. Listening to music, white noise, or sounds from nature seems to relax some people and lessen agitation. Just being present can be calming to the person.

Palliative or hospice care teams may be helpful in suggesting ways for people living with dementia and their families to connect at the end of life. They also may be able to help identify when someone living with dementia is in the last days or weeks of life.

Signs of the final stages of dementia include some of the following:

- Be unable to move around on one's own
- Become agitated or restless
- Be unable to speak or make oneself understood

- Have difficulty swallowing or be unable to swallow
- Develop an irregular breathing pattern
- Have a rattly sound to their breathing
- Have cold hands and feet

Though palliative and hospice care experts have unique experience with what happens at the end of life and may be able to give a sense of timing, it's hard to predict exactly how much time a person has left.

Supporting dementia care partners at the end of life

Caring for people living with dementia at the end of life can be demanding and stressful. Depression and fatigue are common problems for care partners because many feel they are always on call. Care partners may have to cut back on work hours or leave work altogether because of their caregiving responsibilities.

It is not uncommon for those who took care of a person living with advanced dementia to feel a sense of relief when death happens. It is important to realize such feelings are normal. Hospice care experts can provide support to care partners near the end of life as well as help with their grief.

5.13 Palliative and Hospice Care

If given the choice, everyone likely would want to die free of pain and in comfort. Most of us say we'd prefer to die at home, in familiar surroundings, and visited by loved ones. Whether you are in a hospital, a nursing home, or your own home, you will benefit from palliative or comfort care.

Palliative care specialists have expertise in symptom management, including pain and other kinds of discomfort. A palliative care team includes physicians and nurses specially trained in palliative medicine, as well as social workers, chaplains, and nutritionists.

When someone is approaching the last months of life, palliative care can transition into hospice care. A doctor will order hospice care if he or she expects you have less than six months remaining to live. Hospice care is paid for by Medicare and many other insurers.

Knowing how long a person may live is not an exact science. If a person lives longer than six months, hospice can either be renewed, or discontinued for the time being.

Hospice care can be given in any setting — home, nursing home, assisted living, a hospital, or occasionally a residential hospice. Unfortunately, too often people are not offered — or will not accept — this benefit until the last few days of life. Sometimes, families or healthcare providers fear that offering hospice will make a patient lose hope. Discussing early on what your prognosis is and expressing what you want is key.

Hopefully, you have written down your wishes as far as end-of-life care. Otherwise, your family care partners must make those difficult decisions on their own. It can get complicated if care partners disagree. Stating your wishes while you still are able is critically important. Five Wishes is an excellent resource. Visit: *www.fivewishes.org*

John and Susan McFadden have both worked closely with people living and dying with dementia for many years. They reflect on what is different about hospice care for those who can no longer speak for themselves.

"People [without dementia] are very good at talking about fears and hope, their images of death," says Susan. "You can't do that with a lot of folks living with advanced dementia. We never lose our need for touch and the comfort of someone holding our hands. People are using aromatherapy, trying to connect to people through other senses, and giving them a sense of peace at the end."

"Hospice care is, or should be, a different experience for persons living with dementia," says John. "The origins of hospice care lie largely in the cognitive. 'Are you free from pain? Are you at peace with facing your death? Is there anything I can offer that would provide comfort?" When the dying person is living with advanced dementia, there needs to be a shift to simply being present and accompanying the person on the journey. Many hospice chaplains now bring musical instruments rather than pamphlets, and focus on communicating calmness, peace, and joy, as much through appropriate touch as through words."

John advises care partners and medical staff, "Rather than feeling like you're helping someone prepare to die, move to just helping them find peace in the process of dying."



The Good Death: Dementia Doula PK Beville

From an interview conducted by Barb White, Pathways Project Manager

PK Beville, of* Second Wind*, shares her professional journey to end-of-life care in partnership with people living with dementia. PK has been serving people living with dementia since 1983 and founded Second Wind in 1997 to make dreams come true, elevate elders, and change perceptions. PK also created the Virtual Dementia Tour allowing people to walk in the shoes of someone living with dementia and to view the care relationship differently.

Barb: What would you like people to know about your professional journey to end-of-life doula service, and the added dimension of serving folks who are living with dementia?

PK: At *Second Wind* we cared for people from the moment of diagnosis but not at the end of life. And that was so wrong. If we're really going to serve people living with dementia and their families, we really needed to focus on death care. So I got certified as an end of life doula…That took about 8 months and then during that period of time I contacted one of our local hospices and asked if I could work in this type of position. I was upfront and said I wanted to go through all of the training you do with your staff and volunteers and, sadly, I learned there was very little training on dementia care and on death training with dementia.

PK developed both the* Empathic Transitions *kit, for care partners and families, and dementia doula training to ensure that people living with dementia remain in the "seat of power" in creating their own good death.

PK: The assumption everyone makes is that a person with dementia is someone who doesn't have a say in things. There's nothing we can do for them, they're an aside. I can't even imagine how condescending and socially inappropriate that is. And the reason we get away with it is because some people with [advanced] dementia can't always speak for themselves.

I felt that we needed something at *Second Wind* where people can go and learn about how to create a good death for people living with dementia. So now we have *Empathic*

Transitions, and that's embracing people with dementia at the end of their lives and, of course, their families are a part of this, too.

For the first time in history, there are more people with a cognitive impairment of one type or another entering into hospice than with cancer. I believe there are two stages in the final time for the person living with dementia: the advanced dementia care and then the end-of-life care--sitting vigil, setting up the room, creating comfort and peace, whatever the person needs that you have learned by developing the relationship during the advanced stage.

I developed an *Empathic Transitions* kit [for caregivers and families] that includes tools for engagement with a person in advanced dementia, and this also includes an *Imminent Death* package. And all of this comes with a training program so that you know how to use the kit.

I also have dementia doula classes for people who want to develop a space for doula care, whether in elder care, hospice care, wherever they are in their lives. These are the more elite empaths and the training is developed with the understanding that these people will go out into the field and do the work.

Barb: What advice would you give to someone living with a diagnosis of dementia who is beginning to think about end-of-life choices?

PK: I would recommend that people are given [an information sheet] to fill out (e.g., *Dementia Values and Priorities Tool - Compassion & Choices)*, and I recommend that they have "the talk" with their family members about when it gets to be that time and they are unable to talk or advocate for themselves.

And the advocacy part of being a doula is huge. Sometimes that means you're not popular [with medical or facility staff], but the person who is at end-stage holds the seat of power and we must continue to give them the acknowledgement of that seat of power, and if anything is conflicting with that seat of power, it has to be the doula who stands up. That advocacy piece is going to be educational for staff and families.

PK recommends gathering end-of-life information and researching hospice care early in the dementia journey. A hospice with a stated ancillary palliative care service is preferred. A certified end-of-life doula may already be part of the hospice service; if not, find a doula here: INELDA (Find an End-of-Life Doula Near You)

Barb: What is the process for saying you would like to work with a doula and then finding a doula? What is the role of the person who should be in the seat of power in choosing the doula, and the role of the family?

PK: A person living with dementia needs to go ahead and determine which hospice they want. Dementia is a terminal diagnosis, and I like to have people research who they like even if it's years down the road, and to understand how hospice works. You want to be sure you control that dynamic. Hospice is not just for the end, especially with dementia care.

I recommend that they go with a hospice with a stated ancillary piece of palliative care. Then if a person with dementia begins to experience pain and difficulty, they don't even need to have a doctor's order to request palliative care to be kept comfortable and aware of what is going on. I have some patients that have been on palliative care for five years and are not on hospice yet. There are excellent palliative care teams out there that are not part of hospice.

One question for hospice is if they have doulas on their service. If they do, you can be sure that the doula will be contacted when they enter hospice and transitioning is happening. You can also search INELDA (*Find an End-of-Life Doula Near You*); most certified end-of-life doulas are registered there. At Second Wind, we will soon have all our **dementia doulas** listed and where they practice and how to contact them.

Some families are all-in and some do not want to talk about it. The biggest questions that families have…when it comes to transitioning, is how much longer is this going to take? What's happening next? The doula can answer those questions. As a doula, we spend a lot of time in training on learning to read the families.

Barb: In one sentence for each group, what must people living with dementia, their families, and professionals know and do around end-of-life care?

PK: For people living with dementia, run, don't walk, to get familiar with end-of-life information.

For families, don't assume people living with dementia can't make decisions about health care. (Honoring those decisions results in the best care.)

And for professionals—health care workers, social workers, chaplains, anyone caring at the end of life--get certified as a doula so that you are equipped with the needed information about end-of-life care to create a good death.

5.14 Death with Dignity



Susan Wehry, MD, Contributor

What is meant by death with dignity? This phrase usually describes laws that protect taking one's own life with the assistance of another. It is also called medical aid in dying (MAID), assisted suicide, or physician-assisted suicide (PAS). This is not euthanasia. Euthanasia refers to someone else, such as a doctor, giving lethal medication to end someone's life to end their suffering.

Some death with dignity advocates reject the idea that medical aid in dying should be considered assisted suicide at all. They look upon medical aid in dying as just one of many end-of-life medical options. They argue that the term assisted suicide creates stigma.

In 1997, Oregon enacted the first Death with Dignity law. It allowed terminally ill Oregonians to end their lives through voluntary self-administration of a lethal dose of medications prescribed by a physician for that purpose. This law, the Oregon Death with Dignity Act, has become a model for legislation around the United States and access to medical aid in dying in Oregon is no longer restricted to in-state residents.[1]

As of this writing, The District of Columbia and ten states (California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington) and 13 countries outside the United States allow physician-assisted suicide (as it is more generally referred to worldwide).[2] Euthanasia is currently legal in about half of those countries, Belgium, Canada, Colombia, Luxemburg, the Netherlands, New Zealand, Spain and Switzerland.[3]

Although Death with Dignity laws vary somewhat by state, most require some version of the following:

1. A person must have a terminal illness and not be expected to live beyond six months.
2. A person must ask for the medication twice: once orally and again in writing.
3. Two physicians must confirm the person has the capacity to make the decision and the ability to self-administer the prescribed medication.
4. A person also requesting medical aid in dying cannot be experiencing a clinically-significant depression or other mental disorder that may affect judgment.
5. The decision must be voluntary.

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[1] *Death with Dignity Act - Oregon Health Authority*

[2] *States with Legal Medical Aid in Dying (MAID) - Euthanasia*

[3] *Countries Where Euthanasia is Legal / Where Is Euthanasia Legal in 2024?*

In short, death with dignity, like living with dignity, refers to the desire to preserve autonomy, to be treated with respect and to have control over one's life choices and one's body.

Generally, individuals diagnosed with dementia cannot request lethal medication. Although dementia (all-causes) is considered a terminal illness, it is also a chronic illness. Individuals can live—and thrive—for many years with dementia. They are not expected to die within six months. In the final stages, a person living with dementia may no longer have the capacity to make the decision or carry it out. No state permits self-ingestion of lethal medication to be part of an advanced care plan.

In light of the lack of access to medical aid in dying, some people living with dementia have become interested in the idea of maintaining some control of their death by voluntarily stopping eating or drinking. Voluntary stopping of eating and drinking, also known by its acronym VSED, is a complex and still controversial end-of-life option, particularly for individuals living with dementia. It is a "practice in which a currently or prospectively seriously ill patient makes an intentional decision to hasten their own death by completely stopping the intake of all fluids and food."[4]

Proponents of VSED point to the control it provides over the end of life. They see it as a way to preserve autonomy and dignity. Proponents note that VSED is an alternative to other end-of-life options that may not be available, such as living in a state that does not permit medical aid in dying. VSED is generally considered a legal method, similar to choosing not to have life-sustaining interventions, like CPR. The right to refuse life-sustaining and life-prolonging interventions via an advance directive is an established legal, ethical, and moral right.

Many palliative care clinicians see VSED as a compassionate, ethically justifiable option. The process allows time for the patient and their social circle to mentally prepare and to resolve any misunderstandings or communication errors in the decision-making process.[5,6]

[4] From the introduction to "Voluntarily Stopping Eating and Drinking, A compassionate, Widely Available Option for Hastening Death", Quill, TE, Menzel, PT, Pope, ™ and Schwarz, JK, eds.Oxford University Press 2021

[5] Ibid., Part II, chapter 12

[6] Ivanović N, Büche D, Fringer A. Voluntary stopping of eating and drinking at the end of life - a 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliat Care*. 2014;13(1):1. doi:10.1186/1472-684X-13-1

Not everyone agrees of course. Some perceive VSED as unethical or even repulsive. Providing food and water is basic to care. Many question whether withholding it from an incapacitated person can ever be justified. Many health and long-term care facilities are reluctant or unwilling to honor VSED advance directives for patients with dementia.[7] Residents of long-term care or patients in a hospital may experience discomfort, especially thirst, and withholding fluids could arguably be seen as abuse or neglect (even if the person previously expressed a desire to hasten death by VSED).

VSED offers a potential option for individuals wishing to avoid prolonged suffering from dementia. The decision to pursue VSED, like all end-of-life decisions, involves careful consideration. It requires thorough discussions with trusted people and clear documentation of wishes through advance directives.

The phrase "death with dignity" may also be used in other ways. Death with dignity may refer to the wish most people have for a natural death, a wish to die without medical interference, a wish for "letting (me) die." Death with dignity gives voice to the fear that without control over how and when one dies, one risks losing their dignity. In short, death with dignity, like living with dignity, refers to the desire to preserve autonomy, to be treated with respect and to have control over one's life choices and one's body.

The wish to preserve autonomy is a concern shared by people living with, and without, dementia at the end of life. According to Oregon's 2021 report on patients who used the Death with Dignity Act, the three most frequently reported end-of-life concerns were loss of autonomy (93 percent), decreasing ability to participate in activities that made life enjoyable (92 percent), and loss of dignity (68 percent). A little more than half of patients who requested lethal medication said they did not wish to become a burden on family members, friends, and caregivers.[8]

People living with dementia may be especially attuned to concerns about autonomy throughout their changing brain journey. Many have experienced their choices being challenged by care partners and health practitioners who question their capacity to make informed decisions. As more people living with dementia advocate for themselves, this may change.

Death with Dignity laws remain controversial, especially as they relate to people living with dementia. These laws raise ethical questions and may violate religious beliefs. Physicians too must grapple with what it means to prescribe life-ending medication. They must consider whether it violates their oath to do no harm or honors the obligation to do good and to respect patient autonomy. Many express concern that a 'right to die' overseen by the state could become a 'duty to die' for economic reasons. In 2019, The Center for Disability Rights

[7] *Diagnosed With Dementia, She Documented Her Wishes. They Said No.*

[8] *www.healthoregon.org/dwd* Public Health Division, Center for Health Statistics February 28, 2022

People living with dementia who wish to thrive with dignity as well as die with dignity need to have lots of conversations with family, friends, practitioners, and care partners about what matters most to them about living and dying. What makes for a good life? What would make for a good death?

warned lawmakers that New York's proposed Medical Aid in Dying legislation "is a deadly proposition that puts disabled people at risk."[9] As of this writing, New York's law has not passed for nine years in a row.

I think a question worth asking is this: Does dying with dignity require Death with Dignity laws? Dying with dignity is a complex and highly personal issue. People living with dementia who wish to thrive with dignity as well as die with dignity need to have lots of conversations with family, friends, practitioners, and care partners about what matters most to them about living and dying. What makes for a good life? What would make for a good death?

As mentioned in a prior section, these conversations need to be documented in the form of an advance directive. The proxy or surrogate decision-maker should be someone who is trusted and can be counted on to honor the person's choices and values.

At present, in the United States, it is *not* possible to request lethal medication in advance. It is *not* possible to ask that another person request it on your behalf or for another person to administer a lethal medication (euthanasia).

But it *is* possible to:

- Request a palliative care specialist be on your health care team.
- Request that comfort care be provided in advanced stages of dementia.
- State whether or not you wish to receive antibiotics for pneumonia.
- Request not to be resuscitated (DNR) in the event the heart stops.
- State that you wish to be permitted to refuse food and water.
- Request proper palliative care and comfort measures during a VSED process.

[9] *Physician Assisted Suicide Deadly for Disabled*

Thinking and talking about the likely progression of brain changes over the course of dementia may not be easy. Nor is it easy to think and talk about our own mortality. The courage and willingness to do so now can help people living with dementia retain some control over conditions at the end of life and give comfort to themselves, their care partners, and their allies that their values and choices will be honored.

SUGGESTED RESOURCES

Articles

National Institute on Aging, "Telehealth: improving dementia care," 2020. *www.nia.nih.gov/news/telehealth-improving-dementia-care*

Possin, K.L., et al. (2019). Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: The Care Ecosystem randomized clinical trial. *JAMA Internal Medicine*. 179(12):1658-1667.

LaMantia, M.A., et al. (2016). Emergency department use among older adults with dementia. Alzheimer Disease and Associated Disorders 30(1) 35-40.

Segal-Gidan. (2018). Dementia and the ER — a toxic combination. *Annals of Long-Term Care*. *www.hmpgloballearningnetwork.com/site/altc/articles/dementia-and-er-toxic-combination*

Fenker, Richard. (2020). The red button: Creating good choices at the end-of-life for people living with dementia. Cimarron International Publishing.

Kenny, A. (2018). Making tough decisions about end-of-life care in dementia. Johns Hopkins University Press, Baltimore.

"End of Life Decisions — Honoring the Wishes of a Person with Alzheimer's Disease" is a free pamphlet available from the Alzheimer's Association website, alz.org. *www.alz.org/national/documents/brochure_endoflifedecisions.pdf*

Books

Fenker, Richard. (2020). The red button: Creating good choices at the end-of-life for people living with dementia. Cimarron International Publishing.

Kenny, A. (2018). Making tough decisions about end-of-life care in dementia. Johns Hopkins University Press, Baltimore.

Publications

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Websites

Aging Life Care Association (also called geriatric care managers) is made up of professionals who practice a holistic, client-centered approach to caring for older adults or others facing ongoing health challenges.	*www.aginglifecare.org*
Alzheimer's Society-United Against Dementia, "How to know when a person with dementia is nearing the end of life."	*www.alzheimers.org.uk/get-support/help-dementia-care/recognising-when-someone-reaching-end-their-life*
The American Academy of Home Care Medicine trains physicians and promotes home-based primary care.	*www.aahcm.org/*
The Conversation Project a public engagement initiative with a goal to have every person's wishes for end-of-life care expressed and respected.	*theconversationproject.org/*
DispatchHealth offers medical support to patients no matter where they are in their healthcare journey, with services ranging from same-day, high-acuity care to a 30-day alternative to a hospital stay, all delivered straight to the patient's door.	*dispatchhealth.com*
Geriatrics and Extended Care, Department of Veterans Affairs (VA) — Veterans with dementia may be eligible for certain benefits and services.	*www.va.gov/geriatrics/*
Harvard Health Publishing, "The effects of marijuana on your memory", 2021.	*www.health.harvard.edu/mind-and-mood/the-effects-of-marijuana-on-your-memory*
National Center on Complementary and Integrative Health — includes a summary of research related to supplements and dementia.	*www.nccih.nih.gov/health/tips/things-to-know-about-complementary-health-practices-for-cognitive-function-dementia-and-alzheimers-disease*

National Hospice and Palliative Care Organization has a webpage to locate a palliative care specialist or hospice.	*www.nhpco.org/find-a-care-provider*
National Institute on Aging, "Alzheimer's Disease Medications Fact Sheet," 2021.	*order.nia.nih.gov/sites/default/files/2021-09/alzheimers-disease-medications.pdf*

SUPPORT
Demetia Action Alliance
www.daanow.org/donate

SECTION 6: Technology Supports

I find technology exciting and interesting, and I am always learning new ways to help me stay organized, safe, and entertained. Technology helps me enjoy and navigate life a little easier and can be especially helpful for those of us living with dementia and for care partners.

Rev. Dr. Cynthia Huling Hummel, Manual Guide



Technology is another tool you can use to maintain autonomy and independence. Technology offers many beneficial ways to support the changing abilities of people living with dementia, and to alleviate the worry and stress experienced by many care partners.

New technologies are coming on the market continually and are being designed to be more user-friendly and easier to set up and operate. Device and App suggestions, and tips for making the most of your technology to better navigate your day and your way, are included here.

Explore Section 6 and consider how technology can help you:

- Connect With Others
- Enhance Your Independence
- Engage With Your Interests and Passions
- Build Greater Safety and Security
- Manage Your Health

6.1 Connection to Others

Technology provides an array of communication methods so people can keep in touch. Maintaining relationships with people who matter to you is important for your overall well-being. Staying connected helps keep you from becoming isolated or lonely. There are a number of ways to use technology to stay connected with others.

Smartphones

Smartphones have changed how people live. Smartphones are cell phones or mobile phones with advanced features. You can use a smartphone anywhere your mobile phone carrier, such as AT&T, Mint, T-Mobile, and Verizon, has coverage, unlike landline phones that only have service inside your home. They can connect to the Internet to access online information, play games, and watch movies, among hundreds of other uses.

Another advantage of using smartphones for people living with dementia is the built-in cameras, microphones, and speakers. These built-in features not only help you to take pictures and videos, they also allow you to make video calls with your friends and family, . seeing and hearing the person you are speaking with. Being able to see and hear is helpful in processing what is being said. The camera feature is also helpful for people who use sign language to communicate.

You can also use your smartphone to communicate using the text feature. Text messaging sends written messages from one smartphone to another smartphone. The benefit of texting is that it is a quick way to send short messages and responses, such as "I'll be home in five minutes."

Smartphones that are basic and have adapted features, such as large buttons and simplified functions, can be a good choice.

VOIP (Voice Over Internet) to Connect with Others

Another way to stay connected is by using a service known as VOIP, which stands for "voice over internet protocol." You can use a smartphone, laptop, tablet, or desktop computer to access VOIP. On these devices, you can find VOIP on Apple FaceTime, WhatsApp, and Googletalk for free. If the people you are connecting with also have the same VOIP software, you can make free calls anywhere in the world.

Note: Smartphones and most laptops, tablets (touch-screen devices that are similar to a large smartphone), and desktop computers nowadays come equipped with webcams and built-in microphones and speakers. If you are using older model equipment that does not have a webcam, you may want to add a portable webcam so you can make video calls. Similarly, if your equipment lacks sound capacity, you may need to add a headphone and microphone. Portable webcams and microphones and headphones are fairly inexpensive and can be purchased online and at national retailers that sell electronic equipment.

Email

Email is short for "electronic mail." Email became widely used after the development of the Internet. Email allows people to send and receive written messages anytime anywhere in the world with an Internet connection. To use email, you need an electronic device such as a smartphone, laptop, tablet, or desktop computer, connection to the Internet, and an email account, such as Gmail, Outlook, Yahoo, iCloud mail, and AOL.

The following are some of the benefits of email:

- Emails can be sent anywhere in the world with an Internet connection at no cost.
- Copies of emails sent and received are automatically stored so that you can re-read them whenever you want.
- Email messages, unlike text messages, can be any length.
- You can start working on an email and finish it later.
- You can easily attach photos and document files to email messages.
- Email services include an email address book function, so you don't have to remember people's email addresses.
- You can "pin" or flag important emails to be able to find them quickly.

Despite best efforts, everyone ends up receiving spam or junk emails. Spam or junk mails are typically from companies wanting your attention and business. The major email accounts, such as Gmail, iCloud mail, and Outlook, have spam filter features to move these types of emails from your incoming email to a spam folder. Unfortunately, you will still end up with some unwanted email that you can simply delete.

You will need to manage your emails otherwise the volume of emails can become overwhelming. Move emails you want to keep to a SAVED folder. Delete emails you've read and don't need to save. When you hit "delete" the email goes into a TRASH folder. Routinely delete all the emails in the TRASH folder to free up space on your device.

Don't forget to run your security software to ensure that your device is virus free and to reduce the possibility of getting hacked. Ask for help if you don't know how to do this. If you are hacked, get professional help right away to protect your identity and your assets. Contact your phone provider or the Federal Trade Commission site, *ReportFraud.ftc.gov*

Charging Pads

It's easy to forget to charge smart devices, such as a phone, tablet, and watch, and to forget which cord charges which device. Charging pad devices can be a help with this. You simply lay your smart device on the charging pad to charge. The larger charging pads provide space for multiple devices at the same time. If you place the charging pad somewhere that's handy and visible, such as in the kitchen or next to your bed, you are much more likely to remember to charge devices — especially if you don't have to go searching for the power cords.

First thing in the morning and last at night, I check for any computer, smartphone, or app updates as this gives me confidence that hardware problems will not occur.

I like an empty in-basket so when I have replied, when I have taken appropriate action, or printed an important email for a more extensive action, I file it in the appropriate file. This reduces confusion and stress.

I don't have an Apple computer but I have an iPhone and iPad. I have the three devices synced so an appointment made in one syncs to the others. Likewise with my emails and files.

This makes my life so much easier.



Jim Mann, Manual Guide



Ways I Use My Smartphone

Rev. Dr. Cynthia Huling Hummel, Manual Guide

I can organize my schedule, read the news, and visit my grandchildren

If you don't already have a smartphone, you might want to think about getting one. The cost has come way down and many of the phone companies offer a free smartphone with their service plans. Your smartphone is really a little computer that you can put in your pocket or purse that can help you throughout the day. There are many different brands of smartphones and most have the same basic features beyond being used to call people.

If you already have a smartphone that you would like to use for more than calling, you might want to ask a savvy friend to help you set up your smartphone. Alternatively, you can check with your local community center or library or *OATS.org* (Older Adults Technology Services) to see if any classes are offered to help set up a smartphone. Teens can be a great resource, so you might check with your grandchild or a teenage neighbor.

IMPORTANT: You want to make sure you have the security features enabled on your smartphone to prevent someone from getting access to your personal information. Also, be careful of scammers who are always looking for ways to prey on easy targets.

I use an Apple iPhone that responds to my voice commands. I communicate throughout the day with my smartphone's virtual assistant, Siri. You can select a male or a female voice, and can even change the type of accent. My sister's phone, for example, has an Australian accent. I think of Siri as a constant companion who helps me throughout the day, reminding me of what I need to do. I speak with Siri first thing in the morning and Siri is the last one I speak to at night.

Here are some of the ways that I use Siri throughout the day:

- I use Siri as my alarm clock not just in the morning but throughout the day. I can program Siri to set an alarm to remind me of a doctor's appointment that afternoon and a dinner date that night.

- Siri gets me to where I'm going without my having to rely on paper maps. I can program in an address and Siri guides me to my destination. I have certain locations that I have preset — so when I tell Siri to get me home, she knows my address and tells me step by step how to get there.
- I can check the weather on my phone by asking Siri. This is very helpful as I dress and plan my day. I have Siri set up to notify me of weather alerts so I don't get caught without my umbrella or snow shovel handy.
- I use the calendar app on my phone and Siri reminds me of upcoming appointments and meetings. Siri can give me a heads up that a meeting will be starting in X minutes.
- Did you know that Siri can activate the flashlight feature on an iPhone? For instance, I can say, "Siri, turn on the flashlight." Voila — the flashlight lights up!

Besides Siri, there are many other features on my smartphone that are a big help to me. I use my smartphone to pay bills and to stop and start the mail. I can use it to turn smart lights off (more on this later) and on in my home.

Here are other ways I use my smartphone to help me with my daily life:

- I use the voice app to send and check text messages and emails.
- I love to follow the news and instead of getting printed newspapers, I get *The New York Times* and local papers delivered right to my smartphone. I can also access the local, national, and international newsfeeds throughout the day.
- I attend virtual meetings from my phone, including virtual doctor's appointments.
- There are many helpful and free app programs you can easily install on your smartphone. My favorite app is Facetime, which lets me video chat with my grandkids.
- My smartphone is my camera and I take lots of pictures daily that I can easily share with my family and friends.

6.2 Life Enhancement and Supporting Independence

Technologies are providing many life-enhancing benefits including helping to support our independence. Below are some of the technologies that offer helpful benefits for individuals living with dementia.

Voice Activated Assistants

Voice activated assistants, such as Siri (from Apple), Google Assistant (from Google), and Alexa (from Amazon), can also be used to do all sorts of other things that are life enhancing and can help you maintain independence. Here are some things it can do:

- Play music.
- Answer your questions (everything from "Where is Kathmandu?," and "What's today's weather?" to "How do you say I love you in Spanish?").
- Manage your calendar and remind you of events and appointments.
- Create to-do and grocery lists.
- Send text messages.
- Provide reminders, such as where you put your keys.
- Order things online to be shipped directly to you.
- Turn on/off smart lights.

Similar to voice activated assistants, virtual assistants are accessible on smartphones, tablets, and computers, and on standalone devices, such as the Amazon Echo (Alexa), Apple products (Siri), Google Home products (Google Assistant), and Bixby (Samsung).

I use my smartphone calendar and alarms. When I'm somewhere and a new appointment is made, I put it immediately in my phone. I also make use of the calendar's two warning times so I can be reminded, for example, 60 minutes prior and again at 10 minutes. Depending on the tasks to complete for a meeting, I will sometimes have the first alarm set one week before and then reset it.

Jim Mann, Manual Guide





What Alexa Can Do: Mark Timmons

From an interview conducted by Elizabeth Stettler, Indiana University

For Mark Timmons, Alexa is a tool of daily living. With medication reminders, calendar scheduling, indoor lighting management, and more, Alexa makes daily living easier.

Elizabeth: What are some examples of technology that you use every day?

Mark: Alexa is primarily the technology I use around the apartment. *Alexa, light white.* [directed to Alexa during interview].

Alexa: Okay.

[Light color changes in apartment]

Mark: I don't use Alexa to her full extent. I don't need everything yet, but I know there are applications out there so that when the time comes, I can enable her. For now, I use her for reminders —she can remind me when to take my medication. And if I'm watching television, I will take my medication when a commercial break *begins*. By the time a commercial is over, I've forgotten. And now, if I don't tell her I've taken my medication, she'll tell me again and again!

Periodically, Alexa will just announce to me the date, the day, and the time. One issue I sometimes have is confusion about where I am or *when* I am. Sometimes I fall into confusion thinking that my wife is still alive or that my kids are younger; that can be confusing, upsetting, and disorienting. . .. Alexa helps prevent that by announcing to me where I am and when I am.

She is synched with my Google calendar so I can ask what my schedule is, and she says, "You have this meeting at this time." I can set alarms to get me up in the morning. I can keep shopping lists and to-do lists. I can also actually shop through Alexa. Anything I want to order through Amazon, I can just order it with Alexa.

I programmed her so that ten minutes before sunset each day, all my lights will turn on at 30%.... I also programmed the color of light; I like colors! I prefer my lights to be purple. So ten minutes before sunset every day, all my lights turn on to this 30% brightness, nice soft shade of purple. It's soothing for me, and I don't have to remember to turn the lights on. At 1:00 every morning if I haven't remembered to turn the lights off, she turns them off automatically.

Alexa can also help with math calculations, brain games, video calling, medical alerts, and more.

....Now I can't balance a checkbook, so I'll ask her "What's this minus this?" and she has the answer. I can play different types of brain-stimulating games through her that help keep my brain exercised. . . In the future, she'll be able to make phone calls for me!

In the kitchen, I have a version of her they call the Echo Show, which has a video screen on it, so that gives me the ability to make video calls or, for other people who have a similar device in their home, they can check in on me with a video call, which is important for care partners. There are so many other devices, appliances, and services that you can connect: doorbells, thermostats, stoves, ovens. Now, there are also Alexa medical alert systems.

Ecommerce (Online Shopping)

The first major ecommerce platform consumers started using was Amazon. Amazon launched in 1995 primarily selling books online. In less than 30 years, online shopping has grown immensely, revolutionizing how people make purchases. According to an NPR/ Marist poll, 76 percent of adults in the United States shopped online in 2024.

Online shopping can be easy and convenient. Besides not having to leave home, online shopping offers access to a larger selection of items than stores, the ability to compare prices among sellers, and the opportunity to shop anytime, day or night. All you need is a device connected to the Internet, such as a smartphone, tablet, or computer, and a credit card.

According to the Federal Trade Commission, online shopping is the second most common area where consumers are impacted by fraud. Beware of scammers pretending to be legitimate online sellers that can abscond with your payment. For individuals living with dementia whose keen discernment skills may be diminished, it is recommended to shop online only with well-known, reliable companies.

Always pay by credit card rather than a debit card. If you end up in a scammed situation, your credit card company can protect you and manage the fraud. **Never pay for anything online via a money transfer from your bank account.**

Technology Assistance with Meals

Grocery delivery

The revolutionizing of online shopping has also impacted grocery delivery, and purchasing groceries online is a growing trend. It saves going to a store, waiting in lines, and hauling the items home. With online grocery shopping, the groceries are delivered to your home. For people who don't drive, online grocery shopping is especially beneficial. Stores often charge a delivery fee making online grocery shopping more expensive, but the delivery cost and possible driver tip weighed against the maintenance cost of a vehicle (insurance, gas, tires, repairs, etc.) may make the delivery expense a bargain.

Meal kit subscription services

Another growing food trend that makes eating at home easy are meal kit subscription services. While the meal kits are not technological, ordering them requires using a device connected to the Internet. Pre-ordered meal components are delivered to your home.

All of the ingredients needed for the meal are included in pre-measured portions with an easy-to-follow recipe to be assembled and cooked in your kitchen.

There are a number of companies offering meal kit subscription services, such as Blue Apron, Hello Fresh, Home Chef, and Green Chef. There are a wide range of meal and diet choices at varying costs. For someone with dementia, meal kit services can be very beneficial. If assembling the meal is too complicated, you can order the meals and then invite a family member, friend, or neighbor over to help put the meals together

Meal delivery from restaurants

Another option for meals at home is to order fully prepared items from local restaurants and have them delivered to your home. Like meal kits, ordering meals for home delivery from restaurants needs to be done using a device connected to the Internet. (Note that there have been complaints that delivery services such as DoorDash and Grubhub have excessive fees — be sure to find out what the bottom line cost will be and if tipping is expected.)

Smartwatches

Smartwatches became more commonly used once Apple's smartwatch hit the market in 2014. Since then, smartwatch capabilities and features have skyrocketed, and they now are basically wearable computers in the form of a watch. Think of things you can do on your computer, tablet, or smartphone; you can do these on your smartwatch as well.

There are some beneficial features of smartwatches. They can act as pedometers (to count your steps), fitness trackers including heart rate monitoring, and accelerometers for measuring how fast you are traveling.

If you're interested in buying a smartwatch, here are some things to consider:

- Comfort
- Size and display readability
- Battery life
- Water resistance
- Charging mechanism
- Price

Wayfinding

Google Maps is the most widely and commonly used Internet-based map and navigation app used worldwide. It is free and can be downloaded on your smartphone, tablet, or computer. Besides giving you directions, Google Maps can help you locate nearby places (restaurants, banks, businesses, gas stations), get information (business hours, restaurant menus, distance between locations), and see the street view of sites, among many other uses.

Google Maps blue dot feature is especially beneficial for people living with dementia.

The blue dot feature can be used to mark where you parked your car, to share your current location with someone, and to let you know where you are if you get lost while out walking. It's an easy function to use. Open up the Google Maps app. A blue dot will appear on screen showing you where you are on the map. Tap that blue dot, and options will pop up that allow you to share your location with others or mark the place where you parked.

Other Internet-based free wayfinding apps include Waze and Apple Maps.

6.3 Engagement and Socializing

There is an amazing world of entertainment available online that offers a wealth of opportunities to learn new things, have fun, connect with others, and be stimulated.

You can access online activities using your smartphone, tablet, or computer.

Most likely you will need to download an app to access the engagement. Many engagement apps are available for free. The free versions often are accompanied by digital ads that can be confusing. Read reviews about the apps to identify ones that are highly rated, reliable, and work well for people living with dementia.

Digital Photo Frames

A digital photo frame is a computerized device about the size of a picture frame that displays photos electronically in a slideshow-type format. You can set the slideshow of photos to display at whatever speed works best for you. The photos can be wonderfully entertaining and comforting.

Digital photo frames are an easy way to view lots of photos, plus they save the step of having to get photos printed. Some things to consider when purchasing a digital photo frame are:

- Battery or electrically powered
- Memory capacity
- WiFi connectivity
- Other features such as clock and calendar

Games

Games on a tablet are a good way to introduce and encourage people to get familiar with the different finger movements on a touchscreen tablet. You do not have to look for games that are specifically designed for people with cognitive impairment. Explore your interests to find games that are fun, interesting, and user friendly.

Explore your interests to find games that are fun, interesting, and user friendly.

Games can be a good way to introduce computers, as well as being fun. Search for websites that offer free versions of "traditional" games such as:

- Jigsaw puzzles
- Sudoku
- Crosswords
- Card games, such as Solitaire, Hearts, and Gin Rummy

There are also digital games which appeal to the senses and can be fun and engaging. You can search online, using a search engine such as Google or Firefox, for games related to a person's interests. Many games are free to access or download (though they may contain advertising) and most paid-for ones are low cost.

Your Personal Story

Each of us has our own unique life story. Our lives are a collection of experiences that, woven together, make us who we are as a person. The process of developing your life story can be a wonderful activity for you to do and something precious for your family to have. You

may want to invite a close friend or family member to help you write your life story. Besides being a fun way to spend time together, you can reminisce and jog each other's memories about your past.

There are many benefits to recording your personal story, including:

- Serving as a way to remember aspects of your life that enhance your sense of identity.
- Developing closer relationships through sharing personal stories and learning some fascinating things.
- Better personalizing support by non-family care partners.

You can write your life story by hand or type it on your computer. This makes it easier to share with others. There are also online companies that can help you develop your life stories, such as LifeBio, 2nomi, and MemoryWell. The Dementia Action Alliance developed a free bio template available online to make the process fun and easy.

It's important to remember that your personal story can be a work-in-process project and not something that has to be completed all at once. You're the author and you set the pace.



Technology and Creative Passions: Mark Timmons

From an interview conducted by Elizabeth Stettler, Indiana University

Since his diagnosis, Mark's passion for photography and poetry has flourished. Alexa provides editing software that makes technical aspects of Mark's creative work easier, but also applications that have brought new avenues of expression.

Mark: Alexa is the big device here in my house, but I also use other types of technology with my photography. My ability to size up just how a shot should be set up as far as exposure setting and camera speed and aperture setting —those skills are starting to get away from me now, but I can take less-than-perfect pictures home and correct my mistakes with certain editing software. Technology is a huge benefit for people living with any type of brain change.

Elizabeth: What editing software do you use?

Mark: I use Adobe Lightroom to correct for exposure, contrast, etc. For more creative edits, I use a suite of applications from Skylum that allows me to add digital elements to my photographs that were not in the original shot. This allows me to create unique pieces (I call it "Hybrid Photography") while keeping my brain engaged and active. For example, I created a photograph of a distant lighthouse, but the sky was Van Gogh's *Starry Night* sky. One of my newer projects with my photography is using all this technology to combine my poetry with my photography. So now I can superimpose pieces of my poetry onto my photographs and create a whole unique product that way.

Elizabeth: That's so neat!

Mark: It's helped inspire me because sometimes I can take one of my photographs, take my binder of poetry, and say "Ah, that's a perfect match," but then there are times when I've got a photograph that's calling to me to put a poem on it, and I just don't have a poem in my collection that's ready for it, so the photograph can inspire a new poem.

Mark shares his work with others at DAA and beyond.

Elizabeth: Do you post your work online anywhere?

Mark: I do —TikTok! (Laughs). Sometimes I read it aloud on TikTok, sometimes I just post pictures of my work there online. I share my poetry with others in DAA through our many online Zoom groups (*daanow.org*). One day I also hope to publish my writings.

Robotic Pets

Robotic pets, such as cats and dogs, are becoming increasingly popular. Robotic pets (e.g., Joy for All, Paro, Aibo) are toy animals that have life-like features that include sound and movement, such as blinking or moving their heads. They are typically powered by batteries. Many robotic pets have sensors that respond to user movement and touch.

In 2018, New York State's Office for the Aging conducted a pilot study of robotic pets. Sixty older adults were provided with a robotic pet and tracked over a year. Seventy percent of the study participants felt less lonely at the end of the study. Then, in 2020 when New York's Department of Aging had to close its adult day programs due to COVID, the state provided over a thousand robotic cats and dogs to adult day program participants. A May 24, 2021, article in *The New Yorker* by Katie Engelhart noted that a few individuals living with cognitive impairment were disoriented by the robotic pets. One individual called her local aging department to report her cat wasn't eating. In general, though, people liked the pets so much the batteries wore out. By April 2021, New York had given out 2,260 robotic pets and had ordered another thousand.

There is much research about the positive benefits of engaging with pets. While robotic pets are not a replacement for live pets, they can be wonderfully beneficial when having a live pet is not feasible or safe.

Virtual Engagement

With smart devices growing more common, and with screens for viewing, virtual platforms to share real-time content through the Internet evolved. Zoom, Microsoft Teams, and Facebook live streaming are some of the most well-known. A whole new world of engagement opened up with virtual technology. In addition to meeting others face-to-face on your screen, you can explore, learn, and experience a world of wonders from the convenience of your home.

There are countless virtual programs online — many for free — offering interesting, fun, and informational engagement. The following are some examples to get you started

- Tour museums virtually through Google Arts & Culture, which teamed up with over 1,200 museums and galleries around the world to offer virtual tours and special online exhibits. *www.travelandleisure.com/attractions/museums-galleries/museums-with-virtual-tours*
- Experience some of the United States' best national parks from Florida to Alaska. *www.nationalparks.org/connect/blog/take-virtual-visit-national-park*
- Watch the funny antics of sea otters playing or the hypnotic drifting of jellyfish from the Monterey Bay Aquarium. *www.montereybayaquarium.org/animals/live-cams*
- Attend fun programs offered by the Dementia Action Alliance that are especially designed for individuals with cognitive impairment/dementia. *daanow.org/virtual-engagements/*

Virtual Reality

Virtual reality (VR) (e.g., Meta Quest 3, Apple Vision Pro, Valve Index, MyndVR) is a computerized system that allows users to view three-dimensional scenes by wearing a high-tech headset. Users are immersed in a virtual environment that can be explored and interacted with. People may be familiar with the concept of VR from video gaming. Now there are many applications for VR, such as being able to enjoy realistic travel experiences without leaving home. The virtual environment can be almost anything — limited only to the developer's imagination. VR users can tour museums and historic sites, take a walk through foreign cities and parks, watch dolphins frolic in the ocean, and many more engaging and fun things.

Isolation and having fewer opportunities for socializing are commonly experienced by people living with dementia and this can lead to becoming depressed and anxious. VR opens up a new way to engage with the world. Visiting a familiar place from the past can be comforting, touring a new city can be exciting and informational, and taking a walk along a beach can be calming. Experiences can be tailored to items of personal interest.

A Few Words About AI

The field of **Artificial Intelligence (AI)** is ever-changing, and the possibilities for improving the safety, independence, and ongoing engagement of people living with dementia are exciting. You've likely heard of these AI tools:

- **ChatGPT**
- **Microsoft Copilot**
- **Apple Intelligence**
- **Google Gemini**

Ongoing AI research and development promises to continue to expand this list.

AI can help those living with dementia live fuller and richer lives:

- AI sensors can alert care partners to **changes in typical daily routines**, including missed meals, doors left open, and the absence of expected movement that might indicate a fall.
- AI can **facilitate communication and artistic expression**, transforming words into images and images into words. AI can assist with the generating and organizing of ideas.
- AI can **answer** quick trivia questions—"Who was the 14th President of the United States?"—and more practical queries—"How can I request a wheelchair at New York's Kennedy Airport?"
- AI's ability to provide **information about topics of interest** can support new explorations and hobbies.
- AI continues to combine accumulated data points with the lived experience of dementia to **grow our understanding of early diagnosis and disease progression**.
- AI-powered robots currently under development have tremendous potential for **addressing isolation and supporting retained abilities and interests**.

6.4 Safety and Security

> *There are so many products on the market now that make it easier to help you manage and keep safe in your home.*
>
> **Rev. Dr. Cynthia Huling Hummel, Manual Guide**



Digital Clocks with Date and Day of the Week

Feeling confused and disoriented are common symptoms experienced by individuals with dementia. This can include having trouble reading a regular clock face. A digital clock displays the time numerically (12:15) that may be easier to understand. Digital clocks that include the date (May 12, 2025) and the day (Monday) are especially helpful.

Another helpful feature of digital clocks is that the time display can easily be seen in the dark. If you wake up disoriented, seeing the digital clock display 3:00 am, for instance, can be helpful to know that it is not time to wake up yet.

Kitchen Safety

It is easy to become distracted while working in the kitchen. There are a number of electronic devices that can help keep you safe from forgetting to turn off the stove or from leaving something cooking untended.

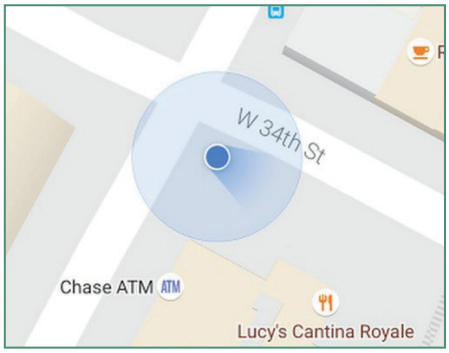
- Products such as CookStop use motion sensors to detect if there is no activity when the oven or stove is on and can shut them off.
- Electric tea kettles are a quick way to boil water. Make sure to get an electric tea kettle with an automatic shut-off feature.

Location and Tracking Devices

Location

Confusion and disorientation are common symptoms of dementia, especially if you are away from home. Online apps accessible on your smartphone or smartwatch can be very useful to help you maintain independence and safety while you're out.

As noted earlier, Google map's blue dot feature can be helpful. The blue dot feature can be used to mark where you parked your car, share your current location with someone, and let you know where you are if you get lost while out walking. It's an easy function to use. Open up the Google map app. A blue dot will appear on your screen showing you where you are on the map. Tap that blue dot, and options will pop up that allow you to share your location with others or mark the place where you parked.



Tracking devices

If you have become disoriented while out walking, a family member and/or close friend may feel concerned about your safety when you are away from home by yourself. One way to acknowledge their caring concern is to activate a free tracking app on your smartphone or smartwatch. This will relieve their worry, while allowing you to continue to be independent.

If you are a family member or friend, you might suggest this option. The individual will need to have some device with them when they leave the house that has technology that can transmit location, such as a smartphone or smartwatch. There are other options that offer location technology, such as wearing a pendant or using a SmartSole insert for shoes.

Nightlights

Most of us need to use the bathroom in the middle of the night. It's not advisable to turn on lights to see the way as you don't want to become fully awake. Nightlights are important to have in your bedroom and bathroom. Nightlight technology has advanced to incorporate motion detection. If you plug in a nightlight in the bedroom, it comes on when it detects you getting out of bed. You can also have a motion detection nightlight in the bathroom. If you need to travel down a hallway to get to the bathroom, you will want a nightlight in the hallway as well.

Nightlight technology has advanced to incorporate motion detection. If you plug in a nightlight in the bedroom, it comes on when it detects you getting out of bed.

Smart Home Technologies

If you are knowledgeable and savvy about technology, congratulations! You are well positioned for the 21st century and the ever-growing market of smart home products.

Not all of us, however, are savvy about technology, including knowing what products are available and would work best for our needs and lifestyle. If this sounds like you, there is good news. There are people/companies that offer consulting and installation services so you are able to utilize smart home technology to make your home life easier, more secure, and safer. Having someone knowledgeable about smart home systems who can explain options and help you decide on products that best meet your needs and budget is a good investment. You don't want to end up buying products piecemeal only to find out they don't work together or do exactly what you thought.

A number of companies offer integrated suites of smart home technology products, including Google Nest, Amazon Smart Home, Apple HomeKit, and Samsung SmartThings Hub. Using the voice assistant or mobile app feature, the following are some of the things these systems can do:

- Activate smart lightbulbs and turn lights on and off and dim the lights.
- Adjust the temperature inside the home.
- Activate items using smart plugs such as coffee makers and music devices.
- Make hands-free calls.
- Set calendars and reminders.
- Add items to a shopping list.
- Activate smart home security including a security camera to see who is at the door.
- Activate turning the TV on to a favorite program, changing channels, and controlling volume.

As a security feature for falls or a health event, indoor camera systems can be programmed to send an alert notification to a family member's, friend's or neighbor's mobile device if there is no movement detected in a set period of time. There is more information on fall safety in the following section.

6.5 Health Management

Fall Detection and Response Apps

Injuries due to falls are among the leading causes of hospitalizations for older adults. The World Health Organization reports that falls are the second leading cause of injury and deaths worldwide. The risk for falls increases the older we get as a result of decreasing physical mobility, strength and balance issues, poor vision, dizziness (side effect of some medications or blood pressure complications), and disorientation, among other causes.

Technologies that can predict falls are in development. If you do fall, what can you do? Most smartphones and smartwatches have gyro sensors that can detect when a fall has occurred. You can activate the fall detection setting on your smartphone or smartwatch. If you fall, the program is activated to send an alert to your emergency contact(s). There are also free apps that provide this feature, such as iFall (for Android users) and Google Maps. Finally, there are fall detection devices available for purchase. Remember, fall detection and alerts will only help you if you have the device on you. (For more on *falls*, see *Supportive Home Modifications*, Section 4.7, page 245.)

Medication Reminders

According to the Kaiser Family Foundation, 89 percent of adults 65 and older take prescription medications. Over half of those who take medications take four or more prescription drugs. Since memory loss is one of the main symptoms of dementia, remembering to take the correct medications on time can be challenging. There are many technologies that can help support you taking the right medications at the right time, including reminder systems, pill dispensers, and devices.

These are a number of apps to remind you when to take your medication and some apps can also remind you when to refill a prescription. Some of these apps are an audible reminder and others provide a visual alert. Medication reminder apps will not work if your phone has no signal, if you put your phone on silent, if your phone's battery runs out, or if you do not have your phone with you. There are also medication dispensers that will dispense the proper dose at the proper time, so that you don't take the medication more than once.

The following are some examples of apps that send you reminders to take your medications and can alert care partners about missed doses:

- MediSafe
- MangoHealth (for Android device users)
- RoundHealth (for iOS device users)
- DoseCast

Medication Management



A Survival Guide to Medication Management

Amy Goyer, Contributor

Oct. 22, 2020.

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https://aarp.org/caregiving/health/info-2020/medication-management.html

One of my most time-consuming and stressful tasks as a care partner was managing multiple medications and supplements for my parents. Being responsible for getting their prescriptions filled and doggedly ensuring there were no adverse drug interactions or side effects was difficult. Tracking and sorting all of the pills, liquids, creams, nasal sprays, and eyedrops — and administering them all — was exhausting.

How did I survive? By finding practical ways to organize and track it all. Here are my top tips for making medication management easier.

Organize for more than a week

Many years ago I helped my parents get set up with pill organizers so that Dad, who had Alzheimer's disease, and Mom, who'd had a stroke, could better track their daily intake. For a time, Dad filled the boxes; my sister Susie filled them when it got too confusing and stressful for him.

When I moved to Arizona to care for my parents, I took over the task. I soon realized that by the time I got all the supplies out and filled one week's pillbox, it didn't take much more time to fill up a second week. Eventually I was filling two months' pill organizers at a time — a great time-saver that also made for fewer shopping trips or online orders.

The biggest problem I've had with pillboxes through the years has been finding a type that had individual compartments big enough to accommodate the plethora of pills my parents took. Before she passed away, Mom took various drugs five times a day (at one time she had an alarming 23 medications, which I whittled down). I actually had to use two boxes for her — one with four compartments, plus a small, single- compartment box.

For Dad, who took pills twice a day, I used giant pill organizers with four rows. Each two rows held a week's meds. I'd fill four of those mega-organizers at a time, for an eight-week supply. Another time-saving option is presorted pill packets delivered directly from a pharmacy. Most of the major chains offer a 30-day supply, with each packet containing all pills to be taken with each dose.

There are also many technology-based pill organizers and dispensers that can help you plan.

Create and maintain a list of meds

With a comprehensive list, it's less likely you'll forget anything while filling the pillboxes. It also helps ensure that any additional caregivers or an emergency-response person can easily find the information.

I recommend making a chart or spreadsheet, with at least these categories:

- Name of medication or supplement, and the strength (e.g., 600 mg tablets)
- Prescribing doctor's name and phone number
- Purpose (blood pressure, thyroid, dementia, blood thinner, pain, etc.)
- Dosage (for example: 600 mg, 1x/day; 25 mg, 2x/day)
- Comments (such as the generic name, special instructions, refill dates or auto-refill information)

I kept a copy of my list in a folder to bring for doctors' appointments or hospital visits. (Bonus: Medical staff will be thrilled and impressed that you have all of this necessary information at your fingertips. I received a lot of kudos from my parents' doctors over the years!)

Take advantage of technology

Pillboxes and medication lists were my low-tech solutions, but I used some high-tech solutions, too. I made the meds list easily accessible at all times by creating it as a Word or Excel file on my computer, which I could access on my smartphone or tablet via a cloud storage app. (I used Dropbox, but there are several other free options.)

I also kept a copy in my Evernote app and another in a caregiving app I used.

Some caregiving apps make the process easier by allowing you to add information about pills by simply taking a photo of the medication bottles (although I prefer to be able to add my notes and comments).

There are also amazing smart electronic pill organizers and dispensers that sound an alarm when it's time to take pills and send notifications to caregivers when meds have or have not been taken. Some of these devices hold multiple weeks at a time, but they may be limited to a certain number of pills in each dose.

Prices range from about $15 for a simple pill organizer with alarms to more sophisticated dispensers that cost between $150 and $1,500. You can also set up motion sensors that notify you when your loved ones go to their pill organizers.

There are even robots that deliver medications in hospitals and long-term care facilities, so maybe one day we will all have one at home that can pop pills into our mouths!

THE BOTTOM LINE: Create a system, high-tech, low-tech, or a combination of both, that works for you and your loved ones and ensures that the correct medications are being taken at the correct times. A little organization can save lives, ease pain, and make everyone's life easier.

Amy Goyer is AARP's family and caregiving expert and author of *Juggling Life, Work and Caregiving*. Connect with Amy on *amygoyer.com*, Facebook, Twitter, in AARP's Online Community and in the AARP Facebook Family Caregivers Group.



How to Choose a Medical Alert System

Amy Goyer

Oct. 22, 2021.

Reprinted with permission from: AARP
https://aarp.org/caregiving/home-care/info-2017/medic-alert-systems-options.html

A medical alert system — often referred to as a personal emergency response system (PERS), medical emergency response system (MERS), health monitor or fall monitor — can provide increased independence for loved ones and peace of mind for family caregivers.

How do you find the one that's best for your situation? It can be complicated. Medical alert systems have evolved far beyond a basic, wearable device (like a bracelet or pendant) with a button that triggers a call to a response center in case of emergency.

Start by evaluating your loved ones' specific needs and abilities, present and future.

Now a medical alert device might include GPS, cellular connectivity, fall detection or prevention, in-home health and well-being monitors, activity trackers, movement sensors and more. Alert services might come with smartphones or as a feature of home security systems.

Start by evaluating your loved ones' specific needs and abilities, present and future. For example, if she has dementia, will she understand how to operate a system — or is something automatic, like a fall-detection device, more appropriate? Does he have a disorder that could hinder communication with a call center, like aphasia or hearing loss? Will limited fine motor skills make putting on a device or pushing a button too difficult?

Here are some key things to think about and questions to ask in choosing a medical alert system. Once you've made a selection, be sure to monitor how it is working. Don't hesitate to switch to another service if it isn't a good fit — it could save a life.

What do you need it to do?

- **Fall detection.** Falls are perhaps the most common motivator for obtaining a medical alert system. Nearly 36 million older Americans a year experience a fall, and more than 1 in 5 falls causes an injury, according to the U.S. Centers for Disease Control and Prevention.
- **Call for help.** Devices with help buttons can connect the wearer to a live person at a response center or to emergency services such as the police or fire department. The button sends a signal to a base unit connected to a phone, which makes the call.
- **Medical monitoring.** Some systems can be set to monitor vital signs and provide medication reminders.
- **Cellular.** Mobile MERS can be used anywhere cellular service is available.
- **Location detection and tracking.** A device with GPS is especially useful if your loved one is still driving and relatively independent.
- **In-car.** These compact devices plug into your vehicle's 12V power outlet (what used to be the cigarette lighter) and have GPS capability. Some can be connected to a smartphone via Bluetooth.
- **Movement monitoring.** Motion detectors and beacons track movement in the home.
- **Daily check-in services.** Some monitoring companies will check in with your loved one every day, electronically or via a live phone call.
- **Activity and fitness tracking.** These have features like step counters to monitor healthy activity and fitness goals.
- **Virtual family connections.** Some systems enable users to make or receive ordinary calls, making it easy for family members and friends to check in.
- **Display time.** Alert devices might include a watch feature. Or vice versa: Some smart watches include health monitoring and fall-detection apps.
- **Home security monitoring.** The system detects danger from fire, smoke, and carbon monoxide.

What kind of equipment will work best?

- **Is it wearable?** You'll want a device your loved one finds comfortable. Look out for sharp edges, or strap materials that may irritate fragile skin. Also, is it attractive or unobtrusive enough that he or she will be willing to wear it?
- **Is it fully waterproof?** Can it be worn in the shower? Can it be fully immersed in water? Many falls happen in the bathroom and kitchen, so this is vital.
- **What's the range?** With an in-home system, find out how far the wearable help button can be from the base unit and still operate. That could be a real problem if, for example, your loved one falls in the yard or garage, or several rooms away from the base.
- **Is the speaker loud enough?** A care recipient with hearing loss might have trouble hearing the person at the response center speaking through the device or the base unit.
- **How's the battery life?** Also ask about the charging method and how you'll know if the battery is low.
- **Will it need technology updates?** If so, ask if the updates are implemented automatically or manually, and make sure you or your loved one is tech-savvy enough to manage them
- **How do you set it up?** If there's a base unit or console; will you need more than one to cover the entire home and yard? Should the unit sit on a table or be wall- mounted? Is it plug-in or battery-operated? (If the former, does it have a battery backup if the power goes out?) Does it require a landline, and does it include cellular in case regular phone service is interrupted? Can you add stationary buttons around the home
- **Is the system movable?** Not all medical-alert providers offer nationwide service (see below). If your loved ones move, can the system move with them?
- **Does it include a lockbox?** Some companies offer to install a lockbox that emergency medical personnel can access if they need to enter the home when the resident is incapacitated.
- **Can others connect via the device?** Some devices allow you to check in with your loved one through the alert system, using a monitoring app on your smartphone, tablet or computer.
- **Can it be added to a home security system?** Check with your home security provider. Be sure to ask if there is an additional fee.

How do monitoring and response work?

- **Call routing.** Can you designate how you want various types of alerts/calls (urgent, nonurgent, emergency) routed? Is the system "monitored" (connected directly to a response center) or "non-monitored" (it dials numbers you designate, such as to a family member, neighbor or emergency services)? Some systems offer both options.
- **Response center.** Does the company operate its own response center or contract externally? Is the center certified? What's the average response time? (It should be a matter of seconds.) Will your loved one be able to talk with a live person via the wearable device, and can the center communicate in your loved one's preferred language if it is not English?
- **Customer service.** Quality customer relations are key. There should be a live person you can call 24/7 with questions about the service. You should also be able to contact the company via email or live chat. Look as well for an easy-to-navigate website with a comprehensive FAQ section.
- **Cybersecurity.** How does the company protect private information and prevent hackers from accessing your system?
- **False alarms.** It's not uncommon for people to accidentally push the help button — is there a negative consequence if they do? Unlimited false alarms is a great feature.

How much does it cost?

- **Fees.** Beware of complicated pricing plans and hidden costs like activation fees. Some companies include the cost of the device itself in the monthly service fee, while some charge extra for the equipment. Ask for a complete price breakdown; some features, such as fall detection, may cost more. Look for a company with no extra fees related to equipment, shipping, installation, activation, or service and repair. Watch out for offers of free service or "donated or used" equipment — they're scams.
- **Contracts.** Don't enter into a long-term contract. You should only have to pay ongoing monthly fees that typically range from $20 to $70 a month, depending on selected features. Be careful about paying for service in advance since you never know when you'll need to stop it temporarily (due to a hospitalization, for instance) or permanently.

- **Guarantees and cancellation policies.** Look for a full money-back guarantee, or at least a free trial period, in case you are not satisfied with the service. And you'll want the ability to cancel at any time with no penalties (and a full refund if monthly fees have already been paid).
- **Discounts.** Ask about discounts for multiple people in the same household or for veterans. There might also be special deals available through membership organizations, health insurance or via a hospital, medical or care organization. See if the company offers reduced prices or a sliding fee scale for people with lower incomes.
- **Insurance.** For the most part, Medicare and private insurance companies will not cover the costs of a medical alert system (although some insurers offer discounts or referrals; check with your provider). In some states, Medicaid may cover all or part of the cost.
- **Tax deductions.** Check with your tax professional to find out if the cost of a medical alert is tax deductible as a medically necessary expense.

Is it available where you live?

Many national companies offer medical alert services, but they may not all be available near you, so call and inquire about service areas. Local companies may be an option, too. In addition to companies that have been in the medical alert business for decades, technology and home security firms are now increasingly offering these services as well.

- **Do an online search.** Use keywords such as "medical alert systems," "personal emergency response systems," "fall detection devices" and "urgent response devices" along with the name of your city or state to find companies that serve your area. Check for customer reviews and complaints with the Better Business Bureau or your state's attorney general or consumer protection agency.
- **Contact your local Area Agency on Aging.** Find your local Area Agency on Aging via the federal government's Eldercare Locator and ask if it has a list of companies offering medical alert services locally. (I contacted mine, and it immediately emailed me a list of 16 national and local companies, including one that is offered through the agency itself.)
- **Check with your senior facility.** If you or your loved ones live in a senior community, it may offer an in-house or external medical alert system among its services. Beware of facilities that only have pull cords in a few places throughout

the room or apartment — people don't always fall or become ill within convenient reach of the cord

- **Get referrals.** Ask friends and family members if they can recommend any medical alert systems they have used.

Amy Goyer is AARP's family and caregiving expert and author of *Juggling Life, Work and Caregiving*. Connect with Amy on *amygoyer.com*, Facebook, Twitter, in AARP's Online Community and in the AARP Facebook Family Caregivers Group.

SUGGESTED RESOURCES

General Supports

Older Adults Technology Services offers online classes to learn how to use technology	*oats.org/world-class-programs/senior-planet-digital-2/*
Aging Connected helps older adults access affordable, accessible at-home internet if they don't have internet	*agingconnected.org/*
Cyber Seniors provides free technology support and training for older adults	*cyberseniors.org/*

Charging pads

Belkin BOOST CHARGE™ Dual Wireless Charging Pads	*www.belkin.com/p/dual-wireless-charging-pads/WIZ002ttWH.html*
ZealSound Qi-Certified Ultra-Slim Triple Wireless Charger Station for Multiple 3 Devices	*https://www.amazon.com/Wireless-ZealSound-Qi-Certified-Ultra-Slim-Compatible/dp/B07D9KT4HP/*

Insignia™ - 20 W Qi Certified Dual Wireless Charging Pad	*www.bestbuy.com/site/insignia-20-w-qi-certified-dual-wireless-charging-pad-for-android-iphone-black/6409300.p?skuId=6409300*

Digital games and activities

Apps

Fireworks Arcade is a free fun filled app for multi-touch and graphics (for both iOS and android devices users)	*www.bigduckgames.com/fireworks*
AquaLife 3D is a free app for users to create a 3D like aquarium (for both iOS and android devices users)	*www.fishgame3d.com/*
Lumosity app claims to improve brain function through the use of engaging brain exercises and activities	*www.lumosity.com/en/*

Online Games

Jigsaw Planet — free online jigsaw puzzles	*www.jigsawplanet.com*
Solitaire—– free online solitaire game	*solitaired.com/*
Word Search — free online word search puzzles	*thewordsearch.com/*
Chess — play chess online for free	*www.chess.com/*

Digital photo frames

Aluratek Digital Photo Frame with Motion Sensor and 4GB Built-in Memory	*aluratek.com/products/digital-photo-frames*
Feelcare Smart WiFi Digital Picture Frame	*www.feelcaregroup.com/product.html*
Nixplay 10.1 inch Smart Digital Photo Frame with WiFi (W10F) - Share Photos and Videos Instantly via Email or App	*www.nixplay.com*

Life Bios

LifeBio	*www.lifebio.org/*
2nomi	*2nomi.com/*

Medication reminders

MediSafe	*www.medisafe.com/*
RoundHealth (for iOS device users)	*apps.apple.com/us/app/round-health/id1059591124*
DoseCast	*apps.apple.com/us/app/dosecast-my-pill-reminder-app/id365191644*
MyTherapy	*www.mytherapyapp.com/*
Medacube	*www.medacube.com*

Night lights

VONT Lyra LED Night Light	Available widely where night lights are sold.
GE Enbrighten LED Motion Sensor Night Light	Available widely where night lights are sold.
Motion Sensor Night Light	*www.techsilver.co.uk/product/motion-sensor-night-light/* (NOTE: This is a British company. Click on US Dollars at top right to order.)
Sengled Smart Light Bulb	Available widely where light bulbs are sold.

Smart home systems

Apple HomeKit	*www.apple.com/shop/accessories/all/homekit*
Google Nest	*store.google.com/us/?hl=en-US&regionRedirect=true*
Amazon Smart Home	*www.amazon.com/Smart-Home/b?ie=UTF8&node=6563140011*

Samsung SmartThings	www.smartthings.com/

Tracking devices

Products

SmartSole is a GPS tracker sealed within a water-resistant, trimmable shoe insert	www.gpssmartsole.com
Garmin Vivofit Fitness Band is a fitness band with built-in GPS	www.garmin.com
AngelSense is a GPS tracker that provides a daily timeline of locations, routines and transit speed and sends an instant alert to care partners if their loved one is in an unfamiliar place	www.angelsense.com/gps-tracker-for-elderly/
Care Band Wearable is wearable, activity and location monitoring wristband to proactively manage dementia	www.carebandremembers.com/products/

Apps

Life360 is an app that lets users share locations, group message, and call for roadside assistance. It has both the paid and premium services	www.life360.com/intl/
Google Maps is a free app for real time GPS navigation and location sharing	www.google.com/maps
iSharing is a free location tracking app to track family members in real time and it comes with alerts	isharingsoft.com/
Boundary Care is a location-tracking app for iPhone and Apple Watch, specially designed to help care partners keep track of people living with dementia	apps.apple.com/us/app/boundarycare/id1474130809?mt=8

Virtual reality

Rendever platform and live programming delivers engaging group experiences using virtual reality (paid service)	www.rendever.com/

MyndVR Headset and Tablet helps reduce anxiety, makes therapy fun and stimulates memory and cognition (paid service)	*www.myndvr.com/*
MetaQuest3S is a standalone headset, simply slide it on and you're immediately ready to get started	*www.meta.com/quest/quest-3s/*

VISIT
Demetia Action Alliance
www.daanow.org

SECTION 7: Care Partnering

With creativity, vision, and planning, almost anything that helps us thrive as humans can help us thrive as humans with dementia.

Pat McHenry, Contributor and Care Partner



Care partnership is empowerment. Care partnership can bring, along with challenges, opportunities to strengthen relationships and maintain a perspective of positivity and hope.

The care partnership stories here, along with shared strategies and resources, will be helpful as you navigate this journey.

Explore Section 7 and consider:

- The Care Partnership Narrative
- Care Partnership Near and Far
- Care Partner Self-Care
- Ongoing Communication and Engagement
- Care Support Alternatives



The Stories Are So Many: Stephen and Susan Taylor

From an interview conducted by Catherine Maloney, Indiana University

Steve Taylor returned to the United States from his time living in England. And that's when Susan and Steve's loving partnership began...

Steve: In fact, when we met, I considered it a date, but she didn't, and it was blind because we had just serendipitously run into each other in the parking lot and were introduced by a mutual friend. We never got a really good look at each other. When we communicated and made the connection by email and agreed to meet up with each other, I considered it to be an initial date.

Susan: I was a singles minister, and I thought I was just meeting with a guy that was single just needing someone to talk to, and to help him find Christ because he had certainly been looking.

Steve: The stories are so many. The first week that we had dated I fell madly in love with her. We were goofing around at the mall and went to a store that was having a close out sale. We walked by the jewelry counter, and we were calling each other "Ma" and "Pa," laughing and giggling, and we looked at rings and said, *"Well, that would be a pretty ring."*

Susan: I was really smitten with him, but I had sworn I would never get married again, because I had a terribly bad first marriage.

Steve: I also had a bad first marriage, and it had been exactly seventeen and a half years of singleness for both of us when we met. We went from that store into the mall and then stopped by Rogers and Holland's jewelers. Lo and behold, we did find a ring that really bedazzled both of us. We went on, and she didn't know that the next day I went and put that ring in the layaway, and I started paying for it. I told my friends and family, and they said *"Whoa, what are you doing, Steve? You just met her."* And I said, *"No"*, I said, *"I know this is the woman I'm going to marry. This is the woman I want to live my life with. I know it."* And they said, *"You're crazy."* I said, *"No, I'm not."* She doesn't know that I have this ring in layaway. I'm not going to tell her. I'm going to wait a year. I planned to date for a year and see if everything worked out well, and if it did then I would ask her but not before that.

And I did that. At the end of the year, we took a trip to see my dad down in Florida. And I had the ring in my pocket this entire trip, but I was afraid to ask her, because, as bad as her first marriage was, I just knew and dreaded that she would say, *"No. No, no!"* And I couldn't ask her, because I was scared to death.

So now we're down to the last day, the night before because we were going to leave in the morning, and I haven't asked her yet. She wants to visit her friend Donna. I knew that if I didn't ask her now, and I ask her after we leave and she says *"Yes,"* she won't have a chance to show Donna the ring. You know, that would be upsetting, so I have to do it now. We had just finished eating at a barbecue place, and I pulled the car right around the corner into a car wash. I had to make an excuse. We had a convertible Mustang that we had rented, and I said, *"I need to sweep the car out." "It's a rental car,"* she said. I'm making all these excuses.

We were supposed to meet them for dinner, but I stopped for a moment. I said, *"Well, I just...there's something I need to talk to you about."* And then I started trying to tell her: I want to spend the rest of my life with her. *"I know you're the special person."* I go on and on. She knows where this is headed by then, and I finally ask her, and I say, *"Susan, will you marry me?"* And her answer was, *"I can't."* I told her it's a yes or no answer so I repeated the question. This back and forth went on many times with her responses being, "maybe", "I'll think about it", "I'll try" and more. I said, *"Please marry me. It'll be a beautiful life."* I finally wore her down and she said yes!

Susan: We were married in the autumn of our lives since we were no longer spring chickens. We tease that it was just in time to take care of each other in our old age and infirmity.

More about Steve and Susan:

Susan being a care partner to her soulmate, Steve, has been a journey of its own. Determined to not let dementia change their relationship to that of merely roommates, Susan and Steve continue to find ways to keep their love alive. Whether it is holding hands, going on dates, announcing their love for each other (including written notes, doing special favors, or complimenting each other's strengths), reminiscing about trips and experiences, or praying together, they are careful to not fall into the trap of "just roommates."

They are also caregivers to Susan's mother, Joan, who is legally blind and lives with them in a mother-in-law suite, so they have added duties. Life never gets boring. Steve helps Joan with carrying groceries or her multiple online purchases inside for her, moving things, fixing things, assembling small items, or spending time sitting down to talk with her.

Susan takes care of all finances for the household, plus helping both Steve and Joan with technology, such as cell phones, telephones, television remotes, computers, or printers. She orders all groceries or other needed items and keeps track of any doctor's appointments. Since Steve and Joan can no longer drive, Susan does all the driving and chauffeuring. Their motto, "We all have our gifts," signifies that each individual has the ability to contribute in their own way.

Susan learned from her father at an early age that you have to laugh at things, even yourself. Steve and Susan enjoy telling jokes, giggling, and even sometimes snorting in laughter. One of the biggest factors in keeping their journey successful is to keep humor involved in everything. Remember always try to see the lighter side of any problem and your journey will be full of joy.

7.1 Care Partnering — Gifts and Challenges

This section of the Manual is devoted to care partners and is mostly written by care partners with love, grace, humor, and creativity. The insights, experiences, and wisdom they share are good shoulders to stand on.

The Manual uses the term "care partner" to acknowledge reciprocity, respect, and partnership in the relationship. With advanced symptoms you may not feel you are in a partnership. You may feel you are shouldering everything. But as many of the stories in this section demonstrate, even when symptoms advance, the person living with dementia has gifts to share — although in different and unexpected ways than before. Some of our contributors prefer to use the term "loved one" to refer to the person living with dementia. We recognize that some care partners have had fraught relationships, and they may be providing support more out of a sense of obligation or duty than love. We hope you can adapt the language and the lessons here to fit your own circumstances.

Care partners can be an adult child, a spouse/partner, a sibling, a grandchild, a parent (of someone living with younger onset dementia), another relative, or a friend. According to the Alzheimer's Association in its 2021 report *Facts and Figures*, 11 million people provide unpaid care to people living with dementia. Of these:

- Roughly two-thirds are women
- Over half are adult children or in-laws

- Two-thirds reside with the person living with dementia
- Thirty percent are over the age of 65

The report notes that even as care partners describe high levels of depression and anxiety, many also express positive feelings about this role:

- Forty-five percent of care partners in a national poll said that caring for someone living with dementia was "very rewarding."
- Many care partners describe feeling good about family togetherness and a sense of helping others.
- Those with support from other family members and friends expressed greater satisfaction than those without such support.

Dementia is known as a companion condition; it affects not only the person who is living with it, but also their family, friends, and the larger community. You unexpectedly are along on a journey of support that will be unique to you and the person in your life living with dementia. While it is not a chosen journey, with a positive and proactive attitude, it can be a time filled with many good things.

"Family care partnering can be cast in such a tragic way," says Jennifer Carson, dementia specialist at the University of Nevada, Reno, and care partner to her father. "And sometimes it can feel like the 36-hour day. But where is the message about the possibility of growth or reciprocity or interdependence? There's a lot of focus on care partner burnout, discussed widely in the literature. Having this kind of terminology doesn't help bolster me as a family care partner. These messages are disheartening. They contribute more stress to my own thinking about my experience."

Dementia is known as a companion condition; it affects not only the person who is living with it, but also their family, friends, and the larger community.

Sherry Dupuis, a dementia specialist with the University of Waterloo in Canada, observes the difference in perspective that she's often found between the person living with dementia and the care partner. "I've been doing this a long time," she says. "People living with dementia really want that positivity, that hope. They don't want to think about the future. They plan

for it and that's important, but they want to get on with living their lives. For care partners, it's a different experience. They wanted to focus on the negativity and how to cope which is completely understandable." Navigating those feelings to strengthen and build relationships is critical for the well-being of all, she says.

We hope you find valuable strategies, wisdom, and inspiration from the following care partner narratives.

7.2 Transforming the Narrative from Tragedy to Thriving



Pat McHenry Sullivan, Contributor

"Thriving with dementia" is a notion I first discovered when I found the Dementia Action Alliance in late 2019, shortly after my husband John was diagnosed with dementia, likely Alzheimer's with possible Lewy bodies.

On the site's "Hear Our Voices" section, I heard many unique stories with common themes of how to find inspiration, hope, and solid support by being proactive with dementia. Here are some samples of insights:

> *At first, the diagnosis led to despair. Then I faced the disease head-on and found many allies and resources.*
>
> *Many of my allies live with dementia of different types. Others are care partners, meaning we all give to and receive help and inspiration from each other.*
>
> *While dealing with dementia, I've mourned the loss of some cherished faculties. I've also developed resilience, empathy, creativity, and other gifts that too often get lost in our normally over-busy world.*
>
> *If thriving is defined by doing the best we can for ourselves and others, standing together in authentic community, sharing sorrows and joy, being as creative and purposeful for as long as possible as well as possible, I thrive big time.*
>
> *... Even when all I can give in the moment is our presence.*

Everyone has his or her own definition of what it means to thrive with dementia, and our definition is yet to be written.

Here are some measures that mean thriving to us:

Our marriage has never been richer. Much of the credit for this comes from our acceptance that "this too will pass," and our agreement to seize the joy of today.

We accept the probability that if John lives long enough, one day his memory and language of words will fail.

That calls us now to expand and enhance ways to communicate through touch, silence, music, laughter, and other ways we don't yet know. We hope that dedicated practice now will help us connect mysteriously even in later-stage dementia.

We take inspiration from former professional ballerina Marta Cinta González Saldaña, whose viral video shortly before she died in 2019 shows how she re-awakened to body and performance memories of Swan Lake to dance beautifully in her wheelchair. (See *www.youtube.com/watch?v=IT_tW3EVDK8*)

I'm inspired by care partner role models like the one in the Saldaña video: never controlling, attentive to cues as simple as Saldaña's hand motions to make the music louder. I'm to be with John not as a therapist, which I'm not, but simply to encourage him, human to human, to try again when it's emotionally or physically difficult.

'Keep on doing what you are doing,'
the doctor told us.
'It's working.'

Our vulnerability and deepening commitment to each other is a solid ground where intimacy grows. John's poor short-term memory erases details of what happens day to day and the names of the practices we use to enrich our lives, but the essence of what we do together — at least for now — he can remember.

John's neurologist recently confirmed that though John sometimes exhibits moderate-stage characteristics, he's still in the early stage of dementia — 14 years after he first was diagnosed with mild cognitive impairment.

"Keep on doing what you are doing," the doctor told us. "It's working."

Our doctor knew when he said "it's working" how much we have benefited from the work of DAA, Dementia Mentors, Re-Imagining Dementia, and a plethora of arts, spiritual, somatic, and other strategies. (For more on *Creative Things to Try*, see Section 7.9,

page 396.) He also knows that what we do to make ourselves and our marriage happier supports our medical and dementia needs, and vice versa.

We can't possibly thrive alone or without blessings from others, including the natural world. As you meet some of the allies and resources in our unintended spiritual, creative, and heroic journey, hopefully you will discover tips or ideas you can use now. You might also adapt or use them as a springboard to discover your own ways to thrive. Everyone's needs, dreams, hopes, and challenges are different. "If you know one person with dementia," it's often said, "you know one person with dementia." Also, "Nothing about us without us" reminds us not to assume as care partners that we know what's best for a person with dementia. Instead, we're guided to find our best way of providing person-centered care.

We can overcome stigma and its impact by practicing blessing. By "blessing," I mean the simple act of seeing each other and ourselves as we are. Here's an example of some steps in blessing:

- *I see you. I see you as you are, not as I wish or fear you to be.*
- *Seeing you, I engage with you and am willing to be impacted by you.*
- *Engaging with you, I call forth the best in you and for you.*
- *I am willing to roll up my sleeves and support your best life.*
- *You define and discern what is best for you for as long as possible.*
- *Through our engaged relationship, we both can thrive.*

When we are in a state of blessing, we're present. Agendas, entrenched beliefs, and assumptions drop away. This supports creativity, playfulness, curiosity, wonder, intuition, and other natural gifts for making the most of life, individually and together. By contrast, the common curse of stigma makes it difficult or impossible to see each other as we really are, which means we can't discover our best ways to thrive with dementia or even to manage it well.

The worst curses are not versions of "Damn you to this bad fate where the worst possible thing can happen to you," but versions of not seeing and engaging with others.

Here's an expression of that type of curse as applied to dementia:

- *I don't see you or want to see you. I may ignore or look past you.*
- *I project upon you my fears and desires.*
- *Not seeing you as you are, I don't engage with you.*

- *Not engaging with you, I don't see or appreciate your worth.*
- *I don't see your true needs, dreams, or potential.*
- *While doing "caregiving," I am not really caring.*

Underlying this curse are projections of our own and others' unwillingness to face such unspoken fears as "what if something like this happens to me? What if I'm shamed when people discover I have no clue about how to deal with dementia? What can I do to protect myself from being swallowed up by others' needs?"

Habits of not confronting dementia worries can easily lead to shame and the story that dementia is necessarily a tragedy filled with doom and gloom. A few false assumptions that come from this narrative are:

- Dementia is either a rapid or dreadfully slow journey into a meaningless vegetative state.
- Having dementia is shameful, not to be discussed.
- There's little you can do to thrive with dementia other than hope for a cure.
- There's no such thing as care partners. The person with dementia is the receiver, their caregiver needs to serve to the point of martyrdom.

The tragedy narrative can easily turn into a vicious cycle of silence, fear, and increased misinformation. The less we face the stigma and our personal concerns, the worse are the outcomes:

- Most people don't investigate the possibility of dementia until they are in later stages, which is too late to create an optimal relationship for thriving with dementia.
- Stigma keeps us from sharing our needs, dreams, tips, and resources, as we might do with other challenges, such as cancer.
- Too few doctors and their patients know how to thrive with dementia.
- Too little money is allocated to creating and publicizing dementia breakthroughs like those reported in this Manual.

Refusing to accept stigma and the tragedy narrative is a gift to ourselves and others.

The earlier we face the possibility of a dementia diagnosis, the more likely it is that (1) we as care partners can build a relationship to support thriving with dementia and

(2) discover and treat conditions that may mimic dementia, such as brain trauma, Lyme disease, or dehydration.

Once we get beyond the stigma and tragedy narrative, we can access our natural gifts such as curiosity and imagination. We can then discern what strategies could help our partner (1) reduce the risk of dementia, (2) delay its onset or progression, and/or (3) thrive with dementia for as long as possible.

7.3 What's Grief Got to Do with It?



Lynette Wilson, MSN, RN, Contributor

We typically think of grief as a response to the death of a person. However, grief is really a natural human response when we lose anything that we love. We experience grief when we go through a divorce, watch a pet die, or give up our social support because of a move to another city. At its core, grief is a process of letting go and learning to accept and live with a loss. Whether we are aware of it or not, grief is a constant companion during the dementia journey.

How intense grief is, what it feels like, and how long it lasts is individual for every person and for every loss. There is no right or wrong way to grieve and no specific timeframe. Grief doesn't go in a straight line, but back and forth, up and down, and sometimes in circles. We don't "get over" grief, but its intensity lessens over time.

So what helps today? Following are some suggestions for learning how to cope with the grief you experience as a care partner.

- **Acknowledge losses as they occur.** You can do this either in writing or verbally, privately or with someone else. Try writing the loss down on a piece of paper, dating it, and putting it in a box or include the loss in your journal if you are keeping an ongoing record of life during the dementia journey. Although I have always enjoyed writing, I found it impossible to journal during our life with dementia. But I did frequently share losses with our daughters verbally.
- **Allow yourself to grieve.** Remember there's no right or wrong way to get through this. Allow yourself to feel however you feel. Grief does not mean you are giving up hope; it just means that you are aware of change and what has been lost. Healing happens if you grieve along the way. You may feel sadness, hopelessness, loneliness, and anger. You can also grieve by being proactive — getting practical information on dementia, finding solutions to the problems you face daily, or doing comforting things

for yourself and for the person living with dementia. Most people experience grief through some blending of these styles.

- **Find ways to take control.** Nothing feels worse than being out of control. Gaining knowledge about what to expect or how to respond to changes related to the impacts of dementia is a powerful way to take control in a situation where you can't change the diagnosis or the ultimate outcome. Even when you can't control what is going on around you, you can learn to control your thoughts, actions, and reactions.

- **Maintain a sense of humor.** I found that there were many truly funny things that happened during our dementia journey. I chased turtles and alligators from the bathroom, listened to explanations for why the horse wanted to go out to play, and had my foot peed on multiple days in a row because getting him seated on the toilet took far too much time. My husband and I frequently laughed together when he said something that made no sense but was clearly funny to him. I cherish those moments when he was very happy.

- **Find and create moments of joy.** We often focus only on our connection to others through verbal communication. Since language abilities are lost to varying degrees during dementia, focus instead on what is communicated through tone of voice, body language, touch, and other nonverbal ways. Being outside in nature or listening to music that you both enjoy allows you to share connections that do not depend on talking.

- **Connect with others.** It's easy to lose connections with others when the demands of everyday life are great or when we are simply too sad to try. Spending time with people who are understanding and supportive gives you insight and energy to keep going. This support may come from family, friends, or members of a dementia support group. Be willing to accept help from others and don't be afraid to ask for help if you need it. And finally, seek counseling if you are finding yourself so overwhelmed or hopeless that it is difficult to function.

- **Practice forgiveness.** This includes forgiving those who disappoint you by not "showing up" in the way you had hoped and forgiving yourself for not being perfect. Confusion and doubt are not signs of failure. Remind yourself frequently that both you and the person with dementia are doing the best you can every minute of every day no matter what doing your best looks like at a given moment.

- **Take care of yourself.** Eat well, sleep, exercise. The question of how to be a good care partner has many answers but taking care of yourself is always one of them. You are now the most important individual in the life of the person with dementia so finding time for yourself and for participating in some activities that are normal for you is essential.

- **Find meaning in what you are doing.** Accept that you will never know the answers to all your questions or find the solutions to all your problems but have confidence and faith that things will work out. Give yourself credit for successes and for your ability to cope in an extremely difficult situation. Being able to find meaning was what did the most to get me through 10 years as a dementia care partner. I believe that we always have the option to choose to learn from what we are going through and to turn that learning into positives for ourselves and for others in our lives.
- **Consider holistic methods of coping.** These methods include guided imagery, meditation, and mindfulness. There are multiple apps available that can be used to practice these skills at home. Massage and acupuncture are often used to help with stress reduction. You can also express your feelings through art, music, and journaling.

One of my favorite quotes related to loss, grief, and coping is something Christopher Robin says to Winnie the Pooh in the book *Pooh's Grand Adventure*. It goes like this:

> *If ever there's a tomorrow when we're not together,*
> *there's something you must remember ...*
> *You're braver than you believe,*
> *and stronger than you seem,*
> *and smarter than you think.*

What a mantra for care partners as they deal with the grief that is an unavoidable part of the dementia journey!

The question of how to be
a good care partner
has many answers
but taking care of yourself
is always one of them.

7.4 Reframing Living with Dementia: 5 P's



Pat Snyder, Contributor

My long journey with my late husband, who had Lewy body dementia, and my many interactions with other dementia care partners taught me what a difference our attitudes truly can make in our experience of the condition and our whole family's experience of it. For those of you who are new to living with dementia and those of you who may feel disheartened, I am hoping this message will give you a new way to reframe how you see yourself as a care partner. Even though you must accept the reality of the diagnosis, that does not mean it totally controls your life going forward. A reframed acceptance means you now take action to learn all you can about how to manage symptoms and how best to live with them.

I found several actions to be truly helpful. I call them *the 5 P's*:

- **Be positive**
- **Be proactive**
- **Be perceptive**
- **Be persistent**
- **Preserve your loved one's personhood**

Be Positive

You can have a negative attitude, but what's the benefit in that? I am not talking about a denial of reality, but, rather, having a positive attitude. Living with dementia is tough. As care partners, we need the most effective tools we can find. Research has proven that positivity builds resilience in those who practice it. Besides, having a positive attitude is free, and it will benefit your well-being.

Negative energy drains us. Positive energy strengthens us. We need all the resilience and strength we can get for this marathon called care partnering. Now … how do we do that?

When you feel consumed by a negative feeling, identify and acknowledge it. This is **self-awareness**. Take time to pause and reflect about what is happening to you inside. Then choose to take action that will *neutralize* or *minimize the impact on you*.

For example:

- **I feel sad** ... so ... I am going to call a friend who will listen and make me laugh ... or I am going to watch an old TV show that made me laugh. You are using the laughter to neutralize the sadness.
- **I feel angry** ... so ... leave the room and take three slow deep breaths and center yourself.

Be Proactive

Be proactive instead of reactive. Rather that reacting as things unfold, try to anticipate issues by educating yourself (join a support group or go online) and staying ahead of things in a proactive way. Find out what resources or tools are available where you live and how to access them.

Being proactive means being willing to speak up when you know something is not right. You are your loved one's advocate — their voice. Share what you are learning with others — especially medical professionals who may not be as familiar as you would hope about your loved one's form of dementia.

It is important to do your homework as a care partner. Learn what you need to know, so that you can ask key questions when you are at a doctor's appointment. "Could we try [another med] for that symptom?" or "What could be causing this symptom?"

Establish a team to support you and your loved one (see *Who Should Be on Your Healthcare Team?*, Section 5.2, page 282). Doing so will feel empowering. Find a knowledgeable doctor who listens to your loved one and to you. Who else should be on your team? Caring, supportive friends, family members, neighbors, and colleagues are a good place to start. Many people find going to a therapist very helpful.

Consider a therapist for the whole family. Having a loved one living with dementia emotionally impacts everyone. A therapist can help you and your family navigate coping skills, communication issues, relationship dynamics, forgiveness of past hurts, and grief issues.

Be Perceptive

Tune in to what is happening around you. Ask others you trust to be objective about your circumstances and what things are priorities to address. It's difficult to be objective when you are in a situation. Trusting others can be hugely helpful in seeing things you might not. Being perceptive helps you to be insightful and sensitive — valuable assets for a care partner.

Be sensitive to your loved one's symptoms. Record changes in physical, psychological, and behavioral symptoms. Report these to the doctor and work together to find solutions. Identify specific triggers that affect disease experience, such as:

- Multiple people speaking at once
- Forgetting to explain what you are about to do before you begin
- Too much change from routine
- Loud voices or sounds
- Wrong lighting
- Rushing
- Too many choices

Be Persistent

Persistence is the opposite of being passive. You stick with your plan. You don't give up. You don't take no for an answer when you are advocating for your loved one. It is a daily choice to be positive, proactive, and perceptive. Be persistent about **taking breaks**, too!

Be persistent about managing stress levels, both for yourself and for your loved one. In many instances, changing my expectations resulted in reduced stress. When I felt less stressed, I found I was calmer all around and could better deal and handle daily life. Knowing that positive outcome was a good motivator and reminder whenever I felt stressed.

Preserve Your Loved One's Personhood

John did not become his dementia condition. His dementia became just one aspect of who he was as a person. What helped me was separating in my mind and heart actions and emotions that were caused by his Lewy body dementia from other actions and emotions. This allowed me to continue to see and enjoy the continued essence of the human being John was. I gave his dementia a name — Lewy. Then when Lewy reared its head, I could blame Lewy instead of John.

I used this technique with our grandchildren. I would say to my grandsons, "That is just mean old Lewy talking to you right now. Your Pops would never speak to you like that. Pops loves you." "Leave the room if Pops looks mad or does something mean. That's just old Lewy, not your Pops. Wait a bit and go back to Pops later." It gave them something to blame and preserved the personhood of their grandfather.

So, to recap:

- Be positive
- Be proactive
- Be perceptive
- Be persistent
- Preserve your loved one's personhood

One way to be a family caregiver is to take the time to figure out every resource in your community: Does your church have a day program? Can someone cover two hours a day to help you? People think they have to do it all themselves. You need to pull people together. If one has financial skills, ask them to pay all the bills. If you live half an hour away, come twice a week and take them to dinner or cook meals to drop off. When family and friends ask how they can help, have a list of 10 things that need to be done.

Tia Powell, MD



7.5 Caring for a Parent



Molly Fisher, LCSW, Contributor

As the adult child with a parent living with dementia, there can be a lot to consider. If you're feeling overwhelmed, breaking down pieces into manageable chunks is very helpful.

Where to Start?

Start with an open and honest conversation with your parent(s). It is really important for you to share your thoughts and feelings about what is going on, even if you think that your parent(s) may not listen.

When my father was experiencing memory loss and confusion, you could see he knew what was happening. I encouraged him to see a doctor, to get a better sense of what he was working with. I remember it so clearly — we were sitting in his room. He was sad. He said he could tell something was wrong and knew what they were going to say. I said that knowing could mean that there are things we can do to help maintain the cognition he has and the potential for participating in studies or in trying medication. I let him know there was a lot of my life he still needed to see — to walk me down the aisle, to meet my children.

It's helpful to get the family (whether of origin or of choice) together so everyone has a chance to understand the situation and to discuss it. The person living with dementia should absolutely be included in this conversation, and if possible, lead it. Leading a discussion about something as important as dementia is empowering and enabling for the individual and a good chance for the family to begin practicing, if not already doing, empowerment and enablement. These are two powerful tools to help support the well-being of the person living with dementia.

If direct, in-person communication isn't possible, consider a video discussion. If you and your parent(s) are estranged, consider writing a letter and not sending it. This can be a cathartic, expressive experience. Think of it as writing in a diary or journal. Or use this as an opportunity to reconnect.

How Much Support Can I/Should I Provide?

Guilt? Shame? Frustrations? Resentments? Many adult children (and spouses/partners) may experience some or all these feelings throughout the course of a dementia-related illness. Take an honest look at your life. What are your commitments, where are you in proximity to your parents, how much time can you give without jeopardizing work, family, and other obligations?

Be open and realistic about what you can do and cannot do. Having a team is very important because no one person can do it all. (See *Who Should Be on Your Healthcare Team?*, Section 5.2, page 282)

If you have had a difficult or estranged relationship, it is okay to not want to give too much of your time, if any. If you don't know what to do or how to handle the situation, speaking with a therapist who has expertise working with families living with dementia can be very helpful.

Try not to listen to unhelpful voices. So what if your friend says they could never imagine placing their parent in assisted living, or judge you for not calling your mom weekly? Relationships are complicated — and not everyone will understand this. Trust your gut. If you know that making this commitment to help care for your parent is going to negatively impact you, that is something to recognize — whether with your partner, therapist, or family. Care partnering is stressful, no matter what the relationship, so if this is creating anxiety, triggering past traumas or somatic experiences, think before you act.

What If I Don't Live Close?

Long distance care partnering can be a challenge. Try to build a team in the same location as your parent. Bringing in a geriatric care manager (also called aging life care manager) is a good place to start, even if it's just a conversation or initial assessment.

Talk with siblings, if applicable, and set the expectations about what each is willing and able to do. Discuss the pros and cons of a move for your parent(s) to be closer to you, or you closer to them.

Try to be realistic. Is your home age-friendly in its design (e.g. stairs)? Do you have young children whose energy can be disruptive to the person's schedule and need for calm as they progress through their illness? Is your spouse on board, as this can create a strain for you, individually or as a couple?

If you can, commit to a set schedule for visits. This way, other care partners and the person living with dementia know when to expect you. Video calls are a great tool for continued contact when you can't be close.

Explore other ways you can contribute, whether it's sending groceries, researching treatments and care options, creating playlists of favorite music, or providing support to siblings and your well parent via daily or weekly calls. Utilize support groups for long-distance care partners.

What If My Siblings and I Don't Agree?

Siblings can be a situation in and of themselves. It's crazy but true that often the stress and strain of dementia in the family can bring back old sibling rivalries or accentuate the strong roles among siblings. Typically, the daughter (or sometimes the daughter-in-law) is the one who takes charge. Older children or the child who lives closest may be looked at to take the lead. Challenge these assumptions if you don't think they are fair or the best for your parent and their wishes.

Ensure that plans are created well before a crisis, including power of attorney and healthcare proxies whom your person chooses.

Communication is key. Getting on the same page with your siblings is ideal. In families where this may seem impossible, getting a sense of who wants what is a starting point and understanding that you may simply agree to disagree.

A group text with your siblings is a great way to communicate without having to be on the phone the whole time. Share updates on the person who is living with dementia after a visit or a doctor's appointment. Include your parent if that would be helpful or possible. Or you may find that you want to connect just as siblings.

Ensure that plans are created well before a crisis, including power of attorney and healthcare proxies whom your person chooses. This way, if things get contentious, you have their voice clearly heard through the legal decisions that have been laid out for care.

What If I Don't Agree with My Parent's Choices?

At the end of the day, these are our parents, and we are their children. We don't like when people tell us what to do, and similarly, parents don't always welcome their children's input

— no matter how sound it is. Our parents are different than our children and try to avoid making that comparison.

Imagine if suddenly, you are no longer able to go to the bathroom alone as you have been doing for 60, 70, 80 years. Imagine that you need someone to undress you and wash you. Imagine you must have someone spoon feed you. This is a great loss and a very real example of the changes that your parent at some point may go through. On some level, they know they have been able to do these things before, and indeed they likely did them for you. Having compassion for how it might feel to receive this assistance can help put the support in perspective.

People can be stubborn, including our parents. They have their own feelings of denial, loss, trauma, shame, and guilt. These feelings shape their opinions and decisions. We can only control what we can control and often that doesn't include other adults. There may be a point where all we can do is state our thoughts and suggestions in a calm manner, share our reasoning, and leave it out there for them to receive.

Learn how to set boundaries. If you become consumed trying to change your parent(s), it will negatively impact you at some point. Setting a limit for yourself is practical and useful.

What this can look like:

- Listen mom, I'm worried about you continuing to lift dad and care for him on your own. I see how it is impacting your health — your back is getting worse, you've lost weight, you aren't sleeping. A good care partner needs to care for themselves. Bringing someone into the home, even for a few hours a week, might be a good idea. I know you keep saying no and having me come help instead. This isn't sustainable. I'm willing to send someone in my place who is better equipped than both of us to help.
- I'm not sleeping, worrying about you and dad. It's not healthy for me seeing you continuing to make the choices that you make. I can't keep being a part of it in this way. I am going to take a few steps back. I can send XYZ support for you to assist, and I'll plan to visit twice a week instead of daily. I need to find balance, and I hope you will too.
- Modeling healthy behaviors and establishing boundaries can be helpful to show siblings and parents that taking the time for yourself (for example) can have positive outcomes. Even if it doesn't create a change within the family, it can help you manage what can feel like an out-of-control situation. It is you taking control of what you control — which is you and how you choose to react and engage.

Working with a geriatric care manager, social worker, or therapist can assist you in boundary setting and communicating around these challenging issues.



One Family's Story: My Dad is Still Living on His Terms

The Carson-Arand Family, Manual Guides

Dave Arand of Port Angeles, Washington, is the primary care partner for his dad, Ray Arand. Ray is retired from law enforcement and Dave and his wife, Katie, are both police officers. Dave's sister, dementia specialist Jennifer Carson of University of Nevada-Reno, is a long-distance care partner. They share their reflections on what they've learned.

When Ray Arand was diagnosed with dementia, he was very clear about one thing: he wanted to remain at home until the end of his life. His children, Dave and Jennifer, were determined to help him achieve that goal.

"We're a working-class family who couldn't afford memory care even if we liked that model," says Jennifer. "The way we're working together to handle this has been successful."

As Ray's need for in-home help grew, his ability to pay for it shrank. That's when Dave came up with a creative plan. He and his wife and kids already lived in the same neighborhood as his father. Why not live together?

"He was having care partners come to his house several hours a day," Dave says. "It was not quite enough. We realized he's got a four-bedroom house, maybe we should combine households, and have my family move in with him. We bought his house, and he set aside the money to pay for his care." The move itself was challenging, as they combined their belongings. Some of their things are still in storage. Another recent challenge: Dave's work schedule was suddenly changed, making it harder for him to check in on his dad or to be there for dinner. Fortunately, Dave's wife, Katie, and teenage son, Tom, pitch in. Overall, the plan is working well.

Early on, after Ray's wife died and he was dealing not only with his grief but with a serious diabetes-related issue and his dementia, he named Dave as his power of attorney and Jennifer his medical power of attorney. In 2019, he made Dave a co-signer on his bank account and Dave began paying bills and managing the money. "Whenever we needed to make a significant financial decision, we made sure Dad was included," Dave says.

Perhaps even more important than the legal and financial power-sharing is their family culture of decision making. "We have always had family meetings around the kitchen table when we have something important to discuss," says Jennifer.

At one such family meeting, they made a commitment to shared decision making when it came to Ray's dementia. That was important both for Ray to not feel he was being stripped of his autonomy, but also for Dave and Jennifer's well-being. "My dad may feel fine about taking some kind of risk, but that same risk can make us feel quite anxious," says Jennifer. "Because my dad loves us, he has been willing to consider our feelings."

Among the important issues they have negotiated together: Ray's decision to give up driving, allowing Dave to safely store Ray's guns, sale of the house, and hiring paid care partners. "We always made sure that our dad was still the decision maker," says Jennifer. "Because of that, my dad chose wisely."

Ray's role in choosing his paid care partners (from the agency Home Instead) is a good example. He interviews potential care partners and decides who would be best. On one occasion when Ray had an uneasy feeling about someone, Dave asked the agency not to send them again. Not that there aren't challenges. When a favorite care partner had to take a leave of absence, it was hard for the agency to find replacements and Dave scrambled to figure out what to do. Like care partnering across the nation, there is a shortage of workers. "You need to build in redundancies and try to have a back-up plan," says Jennifer. "No plan works out perfectly."

Other Lessons the Family Has Learned

- **Share stories from others living with dementia.** Jennifer suggested Ray and Dave attend an online *Dementia Conversations* session with other care partners and people living with dementia. Jennifer co-hosts the free program every Monday with Chuck McClatchey, who has been living with Alzheimer's disease since 2014. "I thought my dad would appreciate meeting people who are living well with dementia and willing to share their experiences — people who are breaking the stigma of dementia. Prior to his diagnosis, my dad didn't really know anyone with dementia. His concept had been shaped by stories my mom and I would share after coming home from work at a nursing home decades ago.

  Ray came to the program once while visiting Jennifer at her home. Then months went by before he expressed an interest in joining the group again. When he did mention it, Dave helped his dad purchase his own tablet. As Ray developed more familiarity and comfort with the other participants, he started coming more often. Now he is a regular, Zooming in nearly every Monday to share his perspective in this supportive community. "It's good to know I'm not alone," Ray explains.

Jennifer adds: "The people who participate in *Dementia Conversations* are not Pollyannas. But they're taking us beyond tragedy as the only view of dementia. Yeah, it's hard, and you'll have obstacles, but you can still experience joy and beauty and happiness."

- **Include others on your support team.** Dave and Katie's household is a welcoming place for extended family, for their teenage son's friends, and for peers in law enforcement who have known Ray for years. Ray is not isolated. Jennifer has educated extended family, in particular her nephew, Tom, and his close friends, about providing positive dementia support.

- **Support each other.** Dave and Katie want to take their sons on a European vacation in November. Jennifer will come home to be with Ray so that Dave and his family can go with peace of mind. These types of changes in support are best when planned well in advance.

- **Create a binder of instructions.** Jennifer created two types of binders: one for direct-care partners (family and professionals) and one for neighbors, extended family, and friends. The one for direct-care partners includes the family's person-centered philosophy, and specific details about how Ray can have a smooth day in a calm environment.

  The other is more general, with a focus on communication and environmental supports, and how to respond if Ray is experiencing distress. In explaining her approach to living with dementia, Jennifer wrote: "People living with dementia are the genuine experts in the experience of dementia. As such, Dad's perspectives, wishes, and preferences should always be sought and respected in any decisions that affect his life. Just be sure to provide the information in a clear manner. Truly engaging my dad as a legitimate contributor to his own experience opens a world of possibilities."

- **Be open and honest with each other.** "One of the biggest things I can think of is the no-[b.s.] rule," says Dave. "Be honest with each other. When you're discussing what issues you're facing, be tactful, but don't dance around a problem. You have to face it head on and work through the problem together. It makes things easier in the long run."

Ultimately, says Jennifer, it's hard work. "But my own relationship with my dad has grown and been strengthened through this experience. We talk about really important things that before we never had cause to talk about. I feel honored that I get to support my dad, and he continues to support the family. It's changed quite a bit, but there's more reciprocity than ever before."



One Sister's Experience: 'You've Always Shown Me the Way'

Karen Gallant

Karen Gallant of Soquel, California, is the younger sister of Coille Hooven, who is living with Alzheimer's disease. Coille is a well-known porcelain artist whose work is exhibited nationally. Karen and Coille's mother also had dementia. After many years of living at home with her husband, Coille moved to a memory care center in Berkeley, and she is now in hospice there. Karen reflects on what the experience has been like for her.

I welcome the opportunity to talk about this not as a big tragedy but as a thing that is part of life. It's striking — when you say, "My sister has Alzheimer's," everybody's response — 100 percent — is "Oh, I'm so sorry." Early on, I'd say, "It's okay — I still really enjoy being with her." I felt I had to defend myself that it wasn't this awful thing.

Her dementia started at least eight years ago, when she said, "I think I've got what Mom had." I noticed that if I was going to have lunch with her, she'd open the door and be surprised to see me. We both saw something was going on. She went to her neurologist, and he said, "You have an excellent brain." Another year went by, and then they retested her and she was told she had early Alzheimer's. I remember distinctly talking to my sister about it, and she was so irritated at people's reactions. People were thinking she wasn't still *her*. She felt the problem wasn't that she was becoming less functional — it was people's reactions around her.

I'd say to my sister, "If you can't remember things, I'll remind you. Let's find things we enjoy together." She once told me, "It's kind of great I don't have to be responsible for things!" I would think of different things to do. We did art projects, we took walks. I had to stop counting on her to come visit me. She couldn't do that anymore.

With my mom, I didn't have the acceptance. I kept trying to fix things. When my sister was still able to go to a restaurant, I took her out and she ordered waffles with fried chicken. She would only eat with her hands. I was trying to nudge her to use a fork and knife, and she got very mad at me and said she knew how to eat. I realize that I was embarrassed by her. I should have just let her enjoy them and get messy and not worried about it.

The relationship began to change. I couldn't have the talks I used to be able to have with her. But it was clear we loved each other, and I still enjoyed being with her. She and her husband Peter kept doing things. There was a show [of her art] in New York that she really seemed to enjoy.

Peter told me I was part of the care team. I would regularly come up for the weekend so he could have a break, and I really enjoyed those times. Until she declined a little further and at one point, when Peter wasn't there, she got very anxious. She no longer felt safe with me. We tried that a couple of more times, but then he was the only person she would be with. I'd still come up for the day, but he had to be there.

Then I would do things that would irritate her. I had to up my skill level. It became a learning adventure. We were in new territory, and I wanted to figure out the best way to do it. It was kind of challenging. I did begin to feel like I was losing her. Then came the time when she didn't know who I was. Here's the funny thing. I felt more angry than anything. I felt something like, "Oh, she doesn't really care about me. It was always about HER!!" Deep family patterns. I was thinking "Doesn't she even appreciate me?" And then I see how selfish I'm being, not her!

It was confusing for me, because until this day she doesn't seem unhappy. I know who she is, and I still love her. I'm glad for that. It's not a relationship of peers anymore, but it's a relationship of love.

The move [to a memory care home] was very traumatic for the family. The first few days were tough. The lead-up to it was dreaded. It was a very tough decision, and it was a difficult transition for her too. I didn't see her until she'd been there for at least a month. By then the story had changed and it was working real well.

She's done well there. Even though she had 24–7 caregivers when she was at home, she was isolated. Here, it's a party. She gets animated by other people. These are other people who are in the same world she is. She is among her peers. Things are going on, and she's part of it. My sister was always a party person.

When I go see her now, her daughter is so loving. I see this as a wonderful way for Molly to experience a loving relationship with her mother. She's decorated my sister's room really nicely. It's not depressing to be there. They've got dogs at the home. The caregivers are so positive, and there are activities in the common room. My sister is not unhappy. It's the weirdest thing. It's not awful. It's curious. It boggles my mind what is going on in her brain. It's so mysterious.

Molly brought her some of the porcelain teacups that Coille made. My sister smiles and enjoys them so much. She knows who Molly is. When my brother went to visit, she seemed to know that he was somebody special.

The last time I visited, Molly and I talked for a while and we stroked her, and then it was time to go. I said, "Bye Coco, you've been a wonderful big sister, you've always shown me the way." She's showing me now how to do this, if it's my fate too.

It's the end of life. This is what happens to us. Some of us go quickly and some of us go slowly like this. It's facing old age. That's helping me.



A Husband's Reflection

Rushern Baker, Manual Guide

Being honest with people and asking for help

Rushern Baker served in Maryland's state legislature and was a two-term County Executive of Prince George's County. His late wife, Christa "Cis" Beverly, had been his political partner before being diagnosed with younger-onset Alzheimer's. After initially trying to keep her diagnosis private, the family went public as a way to reduce stigma and help others. From that point on, he brought Cis with him on the campaign trail he ran for his second term as County Executive. Cis died in 2021.

I grew more in the last 10 years than I ever had before.

We did everything together. We had a ball for a year. It really was what kept her going. In the morning we'd get up, get dressed, and I'd tell her, "You're going with me." She was never left at home by herself. It was stimulation. The worst thing was to leave her alone.

In the past, she was always charming, beautiful, tough. She was a grown up. No one would ever have called Cis "cute." But she was cute during that campaign. She was a funny, whimsical person then. It was great. It made us closer. Everyone loved her. And it was good for us as a family. We were blessed. Win or lose. When we won, even more so, she got a chance to fully embrace it and know it and understand we did this. She was there.

When people ask me to talk about what happened, it's always like "what a great job you did." Not really, I was not good, but you can learn from my mistakes. The biggest was,

you can't do this by yourself. Every day in the beginning was the best day you were going to have. It would get worse.

Ask for help. Once we went public, the world opened up. Her line [sorority] sisters who were concerned about her kicked into hyper gear. A whole network of people would come get her on Sundays, or if I was out, there was a group of people who were always there.

The local Alzheimer's Association was a blessing that I'd wished I'd tapped into in the very beginning. People said I should go to a support group, and I didn't — all bad mistakes. When I got desperate, I found through the Alzheimer's Association how I could help her brush her teeth. It was a support group right there. I wanted to be part of it.

> *Miss Cissy was tough. But she invested so much in me, even through her dementia. She would walk through her house and carry her degrees. And one day she said to me, "You don't have one of these." And I said, "No ma'am, I don't." And she turned to me and said, "Why not?" And I could not answer her. I want to tell Miss Cissy today I do have my degree. I have my bachelor's and I have my master's, and this is because of Miss Cissy saying, "Why not?"*
>
> **Sylvia Wilson, professional care partner, at the memorial service for Christa "Cis" Beverly**

There was one point when she thought everybody was the enemy. She didn't recognize our son. And then she didn't trust people and would lash out. She could tell when people were nervous around her. We went to our son's graduation, and she hit somebody with her umbrella. Then she'd look at me and start laughing.

What I say to folks is be honest with people, ask for help. I wish I could get this across. Because of stigma, everyone thinks their life is over. It isn't over. You need to find new ways to thrive.

If everybody is saying, "I feel so bad for you," it doesn't help me. You want somebody to say, "It's going to be tough, but you're going to have tough times in life no matter what. You know what you're dealing with and believe it or not, people have gotten through it."

The last five years she stopped talking, other than one or two words. Every now and then, she'd look at me and she'd say, "No, that's not right." It would be a moment of clarity.

Once I embraced that life would be different every day that I came home, it was a new normal. I never stopped having conversations about what I was doing during the day or asking for her opinion. A lot of times I could read it in her eyes.

I still took her everywhere. If I went to a ball game, then Cis was coming. I like classical music, and we'd go to concerts at University of Maryland. If you're uncomfortable with her being there, that's your problem.

You can make your life full and their life full and rich. It was that way until the very end. It does not have to be unhappy and unfulfilling, and it can be richer than you ever thought. She saved the best for the last 10 years. I grew more in the last 10 years than I ever had before — it forced me to listen to her. I had to pay attention.

7.6 Coping with Expressions of Distress

Caring about someone living with dementia can play havoc on your emotions. You can't visually see the brain changes to have a sense of what is happening or when there is a change. Most forms of dementia are degenerative, meaning that brain changes and impairments are not singular events but rather are ongoing and can occur without warning. These unknowns can cause you (and them) to feel frustrated, angry, upset, fearful, and fatigued among other emotions.

"If I have to do something — pay a bill, get the stuff ready for the taxes, clean the house — I need to be left alone or I can't concentrate, and I just lose patience. I feel bad for him, but I feel bad for me too," says Sheila Felsen, whose husband of 57 years has mixed dementia. She has tried signing him up for classes and support groups, but he tends to dominate the group. "He likes to be the center of attention, and he likes an audience. He's used to being

the person in charge — he had a lot of people working for him. So it's very hard for him. My heart goes out to him."

For most people living with dementia, the disease process eventually prevents them from verbally communicating their wants and needs. They can feel that no one is listening to them and that they can't fix what's bothering them, whether they're bored, or feel too cold or too warm, or simply want to take a walk in the fresh air. They may express their frustrations (often called "behaviors") in ways that are hurtful or scary or alarming to themselves and to those around them. Too often, especially in care settings, the response has been to sedate people to calm them down. Experienced care partners and professional experts say that most of the time, these expressions of distress can be eased by addressing the underlying cause. Rather than load people up with medications and the side effects they bring, care partners can become skilled at anticipating or figuring out what's upsetting and eliminating or solving the problem. (See *The Power Your Attitudes and Actions Can Have*, Section 7.7, page 391) This is hard work, but it will pay off for both of you.

Anne Ellett, a nurse practitioner who has worked for decades with people living with dementia in a variety of settings, has found that putting herself in the person's shoes is helpful. "When people are no longer able to use words and they get so frustrated and then they slap someone who's trying to help them, could we just consider that's a normal reaction to not being able to control your environment or to feeling threatened because they're not being listened to? The person who is banging on the door to get out — that's pretty normal behavior if any of us were locked in. Or the wandering — they're searching for something. They're looking for something familiar or comforting. I try to approach challenging behavior in that way."

Supporting Meaningful Engagement

Depending on the form of dementia, individuals can lose the cognitive ability to self-initiate activities and tasks. While it may appear that they are not interested in doing an activity or task, it is highly possible they don't know how to initiate it. Gently asking whether they need a little help getting started with something can be a caring way to support them without diminishing their self-worth.

Neural damage to the brain that impairs the ability to initiate activities can result in the individual becoming inactive and bored. Distressed behavior can signal that they need support to help get involved in an interesting activity or to go out. A physiological response triggers in the brain when a person is meaningfully engaged and emotionally connected. Naturally-produced brain chemicals, known as neurotransmitters, such as endorphins,

oxytocin, and serotonin, are released into the body. These produce good feelings and a sense of well-being.

The opposite can occur when people are not well supported emotionally. When an individual is bored, fearful, lonely, and inactive, the body produces different neurotransmitters, such as cortisol, adrenaline, and norepinephrine. These neurotransmitters serve as important protective measures when, for instance, a hand touches something hot, but they are not beneficial for everyday life. Anyone can learn to successfully support meaningful engagement with a little effort. The more you do it, the better you will get. Staying meaningfully engaged and emotionally connected are essential for well-being.

Skillful Communication

Individuals living with dementia often have trouble finding words and communicating verbally (expressive speech). Care partners often mistakenly think that if the individual has difficulty expressing themselves, they also don't understand what is said (receptive speech). This may not be true.

Here's how you can foster better communication:

- Stand in front of the individual at their eye level. Facial expressions and lip movements can be helpful.
- Slow down your speech so that what you're sharing can be processed by the brain.
- Ask how you can best support the person living with dementia when they can't find the right words. Would they prefer additional time to come up with the words? Word suggestions? Visual cues?
- Use short, simple sentences that are easier to process.
- Ask single questions rather than making a statement containing several questions.
- Be pleasant and relaxed when you speak. Your mood is contagious!

Empowering communication supports decision-making control and preserves dignity and personhood.

Give Yourself a Break

Sheila Felsen struggles with the constant demands she faces. As his condition worsens, her husband wants her by his side all the time. She worries about her own health. She has found that turning to others helps, including:

- **Paid caregivers** — even 15 hours a week, a few hours a visit, gives her some breathing room to complete tasks or get out of the house for a bit.
- **Support groups** — she is in a support group on Facebook for care partners of people living with dementia, where she's gotten great advice on practical things like purchasing supplies and problems with medications. "The most helpful was to find that some of the things he does now are normal. My husband will shove anything in his pockets — a gavel, my medicine. I learned this is very normal too."
- **Being with friends** — "My friends have been wonderful. I started a foody group, and we go out once a month to international restaurants. They always include my husband."

7.7 The Power Your Attitude and Actions Can Have



Pat Snyder, Contributor

Your attitude and actions can have a powerful effect on family life with a person living with dementia. Before you act, remember to recognize that the person living with dementia is not a problem. The person has a medical condition causing problems.

If the person living with dementia is doing something unexpected, likely they are not doing it on purpose. Their brain is malfunctioning. Just as you would not expect someone with a broken arm to lift a heavy object, you cannot expect someone with cognitive impairment to problem solve and do everything as they did before.

Generally, behavioral expressions are a response to what is happening in their environment or within themselves. This is the way for them to communicate their needs and concerns. If a behavioral expression is problematic, **be a detective**. Examine the events that led up to the problem. What might have triggered this?

When you try various approaches to helping, examine those events to figure out what made it better or what made it worse. This trial-and-error technique will guide you in ways to manage things in the future.

- **Respond to the situation.** When we are confronted with upsetting behavior from our loved ones, which of these choices puts us more in control of the situation? To respond to it or to react to it? Which one shows that we have done some homework and given some thought to better ways to deal with it? Which one is more proactive and likely to result in a better outcome? Responding puts you in a proactive position rather than a reactive one.

  There are some basic techniques that have worked for me most of the time.

> *Generally, behavioral expressions are a response to what is happening in their environment or within themselves. This is the way for them to communicate their needs and concerns.*

- **Trust your own instincts.** Instincts are those still quiet voices in you that move you to make choices. Others may say what they think you should do, but you know yourself and your loved one better than anyone. That often puts you in a position to instinctively know what to do.
- **Use the opposite emotion to neutralize a negative emotion.** For example, when your loved one is angry, try to be cool and collected. Ignore their words and respond to the underlying emotion. It truly is best to not react by arguing or becoming overly emotional yourself. When they are negative, you be positive. It is almost impossible to have an argument by yourself.
- **Sometimes just ignore what is happening and leave the room.** Say, "Oops! I forgot something." Then exit and take some deep breaths to reset.
- **Learn from what did not work.** Rather than wallowing in guilt, treat these events as opportunities where you learn what NOT to do. Your response or approach influences their reaction and mood. So how can you do it differently next time?
- **Allow yourself to fail then quickly forgive yourself.** Save your energy for the work of today. Making good memories right now in small moments is much better for you and everyone else in your story.
- **Everyone needs a place to vent when we get frustrated.** Trusted friends, support group, and Memory Café members can be good shoulders for you to express your

frustrations on. They understand that sometimes it's helpful for you as a primary care partner to vent. Don't be surprised if you find yourself laughing with them after venting.

- **Consider the effects of medications.** Sometimes expressions of distress are a result of infections, dehydration, blood pressure or blood sugar levels that are off, pain, or medication side effects or interactions. Consider whether a new medication or increase in a medication may be causing a problem. Many prescribed and over-the-counter medications can have behavioral side effects. Talk with your pharmacist about side effects and potential medication interaction issues. Regularly scheduling visits with your primary care physician and other specialists will keep you in close touch so health issues can be monitored.

Management Strategies

- **Use a problem-solving approach to identify the cause of what's going on and choose a strategy.** Define the behavior. What might be causing it? Is there a medical issue? Did something or someone trigger it? Is it disturbing to the person living with dementia? Some behavior does not cause them stress, so no intervention is needed — even if it is disturbing to you.

- **Stay calm and carry on.** Speak in a calm voice. Use reassuring words that fit the context. Keep your face composed and your body language relaxed. When John approached me one day in the doorway of our bathroom as I was brushing my teeth, held up his hands like claws and grimaced at me showing his teeth ... I looked at him, looked back at the mirror, made some comment about getting ready for bed, finished my teeth, and walked into our bedroom through another door. When I did not react, but stayed calm and relaxed, his agitated behavior evaporated into thin air. How you react can calm agitation.

- **Speak to those underlying emotions when you respond.** You may have to say you are sorry in many situations. It does not matter what reality is here. Just speak to the underlying feeling rather than reacting to whatever has just been said. Dementia specialist Teepa Snow recommends these ways to say, "I'm sorry."

  "I'm sorry …

  ... I was trying to help.

  ... I made you feel (emotion) angry, irritated, frustrated, sad, isolated…

  ... This is hard! (for both of us)."

- **Validation can be useful.** Another technique that can be helpful is validation. This means you meet them where they are emotionally to validate them. You can do this by repeating what they said or something close to it. Or you can speak directly to the emotion behind it by saying something like "That must feel awful." You are joining them. Stay calm.

- **Redirection can help.** When John said he was leaving me to go out West with his young care partner, I repeated his words calmly back to him and that affirmed what he had just said. This allowed me to move the conversation to a safer emotional place. I repeated "going out West" a couple of times. Then I got a faraway look in my eyes and said, "I remember when we took the kids out West and we hiked through the Narrows at Mt Zion Park, saw the Redwoods …" John got the same look on his face and said, "Yeah!" with contentment as he relaxed in his recliner. I quickly exited the room to "get some ice cream for us."

  You can say things like "I can see that you are upset. We are in this together." If they want to go home, say "What should we do at home?" Or "tell me about where you grew up." To redirect, you could say, "Let's go run some errands. I like it when you come with me."

- **Leave the room briefly.** I used this strategy a lot when John's behavior was causing me to feel stressed. I would make an excuse and leave the room, take some deep breaths, and say a quick "Help me, Lord" prayer, and reenter with a smile and often some treat for John. He almost always had reset by then, and could focus on my upbeat tone and whatever goodie I brought him.

- **Use gentle touch as a calming technique.** I massaged John's feet and legs a lot to soothe muscle cramps but also to comfort him. The lavender lotion I use relaxes me while it relaxes him. I placed a small amount on his neck and shoulders, so he can smell it. I stroked his face with affection. I wanted John to feel loved and valued. It seemed to reassure and help him stay calm.

- **Say "I love you" 10,000 times.** It brings comfort and security. It makes clear how much you value them. It strengthens their emotional memory. The more you say it, the more it grows within you. I believe that ... Love is the most powerful force in the universe. It is patient ... kind ... is not self-seeking ... is not easily angered ... and keeps no record of wrongs. It always protects ... always trusts ... always hopes ... always perseveres.

  That is the kind of power I strongly recommend that you tap into with your whole heart in this journey. And when you do, you may be surprised at who you are at the end of it. When you look back you just may find that you have left a legacy of strong love and kindness for your children and grandchildren to embrace as they journey through life. **Love ... is a powerful tool.**

7.8 Care Partner Sex and Intimacy



Emily Franke, MSW, LSW, Contributor

It is very common for care partners to find that taking on a caregiving role affects their desire for, or expression of, intimacy and sexuality in their relationship.

Try using *the 3 T's* framework — Talking, Time, Touching. (See *Intimacy and Sexuality*, Section 3.3, page 196)

- **Time:** Allowing more time for connection and putting less importance on a particular physical act or outcome (like orgasm)
- **Touch:** Emphasizing affectionate touch versus instrumental touch (for example: if you help someone bathe, you may turn instrumental touch like washing into affectionate touch like massage)
- **Talking:** Acknowledging and communicating about sexual and intimacy needs

Throughout any relationship seeking consent for touch, both sexual and nonsexual, is important and likely as nuanced as your relationship. Consider how your partner's dementia diagnosis may affect their ability to understand and consent. There is no straightforward rule to follow regarding consent. Continue to check in with your partner regarding all types of touch (more talking!).

The effects of dementia can alter a person's sexual expression and behavior, and these changes may not be something a person can control or fully understand. Seeking support from a counselor, therapist, or support group is a productive way to explore your feelings and get tips for addressing the problems you encounter.

7.9 Creative Things to Try



Pat McHenry Sullivan, Contributor

John's total lack of shame around dementia freed me to talk to anyone, anywhere, about our needs and dreams. This led to wonderful opportunities including:

- Meeting a fellow attendee at a talk on dementia who told me of a research program at University of California, Davis, Alzheimer's Disease Center–East Bay in Walnut Creek which gave John a free, thorough assessment and diagnosis of his dementia, then a free 18-month thorough follow-up.
- The resources provided by the neurologists at UC Davis led us to many groups where people shared methods for dealing with different aspects of dementia.
- Each bit of research led to others, while friends and families offered their own ideas and support.
- John and I discussed and chose how to use these resources together. Gradually we discovered that anything that supports a rich life is likely to support dementia and vice versa.

We'll forever be grateful to friends Marilyn Flower and Siddika Angle for inviting John to join them for improv classes at Oakland, California's world-renowned training for seniors in the performing arts, Stagebridge (*stagebridge.org*). Their enthusiasm for Stagebridge convinced him to try it.

Improv has become integral to our lives. It guides us through John's times of confusion and my being overwhelmed as a care partner, household administrator, and a working writer/speaker.

He came home standing taller, more confident, and committed to ongoing improv training. That was five years ago. He would still be doing improv at Stagebridge but for the pandemic lockdown. He'd be returning, but we are now moving to Virginia, where we will get superb family support.

Improv has become integral to our lives. It guides us through John's times of confusion and my being overwhelmed as a care partner, household administrator, and a working writer/speaker.

We've even learned how to have fun letting go of frustrations and anger together and individually by fighting in gibberish or singing scat-style like his beloved Louis Armstrong and Ella Fitzgerald.

Imagine: what would our life be like if stigma or the tragedy narrative had kept Siddika and Marilyn from suggesting that improv would be fun for John? What does it cost you when stigma or shame prevent you from sharing your needs and dreams with people? How do you win when you live — even for a short time — beyond shame or stigma?

What illusions or feelings of shame do you have around care partnering? How can you best accept and bless who you are now so that you and your partner can thrive?

With creativity, vision, and planning, almost anything that helps us thrive as humans can help us thrive as humans with dementia.

Until recently, almost all dementia caring activities were based on the medical model. Today, body/mind/spirit and creativity work are rapidly expanding the opportunities for people living with dementia and their care partners.

This word cloud shows just a few of the modes, practices, and attitudes that are contributing to a new dementia world based on making thriving the new norm.



Every practice or group mentioned in this essay used one or more of the approaches above, plus others.

When you look at this model, what surprises you? Which of the words makes you want to learn about the concepts or resources behind them? What would you add if you made your own word cloud of possibilities?

The following are a few examples of our favorite practices based on seeing ourselves and each other more clearly, bringing what we've learned from research into our lives, and becoming creative. Throughout this Manual are many other resources you can adapt to your particular thriving dreams.

Every practice, resource, tip, or ally is presented as a starting point for your own exploration and creativity. Feel free to copy what we've done or allow ideas here to be a catalyst for your own creativity.

Above all, let your mind be open to new possibilities. Then as you explore an idea, imagine how it might work for you. Use whatever visioning and planning skills you already have or get the help of others who have those skills. Then discern what's most likely to be right for you. Enjoy!

Finding Your Best Resources and Allies Starts with Research

Research is curiosity in action. By research, we don't mean using the scientific method, but learning about topics that will help us live more fully. If you don't yet know how to do research, your first project may start by listing basic questions (these can be for you or your partner or both) like:

- What do I know about dementia?
- What really matters to me, and how do I want to make the best of the rest of my life?
- What else do I need to know so I can handle this specific challenge or dream?
- Who can help me, and how can I contact them?

A good place to start is with your local librarian and social workers. Ask your health plan or local dementia organization to refer you to a social worker. One social worker found us a $1,000 respite grant to hire an art tutor for John. That freed me up and delighted him for many hours. Here are some of the resources that we found helpful:

- Websites for Dementia Action Alliance and Dementia Mentors are great sources, including events for your loved one or yourself, and stories, videos, and other

resources about how to thrive with dementia. Visit: *daanow.org* and *dementiamentors.org*

- The Alzheimer's Foundation of America is an excellent information, resources, and fundraising site for dementias of all kinds. Their 24/7 National Tollfree Helpline, 866-232-8484, is a well-staffed superb source for referrals to elder care law attorneys or social workers who can handle tough challenges. Visit: *alzfdn.org*

- Re-Imagining Dementia, A Creative Coalition for Justice is a resource for those who want to transform the tragedy narrative through laughter, play, arts, and social therapy for the benefit of both of you. The site is filled with poetry, articles, photography, and other creative expressions. Visit: *www.reimaginingdementia.com*

In the 2019 Washington Post article *Changing the Tragedy Narrative: Why a Growing Camp is Promoting a More Joyful Approach to Alzheimer's* by Tara Bahrampour, Mary Fridley of the East Side Institute notes that "Dementia is enormously painful, but I truly believe it is an opportunity, if people so choose, to be improvisational, to be silly, to play, to free ourselves from the constraints of truth and knowing and assumptions." We have certainly found that to be true.

Resources for you as a care partner: education, training, help with specific challenges, and self-care.

Pre-pandemic, most assisted living and memory care homes in our area marketed their services by providing free programs, often by leaders in the dementia field. So did many senior centers and Village Movement groups (*vtvnetwork.org*). Today, even as many groups re-open, many will continue to offer programs via Zoom, so you can access educational resources anywhere you live.

Other suggested training and educational resources:

- Pat Snyder, a care partner educator based in North Carolina who contributed two of the essays in this Section of the Manual, offers a YouTube Channel filled with her insights and those of colleagues and medical experts on Lewy body and other forms of dementia. Visit: *www.youtube.com/channel/UCrjzZYVyeopBjaslMmCLH3g*

- Teepa Snow's newsletters, Instagram, and videos all promote her Positive Approach to Care as well as paid training for individuals and companies that care for people living with dementia. Check out free webinars and other training possibilities and get on her email newsletter at: *www.teepasnow.com*. Look also for the fun Brain Café which you and your partner can enjoy together. Then there's her wonderful YouTube Channel at: *www.youtube.com/channel/UCSXrEX7LkWOmfTaV6u1C7wQ*

- HFC, formerly Hilarity for Charity, was founded in 2012 by actors and filmmakers Seth Rogan and Lauren Miller Rogan. With the help of friends, they offer comedy sessions, with the intent of erasing stigma, bringing younger people into awareness of the disease, and raising funds for research and care partner support. Today they also provide regular free support groups and webinars at: *wearehfc.org*
- Family Caregiver Alliance offers both national and regional services, online and in-person. They have a collection of videos of caregiving tips and self-care, plus links to research stories and clinical trials, some of which may offer compensation. Visit: *www.caregiver.org*
- Neighborhood resources, such as local listservs, are good sources of allies, resources, and events. They could help you get a free walker or give one away, build a support team, or find a support group.

Resources you can use together

- Art Is ... In, free weekly or bi-weekly art lessons for persons living with dementia and their care partners to use together, with free art supplies, poetry to discuss, and questions. Sponsored by the Center for Comprehensive Care and Research for Memory Disorders at the University of Chicago Medicine in partnership with GoldMind Arts. Visit: *thememorycenter.uchicago.edu/artisin/*
- Moving Together Senior Health's research study incorporates the Feldenkrais Method, a type of body work; mindfulness meditation; and music to increase cognitive capabilities. It's part of a larger program at Together Senior Health that offers ongoing movement programs. For information on the research program, visit: *www.togetherseniorhealth.com/our-programs*
- Many activities of DAA and other groups can be done together, especially the ones related to spirituality, arts, and educational programs.

Here are some of the rituals and activities John and I invented or adapted that you may enjoy:

- Start your day with a song, such as "We All Stand Together," by Paul McCartney and the Frog Chorus. Currently, John sings this as soon as he hears me getting up. Visit: *www.youtube.com/watch?v=gVfaf43W9cM*
- Follow your morning song with your statement of purpose, e.g., "Today I choose to find more joy in surprising places or activities."

- End your day with at least three expressions of gratitude. This prepares you for relaxed sleep and affirms what's good in your lives. This is the best antidote I know for busting stress, burnout, or exhaustion.
- Grieve as you go, by naming your small losses, then claiming what they mean to you. This normally leads to creative ideas and new hope.
- Do any kind of art and movement together. Our latest fun is to put on classical music and act like symphony conductors with exaggerated body and eye movements. Great for transforming stuffiness, frustration, and tiredness.
- One of you talks gibberish; the other translates.
- Watch videos of beautiful places on Share Care Videos through Firefox and other TV providers. As we watch, relaxing visual affirmations often flow freely. Birds fly tension away, tropical fish swim away with our worries. Wide vistas expand our vision, waterfalls cleanse our brain.

The Best Laid Plans of Care Partners Often Go Awry

Critical factors for John's and my ability to thrive much of the time are our years of spiritual practice and my decades of stress release (not just management!) practices, mixed with the ability to laugh at ourselves and with each other. These habits help sustain us in tough times that inevitably make the job of care partnering harder than normal.

That's true, even when Super Bad Chap (John's joke name for dementia so we can get mad at his condition, not each other) seems determined to send us back to Doom, Gloom, and Tragedy Land for his own amusement.

It's true: we can't control our experiences with dementia any more than we can stop or start the ocean tides. But we can trade thoughts of doom, gloom, tragedy, or stigma for empowering insights from our imagination, blessings, curiosity, role models, and other wisdom sources. As we change our thoughts, we can change our actions, which can lead to another day of thriving with dementia. Even when times are unexpectedly difficult.

7.10 What's Your Plan B?

Whether or not you or someone you care for and support is living with dementia, it's good to have a Plan B for your future. Most Americans want to stay in their own homes forever, but that is not always possible.

"Whether or not you can remain at home depends on family and financial resources," says dementia specialist Joanne Rader RN. "Some states will pay family members rather than have someone moved to an expensive care facility. It also depends a lot on the care partner. Some can make the shift to full-time care partnering, and some cannot. I think everyone should develop a Plan B because life is unpredictable."

For starters, your home might be more difficult to manage as physical needs change. A flight of stairs may be great for exercise now but may become dangerous as vision and spatial perception shifts. It's a good idea to have an occupational therapist or aging-in-place expert walk through your home with an eye towards safety and comfort. (See *Living Safely in Your Home*, Sections 3.5, page 210; and *Supportive Home Modifications*, Section 4.7, page 245.)

In addition to thinking about your home setting, consider if you will be able to provide caring support to your family member 24/7 as the disease progresses. As you consider how you might get help, a first step is to look at your finances. Is there enough to pay for home care, and if so, for how many hours a week/month? What type of care might you need? According to Homecare.org, 10 hours or so a week of companion care averages $1,100 or so a month, and round-the-clock home health care averages more than $17,000 a month. Assume that care needs are likely to increase over time. Visit: *www.homecare.org/the-cost-of-24-7-in-home-care/*

Most communities have adult day programs that can provide the care partner with respite and the person living with dementia a chance to be around other people. Programs, which average $95 a day (or less if you qualify), typically include meals, transportation, social activities, and exercise. This can be a good option. Contact your local area agency on aging to learn more about what day programs are available in your area.

At some point, you may feel you can't manage at home, and you may consider a long-term care community. "Making that transition from caring for somebody at home to placing their care with someone else can be so painful," says Kim McRae of the Culture Change Network of Georgia. "People describe it as the most difficult thing in their life. It feels like they're choosing to let that person down, but too many times I've seen care partners continue to care by themselves or with limited help until they're so exhausted that they have health problems."

Before that day comes, Anne Ellett says, you need to ask yourself, "Is this home environment really going to work when this person maybe isn't mobile anymore, maybe can't get to the bathroom by themselves, when the person gets anxious and wants to leave? What is our plan

and what needs might there be? I encourage people to go out and visit local residential care options even if they have absolutely no intention of moving someone there. What if there is an emergency or the person has to go to the hospital, and the doctor says they can't go back home? If you don't have prior knowledge of options, then you're going to make that decision blind. If nothing else, you might need some other resources that the places have. Maybe they have a day program. You might find one that might be suitable for occasional respite care."

> *Families need not just someone on the other end of the computer. There are studies that show the value of in-person family education groups. Being able to be in community with people who are going through what you are. You can laugh, cry, scream, and learn from each other.*
>
> **Pam Brandon, founder of Age-U-Cate Training Institute**



Often care partners put off planning for a potential move, either because of the cost or because they don't want to upset the person living with dementia. Ask people you know or hire a geriatric care manager (also called aging life care specialist) to recommend a few assisted living or other care communities that are well regarded. Contact the communities and ask if you can come for lunch and a tour, ideally with your family member. Get a sense of the environment and how residents there seem. For more information, visit the National Consumer Voice for Quality Long-Term Care. They have great resources for family members.

And remember, once people have settled in, the move may actually be an improvement. Don't see it as a failure on your part. Sometimes the person living with dementia thrives when they are less isolated in their own home. Moving to a community with more activity and connections may be a good alternative.

SUGGESTED RESOURCES

Books

Bell, V. and Troxel, D., (2012). *A Dignified Life — The Best Friends Approach to Alzheimer's Care.* Health Professions Press.

Brackey, J. 2016. *Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers.* (5th edition). Purdue University Press.

Snyder, P. (2012). *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease.*

Publications

CaringKind, "Finding Comfort: Living with Advanced Dementia in Residential Care," 2022.

Emmons, R., (2013). "How gratitude can help you through hard times," Greater Good, University of California, Berkeley.

Websites

SPECAL® Method is based on an innovative way of understanding dementia from the point of view of the person with the condition	*contenteddementiatrust.org*
The Consumer Voice is an organization representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves	*theconsumervoice.org*

SUPPORT
Demetia Action Alliance
www.daanow.org/donate

SECTION 8: Learning About MCI and Dementia

Many people do not get diagnosed until they are experiencing moderate symptoms. Delaying diagnosis until this point limits the opportunities for proactive actions to slow or delay progression of symptoms.

Sherrie All, PhD, Contributor



Information detailing the types, risk factors, symptoms, diagnostic procedures, and more of Mild Cognitive Impairment (MCI) and dementia is provided here by trusted sources in the United States and beyond.

Explore Section 8 and learn more about:

- Mild Cognitive Impairment
- Alzheimer's Disease
- Vascular Dementia
- Lewy Body Dementia
- Frontotemporal Dementia (FTD)
- Mixed Dementia
- Dementia Due To Other Diseases And Conditions

8.1 What is Mild Cognitive Impairment?

Mild cognitive impairment (MCI) is a condition that causes some problems with cognitive abilities, such as memory or math. The cognitive symptoms are not sufficient to interfere significantly with daily life. Most people experience a gradual decline in mental abilities as they age. In the case of MCI, the decline in cognitive abilities is greater than that of normal aging. It is common in aging, for example, to pause at times to remember directions or words. It is not common, however, to lose things often, forget to go to events or appointments, or have more trouble coming up with words than other people of the same age.

An estimated 5 to 20 percent of people 65 and older are living with MCI. It is not a form of dementia, although a person living with MCI is more likely to develop dementia. Many people who are diagnosed with MCI use this as an opportunity to improve their lifestyle. There are many things a person can do to help reduce their chances of MCI progressing to dementia (see *Pillars of Well-Being*, Section 2.2, page 114).

Symptoms of MCI

People who have MCI do not experience personality or other behavioral changes that are characteristic of dementia. Signs of MCI can include:

- Memory — losing things often, forgetting to go to an event or appointment
- Reasoning, planning, or problem-solving — struggling with thinking things through
- Attention — being very easily distracted
- Language — taking much longer coming up with words than other people of the same age
- Visual depth perception — struggling to interpret an object in three dimensions, judge distances, or navigate stairs

For a person living with MCI, these cognitive changes may cause minor problems or may require help with more demanding daily tasks, such as paying bills, managing medication, and driving. MCI does not cause major problems with everyday living activities, such as shopping, preparing meals, taking care of a pet, and doing laundry. If there is a significant impact on everyday activities, this may suggest something other than MCI is happening.

Types of MCI

There are two types of MCI based on the cognitive areas affected: amnestic MCI which primarily affects memory; and non-amnestic MCI which affects other cognitive abilities such as language, reasoning, and attention. Research suggests that amnestic MCI is about twice as common as non-amnestic MCI. Symptoms are not severe in either type, but the symptoms can be upsetting and disruptive.

Diagnosing MCI

MCI is usually diagnosed by similar testing methods used for dementia. The diagnostic process begins with a comprehensive medical history, including what medications are being taken and a discussion about the types of cognitive changes being experienced, and any other relevant information. This is generally followed by a physical examination and blood tests to rule out other causes of cognitive changes such as depression, stress, medication side effects or interactions, or a nutritional deficiency.

If other causes have been ruled out, general tests for cognitive function are then conducted. Not all physicians are knowledgeable about cognitive conditions and may refer you to a neurologist or a neuropsychologist for the cognitive testing.

Managing MCI

There is no standard treatment or approved medication for MCI, but there are things a person can do to keep healthy and manage changes in cognition. The following are some recommendations:

- Follow a daily routine
- Use memory tools such as calendars, to-do lists, and notes to yourself
- Put commonly used objects in the same place each day

- ✦ Learn a new skill
- ✦ Volunteer in your community, at a school, or at your place of worship
- ✦ Spend time with friends and family
- ✦ Get enough sleep, generally seven to eight hours each night
- ✦ Exercise and eat well
- ✦ Don’t drink a lot of alcohol
- ✦ Get help if you feel depressed for weeks at a time

Because MCI may be an early sign of more serious memory problems, it’s important to see a doctor or specialist every six to 12 months. A doctor can help track changes in memory and thinking skills over time. It is helpful to keep a record of cognitive changes you experience and when you experience the changes.

People living with MCI might also consider participating in clinical trials or studies. Clinical trials are research studies that help test if a treatment, like a new drug, is safe and effective in people. To find out more about participating in clinical trials for people with cognitive changes, call the Alzheimer’s and Related Dementias Education and Referral (ADEAR) Center at 1–800–438–4380.

Does MCI Lead to Dementia?

According to the National Institute on Aging, researchers have found that more people living with MCI than those without it go on to develop a form of dementia. An estimated 10 to 20 percent of people age 65 or older living with MCI develop dementia over a one-year period. However, not everyone who has MCI develops dementia. In many cases, the symptoms of MCI may stay the same or even improve. Research suggests that genetic factors may play a role in who will develop MCI, as they do with dementia. Studies are underway to learn why some people living with MCI progress to dementia and others do not.

8.2 Dementia

This Manual is inclusive for people who are experiencing some cognitive changes, have been diagnosed with mild cognitive impairment, or who have been diagnosed with a form of dementia. Instead of writing cognitive impairment/dementia throughout the Manual, we use the term "dementia" for brevity to mean any type of cognitive change.

There are some excellent online sources for information about dementia. This section includes, with permission, information about dementia from a variety of trusted sources. These sources are a good place to start if you have questions about your condition and up-to-date research.

Dementia is a degeneration of the brain that causes a progressive decline in people's ability to think, reason, make decisions, communicate, and remember. Their personality, behavior, and mood can also be affected. Everyone's experience of dementia is unique, and the progression of the condition varies. Some symptoms are more likely to occur with certain types of dementia.

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https://my.clevelandclinic.org/health/diseases/9170-dementia

Does Memory Loss Mean Dementia is Starting?

One common misbelief about memory loss is that it always means you or a loved one has dementia. There are many causes of memory loss. Memory loss alone doesn't necessarily confirm a diagnosis of dementia.

It's also true that some memory changes are normal as people age (some neurons in your brain naturally die as we age). However, this type of memory loss isn't functionally disabling, meaning it doesn't interfere with daily life.

Dementia interferes with your ability to function. Dementia isn't forgetting where you left your keys. A person living with dementia can have situations like forgetting what keys are used for. Dementia is not a normal part of aging.

Who Gets Dementia?

Dementia is considered a late-life disease because it tends to develop mostly in people who are older. About five to eight percent of all people over the age of 65 have some form of dementia, and this number doubles every five years above that age. It's estimated that as many as half of people 85 years of age and older are living with dementia.

The number of people aged 65 and older who have Alzheimer's disease and related dementias by race is:

- Blacks: 14%
- Hispanics: 12%
- Non-Hispanic whites: 10%
- American Indian and Alaska Natives: 9%
- Asian and Pacific Islanders: 8%

How Common is Dementia?

The U.S. Centers for Disease Control and Prevention (CDC) estimate that five million U.S. adults aged 65 or older have Alzheimer's and related dementia. By 2060, the CDC projects that about 14 million people will be living with dementia, which is about 3.3 percent of the population.

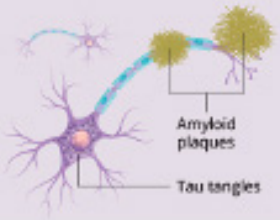
Understanding Different Types of Dementia

As we age, it's normal to lose some neurons in the brain. People living with dementia, however, experience far greater loss. Many neurons stop working, lose connections with other brain cells, and eventually die. At first, symptoms can be mild, but they get worse over time. Read on to learn more about four different types of dementia.



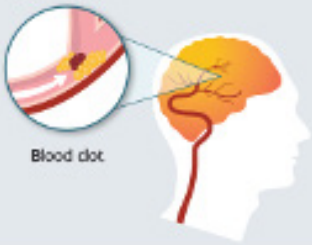
TYPES OF DEMENTIA

Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
What Is Happening in the Brain?*			
Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain.	Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes.	Abnormal deposits of the alpha-synuclein protein, called "Lewy bodies," affect the brain's chemical messengers.	Conditions, such as blood clots, disrupt blood flow in the brain.









*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.

Living with dementia can be challenging, but there are ways to manage it. To learn more about these types of dementia and other conditions that can cause dementia, visit **www.nia.nih.gov/health/what-is-dementia**.

NIH National Institute on Aging

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https://my.clevelandclinic.org/health/diseases/9170-dementia

Types of Primary Dementia

ALZHEIMER'S DISEASE

This is the most common type of dementia. Two abnormal proteins build up in your brain: tau and amyloid proteins. These proteins disrupt communication between nerve cells in your brain. Nerve cells die, starting in one area and spreading as more nerve cells die in other areas. Symptoms include short-term memory loss, confusion, personality and behavior changes. Trouble talking, remembering distant memories and issues with walking happen later in the disease. Alzheimer's disease mainly affects adults who are older — up to 10% of those over age 65 and about 50% of people older than 85 have the disease. Family history is an important risk factor. Approximately 60% to 80% of people with dementia have this type.

VASCULAR DEMENTIA

This is the second most common type of dementia. It's caused by conditions such as *strokes* or *atherosclerosis*, which block and damage *blood vessels* in your brain. Symptoms include memory problems, confusion and trouble concentrating and completing tasks. The decline may appear suddenly (following a major stroke) or in steps (following a series of *mini strokes*). Risk factors include *high blood pressure*, *diabetes* and *high cholesterol levels*. About 15% to 25% of people with dementia have vascular dementia.

LEWY BODY DEMENTIA

This condition involves the buildup of clumps of proteins — called Lewy bodies — in your brain's nerve cells. Lewy bodies damage nerve cells. Symptoms include movement and balance problems, changes in sleep patterns, memory loss, planning and problem-solving difficulties, and visual hallucinations and delusions. About 5% to 10% of dementias are Lewy Body dementia.

FRONTOTEMPORAL DEMENTIA (FTD)

This dementia results from damage to the *frontal and temporal lobes* of your brain. The damage is caused by the buildup of abnormal proteins in these areas. It causes changes in social behavior, personality, and/or loss of language skills

(speaking, understanding or forgetting the meaning of common words) or motor coordination. FTD is a common cause of early dementia, often occurring in people between the ages of 45 and 64. Between 5% and 6% of all dementias are FTD.

MIXED DEMENTIA

This is a combination of two or more types of dementia. The most common combination is Alzheimer's disease with vascular dementia. It's most common in people 80 years of age and over. It's often hard to diagnose because symptoms of one dementia may be more obvious and/or many symptoms of each type overlap. The decline is faster in people who have mixed dementia compared with those who only have one type.

Dementia Due to Other Diseases and Conditions

HUNTINGTON'S DISEASE

A single defective gene causes this brain disorder. The disease causes a breakdown in your brain's nerve cells, which causes body movement control problems, as well as thinking, decision-making and memory trouble, and personality changes.

PARKINSON'S DISEASE

Many people in the later stages of Parkinson's disease develop dementia. Symptoms include trouble with thinking and memory, hallucinations and delusions, depression and trouble with speech.

CREUTZFELDT-JAKOB DISEASE

This rare infective brain disease affects about only 1 in 1 million people. An abnormal protein in your brain called prions causes the disease. These prions clump together and cause nerve cell death in your brain. Symptoms include problems with thinking, memory, communication, planning and/or judgment, confusion, behavior changes, agitation and depression.

WERNICKE-KORSAKOFF SYNDROME

This brain disorder is caused by a severe *thiamine (vitamin B1) deficiency*. This can result in bleeding in key areas related to memory in your brain. It's most commonly caused by *alcohol use disorder* but can also be due to malnutrition and chronic infection. Symptoms include *double vision*, loss of muscle

coordination, and difficulty processing information, learning new skills and remembering things.

TRAUMATIC BRAIN INJURY

Repeated blows to your head can cause this injury. It's most often seen in football players, boxers, soldiers and people who've had a vehicle accident. Dementia symptoms, which appear years later, include memory loss, behavior or mood changes, slurred speech and headaches.

Dementias Due to Reversible Causes

Some conditions can cause dementia-like symptoms that can be reversed with treatment, including:

NORMAL PRESSURE HYDROCEPHALUS (NPH)

This condition happens when cerebrospinal fluid (CSF) builds up in your brain's spaces (ventricles). The excess buildup harms your brain. NPH can be caused by a brain infection, brain injury, brain bleed or previous brain surgery. Symptoms include poor balance, forgetfulness, trouble paying attention, mood swings, frequent falls and loss of bladder control. Your healthcare provider can drain excess fluid through the surgical placement of a shunt (tube).

VITAMIN DEFICIENCY

Not getting enough vitamin B1, B6, B12 and vitamin E in your diet can cause dementia-like symptoms.

INFECTIONS

Infections that can cause dementia-like symptoms include *HIV infection*, *syphilis* and *Lyme disease*. Symptoms reported with *COVID-19* infection include *"brain fog"* and acute delirium. Because of the inflammation and stroke risk seen with COVID-19 infection, both short- and long-term cognitive effects are being investigated. *Urinary tract infections (UTIs)* and infections in your lungs in the elderly can also result in dementia-like symptoms. Other central *nervous system* infections and brain infections caused by fungi, bacteria and parasites can also cause cognitive symptoms.

METABOLIC AND ENDOCRINE CONDITIONS

Conditions that can mimic dementia include *Addison's disease*, *Cushing's disease*, low blood sugar (*hypoglycemia*) exposure to heavy metals (like arsenic or mercury), high calcium levels (*hypercalcemia*, often due to hyperparathyroidism), *liver cirrhosis* and thyroid problems.

MEDICATION SIDE EFFECTS

Some medications, in some people, can mimic dementia symptoms. These include sleeping pills, anti-anxiety drugs, antidepressants, anti-seizure drugs, antiparkinson drugs, nonbenzodiazepine sedatives, narcotic pain relievers, statins and others. Ask your healthcare provider to review your medications if you have any dementia-like symptoms.

OTHER CAUSES

Other causes of dementia-like symptoms include *brain tumors* and *subdural hematomas* (brain bleeds between your brain's surface and the covering over your brain).

8.3 What's the Difference Between Dementia and Alzheimer's Disease?

Dementia is a description of the state of a person's mental function and not a specific disease. Dementia is an "umbrella term" describing cognitive decline that's severe enough to interfere with daily living.

There are many underlying causes of dementia, including Alzheimer's disease and Parkinson's disease. Alzheimer's disease is the most common underlying cause of dementia.



Making the Case for an Early Diagnosis

Sherrie All, PhD, Contributor

Sherrie is founder and owner of the Centers for Cognitive Wellness

Many people do not get diagnosed with dementia until they are experiencing moderate symptoms. Delaying diagnosis until this point limits the opportunities for proactive actions that could slow or delay progression of symptoms.

Your primary care physician, occupational or speech therapist, or other healthcare professional should be able to screen your cognition using a standardized cognitive screening tool like the Montreal Cognitive Assessment (MoCA) or St. Louis University Mental Status (SLUMS). **It is not recommended that you look for these tests on the internet or study up because that will only weaken test results.**

Unfortunately, many healthcare practitioners use ineffective cognitive screening tools. If your doctor only asks you six or so questions during your annual physical and gives you a clean bill of cognitive health, ask for a more detailed screening. The Mini-Mental Status Examination (MMSE) is generally outdated and often administered in an unstandardized way, plus it was never designed to be sensitive to mild cognitive impairment, so it is likely to miss early, potentially treatable changes. **If you are only asked to remember a list of three words and not five words, this is a sign of getting an incomplete cognitive screen test.**

It is not recommended that you look for these tests on the internet or study up because that will only weaken test results.

If you are seeing your healthcare provider specifically because you are experiencing cognitive changes, ask to be given the MoCA or SLUMS cognitive screening test. If your healthcare provider does not use these screening tests, ask to be referred to a specialist who conducts more thorough cognitive screens, such as a neuropsychologist or neurologist.

Diagnostic Process

Your doctor will first rule out conditions that can cause confusion and memory problems that are reversible, such as depression, stress, vitamin B-12 deficiency, medication reactions, or low levels of thyroid. A physical exam, thorough medical history, and blood work are done to rule out conditions that may be affecting your cognition. You will likely be given written tests and asked questions that in the past you would have answered easily but may now find challenging.

Thorough cognitive and neurological testing can take many hours and can be very tiring and humbling. The various testing is used to assess thinking, memory, problem solving, language and math skills, as well as balance, sensory response, and reflexes.

These tests are designed to be very sensitive. You will not get every answer right. While it may feel like you're not doing very well, you may be doing just fine. We have to push you beyond your capacity. If you think you got a question wrong, you may not have. And it's not a big deal if you did get it wrong. Don't ruminate on the last question, let it go. Focus on this next question.

Finding anything early, we have intervention tools and the intervention is meaningful at that point. The longer you are able to be independent and be proactive about your brain health, the better quality of life you'll have. Testing can be uncomfortable but it's really important.

In addition to cognitive tests, your doctor may order:

- An MRI to look for brain shrinkage or a brain tumor
- A spinal tap to look for biomarkers of Alzheimer's disease, called amyloid plaques and tau tangles
- A PET scan to differentiate frontotemporal or Lewy body dementia from Alzheimer's disease
- A sleep study if Lewy body dementia is suspected

If your healthcare provider does not use the MoCA or SLUMS screening tests, ask to be referred to a specialist who conducts more thorough cognitive screens, such as a neuropsychologist or neurologist.

Be sure to check whether Medicare or other insurance will pay for these tests before undergoing them.

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https://www.dementiauk.org/about-dementia/young-onset-dementia/what-is-young-onset-dementia/

8.4 Young Onset Dementia

Dementia is described as "young onset" when symptoms develop before the age of 65, usually between 30 to 65 years of age. It is also referred to as "early onset" or "working age" dementia, but these terms can cause confusion. "Early onset" can be interpreted as the *early stages* of dementia and "working age" is now less defined as retirement age is more flexible.

As dementia is frequently, and wrongly, thought of as a condition that is just associated with old age, the early symptoms of young onset dementia are not always recognized and may be attributed to other causes including depression, stress, menopause, physical health problems, and relationship issues. This can lead to a significant delay (on average four years) in getting an accurate diagnosis and access to appropriate support. This can have a negative impact on not just the person living with dementia's life but also the whole family.

How Does Young Onset Dementia Develop?

The early symptoms of young onset dementia may not be memory loss. Symptoms can differ from one person to another depending on the type of dementia a person has, and which parts of the brain it affects.

Dementias affecting the frontal and temporal lobes of the brain are more common in younger people so it is more likely that the early symptoms may include changes in:

- Personality
- Behavior
- Language
- Social functioning
- *Relationships* with others

- Activities of everyday living
- Motivation
- Mood (e.g., *depression*, *anxiety*)
- Concentration levels
- Decision making and problem solving
- Vision and spatial awareness

In addition, the person may not recognize the changes or may be reluctant to accept there is anything wrong when they are otherwise fit and well, and so put off visiting their doctor.

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https://www.alzint.org/about/risk-factors-risk-reduction/

8.5 Risk Factors for Dementia

There are many factors which have been linked to the development of dementia. Some are risk factors, while others appear to be predictive.

Risk factors are characteristics that appear to have some relationship to the development of a disease. If these risk factors are present, there is an increased chance, but not a certainty, that the disease will develop. For example, not everyone who smokes develops heart disease and not everyone with heart disease has been a smoker. However, smoking is a strong risk factor for heart disease.

Some risk factors can be modified, for example lowering blood pressure reduces the risk of a stroke. Other risk factors cannot be modified, such as age or family history.

The greatest risk factor for dementia is increasing age. Although age increases risk, dementia is not a normal part of aging.

We know there are more than 20 genes which affect a person's risk of developing dementia. The gene APOE was the first known to increase a person's risk of developing Alzheimer's disease, and it is still the strongest risk gene known. There are also genes which directly cause dementia, but these deterministic genes are rare — they are estimated to account for less than one percent of dementia cases and cause young-onset forms in which symptoms usually develop before the age of 60.



Women are more likely to develop Alzheimer's disease than men, even accounting for the fact that women live longer on average. The reasons for this are unclear.

Modifiable risk factors

Although we can't change our genes or stop aging, there are changes that we can make to reduce our risk of dementia, either lifestyle changes as individuals or wider changes across society. A growing body of research evidence exists for 12 potentially modifiable risk factors. We might prevent or delay up to 40 percent of cases of dementia, if we were able to modify all of the risk factors.

Although behavior change is difficult and some associations might not be causal, individuals have a huge potential to reduce their dementia risk. Many of the risk factors

are also shared with other non-communicable diseases such as heart disease, cancer, diabetes, and chronic respiratory diseases.

Keeping active, eating well, and engaging in social activities all promote good brain health and may reduce your risk of developing dementia. Keeping your heart healthy, including by avoiding smoking and excessive alcohol consumption, can lower your risk of dementia and other diseases too.

The following is a list of risk factors for dementia along with suggestions of how to counteract them and reduce risk.

PHYSICAL INACTIVITY

Regular physical activity is one of the best ways to reduce your risk of dementia. It's good for your heart, circulation, weight, and mental wellbeing. It is recommended that adults aim for either 150 minutes of moderate aerobic activity or 75 minutes of vigorous aerobic activity each week.

SMOKING

Smoking greatly increases your risk of developing dementia. You're also increasing your risk of other conditions, including type 2 diabetes, stroke, and lung and other cancers. It's never too late to quit — stopping smoking later in life also reduces the risk of dementia.

EXCESSIVE ALCOHOL CONSUMPTION

Alcohol misuse and drinking more than 21 drinks with alcohol in a week increase the risk of dementia. The harmful use of alcohol is a causal factor in more than 200 disease and injury conditions. There is a causal relationship between harmful use of alcohol and a range of mental and behavioral disorders, other non-communicable diseases as well as injuries.

AIR POLLUTION

A growing amount of research evidence shows that air pollution increases the risk of dementia. Policymakers should expedite improvements in air quality, particularly in areas with high air pollution.

HEAD INJURY

Head injuries are most commonly caused by car, motorcycle, and bicycle accidents; military exposures; boxing, football, hockey and other sports; firearms and violent assaults; and falls. Policymakers should use public health and other policy measures to reduce head injuries.

INFREQUENT SOCIAL CONTACT

It is well established that social connectedness reduces the risk of dementia. Social contact enhances cognitive reserve or encourages beneficial behaviors. There is not much evidence for any specific activity protecting against dementia. Joining a club or community group are good ways to stay socially active.

LESS EDUCATION

A low level of education in early life affects cognitive reserve and is one of the most significant risk factors for dementia. Policymakers should prioritize childhood education for all.

OBESITY

Particularly in mid-life, obesity is associated with an increased risk of dementia. Obesity is also associated with other non-communicable diseases and can generally be addressed through lifestyle changes such as diet and exercise.

HYPERTENSION

Hypertension (high blood pressure) in mid-life increases a person's risk of dementia, as well as causing other health problems. Medication for hypertension is the only known effective preventive medication for dementia.

DIABETES

Type 2 diabetes is a clear risk factor for development of future dementia. Whether any particular medication helps with this is unclear, but treatment of diabetes is important for other health reasons.

DEPRESSION

Depression is associated with dementia incidence. Depression is part of the prodrome of dementia (a symptom that occurs before the symptoms that are used for diagnosis). It is not clear to what extent dementia may be caused by depression or the reverse. In any case, it is important to manage and treat depression because it is associated with increased disability, physical illnesses, and worse outcomes for people living with dementia.

HEARING IMPAIRMENT

People with hearing loss have a significantly increased risk of dementia. Using hearing aids seems to reduce the risk. As hearing loss is one of the risk factors which affects the most people, addressing it could result in a large impact on the number of people developing dementia.

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https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447

8.6 Alzheimer's Disease

Memory

People with Alzheimer's disease may:

- Repeat statements and questions over and over.
- Forget conversations, appointments or events.
- Misplace items, often putting them in places that don't make sense.
- Get lost in places they used to know well.
- Forget the names of family members and everyday objects.
- Have trouble finding the right words, expressing thoughts or having

Thinking and reasoning

Alzheimer's disease causes trouble concentrating and thinking, especially about abstract concepts such as numbers. Doing more than one task at once is especially hard. It may be challenging to manage finances, balance checkbooks and pay bills on time.

Making judgments and decisions

Alzheimer's disease makes it hard to make sensible decisions and judgments. People with Alzheimer's disease may make poor choices in social settings or wear clothes for the wrong type of weather. Everyday problems may be hard to solve.

Planning and performing familiar tasks

Routine activities that involve completing steps in a certain order also can be hard for people with Alzheimer's disease. They may have trouble planning and cooking a meal or playing a favorite game. As Alzheimer's disease becomes advanced, people forget how to do basic tasks such as dressing and bathing.

Changes in personality and behavior

Symptoms may include:

- Depression.
- Loss of interest in activities.
- Social withdrawal.
- Mood swings.
- Not trusting others.
- Anger or aggression.
- Changes in sleeping habits.
- Wandering.
- Loss of inhibitions.
- Delusions, such as believing something has been stolen when it hasn't.

Preserved skills

Despite major changes to memory and skills, people with Alzheimer's disease are able to keep some skills even as symptoms get worse. These are known as preserved skills. They may include reading or listening to books, telling stories, sharing memories, singing, listening to music, dancing, drawing, or doing crafts.

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https://www.nia.nih.gov/health/frontotemporal-disorders/what-are-frontotemporal-disorders-causes-symptoms-and-treatment

Alzheimer's Disease Fact Sheet

Alzheimer's disease is a brain disorder that slowly destroys memory and thinking skills, and eventually, the ability to carry out the simplest tasks. In most people with Alzheimer's, symptoms first appear later in life. Estimates vary, but experts suggest that more than 6 million Americans, most of them age 65 or older, may have Alzheimer's.

Alzheimer's is currently ranked as the seventh leading cause of death in the United States and is the most common cause of dementia among older adults.

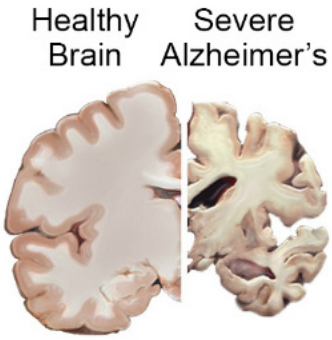
Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — and behavioral abilities to such an extent that it interferes with a person's daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for help with basic activities of daily living.

The causes of dementia can vary depending on the types of brain changes that may be taking place. Other forms of dementia include Lewy body dementia, frontotemporal disorders, and vascular dementia. It is common for people to have mixed dementia — a combination of two or more types of dementia. For example, some people have both Alzheimer's and vascular dementia.

Alzheimer's disease is named after Dr. Alois Alzheimer. In 1906, Dr. Alzheimer noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems, and unpredictable behavior. After she died, he examined her brain and found many abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary, or tau, tangles).

These plaques and tangles in the brain are still considered some of the main features of Alzheimer's. Another feature is the loss of connections between neurons in the brain. Neurons transmit messages between different parts of the brain, and from the brain to muscles and organs in the body.

How does Alzheimer's disease affect the brain?



Scientists continue to unravel the complex brain changes involved in Alzheimer's. Changes in the brain may begin a decade or more before symptoms appear. During this very early stage of Alzheimer's, toxic changes are taking place in the brain, including abnormal buildups of proteins that form amyloid plaques and tau tangles. Previously healthy neurons stop functioning, lose connections with other neurons, and die. Many other complex brain changes are thought to play a role in Alzheimer's as well.

The damage initially appears to take place in the hippocampus and the entorhinal cortex, which are parts of the brain that are essential in forming memories. As more neurons die, additional parts of the brain are affected and begin to shrink. By the final stage of Alzheimer's, damage is widespread and brain tissue has shrunk significantly.

Signs and symptoms of Alzheimer's disease

Memory problems are typically one of the first signs of cognitive impairment related to Alzheimer's. Some people with memory problems have a condition called mild cognitive impairment (MCI). With MCI, people have more memory problems than normal for their age, but their symptoms do not interfere with their everyday lives. Movement difficulties and problems with the sense of smell have also been linked to MCI. Older people with MCI are at greater risk for developing Alzheimer's, but not all of them do so. Some may even revert to normal cognition.

The first symptoms of Alzheimer's vary from person to person. For many, decline in nonmemory aspects of cognition, such as word finding, vision/spatial issues, and impaired reasoning or judgment may signal the very early stages of the disease. Researchers are studying biomarkers (biological signs of disease found in brain images, cerebrospinal fluid, and blood) to detect early changes in the brains of people with MCI and in cognitively normal people who may be at greater risk for Alzheimer's. More research is needed before these techniques can be used broadly and routinely to diagnose Alzheimer's in a health care provider's office.

Stages of Alzheimer's disease

Mild Alzheimer's disease

As Alzheimer's worsens, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes. People are often diagnosed in this stage.

Moderate Alzheimer's disease

In this stage, damage occurs in areas of the brain that control language, reasoning, conscious thought, and sensory processing, such as the ability to correctly detect sounds and smells. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may have hallucinations, delusions, and paranoia and may behave impulsively.

Severe Alzheimer's disease

Ultimately, plaques and tangles spread throughout the brain, and brain tissue shrinks significantly. People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end of life, the person may be in bed most or all of the time as the body shuts down.

What causes Alzheimer's disease?

In recent years, scientists have made tremendous progress in better understanding Alzheimer's and the momentum continues to grow. Still, scientists don't yet fully understand what causes Alzheimer's disease in most people. The causes probably include a combination of age-related changes in the brain, along with genetic, environmental, and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of developing Alzheimer's may differ from person to person.

The basics of Alzheimer's disease

Scientists are conducting studies to learn more about plaques, tangles, and other biological features of Alzheimer's. Advances in brain imaging techniques enable researchers to see the development and spread of abnormal amyloid and tau proteins in the living brain, as well as changes in brain structure and function. Scientists are also exploring the very earliest steps in the disease process by studying changes in the brain and body fluids that can be detected years before Alzheimer's symptoms appear. Findings from these studies will help improve our understanding of the causes of Alzheimer's and make diagnosis easier.

One of the great mysteries of Alzheimer's is why it largely affects older adults. Research on normal brain aging is exploring this question. For example, scientists are learning how age-related changes in the brain may harm neurons and affect other types of brain cells to contribute to Alzheimer's damage. These age-related changes include atrophy (shrinking) of certain parts of the brain, inflammation, blood vessel damage, production of unstable molecules called free radicals, and mitochondrial dysfunction (a breakdown of energy production within a cell).

Alzheimer's disease genetics

In most cases, Alzheimer's does not have a single genetic cause. Instead, it is likely influenced by multiple genes in combination with lifestyle and environmental factors. Changes in genes, called genetic variations, may increase or decrease a person's risk of developing the disease.

Scientists currently know of more than 80 genetic regions associated with Alzheimer's. Of the genetic variants associated with Alzheimer's so far, only three are known to cause the disease. Although it happens rarely, when someone inherits an altered version of one of these genes — APP, PSEN1, or PSEN2 — they will likely develop Alzheimer's before age 65 and sometimes much earlier.

People with Down syndrome also have a higher risk of developing Alzheimer's earlier in life. Down syndrome results from having an extra chromosome 21, which carries the APP gene that produces the amyloid precursor protein. Too much of this protein leads to build-up of beta-amyloid plaques in the brain. Estimates suggest that 50% or more of people living with Down syndrome will develop Alzheimer's with symptoms appearing in their 50s and 60s.

Another genetic variation, in the APOE gene, which has several forms, is known to influence the risk of Alzheimer's. Specifically, APOE ε4 increases a person's risk of

developing Alzheimer's and is also associated with developing Alzheimer's earlier in life for certain populations. APOE ε2 may provide some protection against Alzheimer's.

Changes in different genes, along with other biomedical, lifestyle, and environmental factors, play a role in potentially developing Alzheimer's. Still, it is never known for certain if any individual will or will not develop the disease.

For more about Alzheimer's genetics research, see NIA's *Alzheimer's Disease Genetics Fact Sheet*.

Health, environmental, and lifestyle factors

Research suggests that a host of factors beyond genetics may play a role in the development and course of Alzheimer's. There is a great deal of interest, for example, in the relationship between cognitive decline and vascular conditions, such as heart disease, stroke, and high blood pressure, as well as metabolic diseases, such as diabetes and obesity. Ongoing research will help us understand whether and how reducing risk factors for these conditions may also reduce the risk of Alzheimer's.

A nutritious diet, physical activity, social engagement, and mentally stimulating pursuits have all been associated with helping people stay healthy as they age. These factors might also help reduce the risk of cognitive decline and Alzheimer's. Researchers are testing some of these possibilities in clinical trials.

How is Alzheimer's disease diagnosed?

Doctors use several methods and tools to help determine whether a person who is having memory problems has Alzheimer's.

To diagnose Alzheimer's, doctors may:

- Ask the person and a family member or friend questions about overall health, use of prescription and over-the-counter medicines, diet, past medical problems, ability to carry out daily activities, and changes in behavior and personality.
- Conduct tests of memory, problem solving, attention, counting, and language.
- Order blood, urine, and other standard medical tests to help identify other possible causes of the problem.

- Administer tests to determine if depression or another mental health condition is causing or contributing to a person's symptoms.
- Collect cerebrospinal fluid via a spinal tap or order blood tests to measure the levels of proteins associated with Alzheimer's and related dementias.
- Perform brain scans, such as CT, MRI, or PET (positron emission tomography), to support an Alzheimer's diagnosis or to rule out other possible causes for symptoms.

These tests may be repeated to give doctors information about how the person's memory and other cognitive functions are changing over time.

People with memory and thinking concerns should talk to their doctor to find out whether their symptoms are due to Alzheimer's or to another cause, such as stroke, tumor, Parkinson's disease, sleep disturbances, side effects of medication, an infection, or another type of dementia. Some of these conditions may be treatable and, possibly, reversible.

If the diagnosis is Alzheimer's, beginning treatment as early as possible in the disease process may help preserve daily functioning for a while. An early diagnosis also helps families plan for the future. They can take care of financial and legal matters, address potential safety issues, learn about living arrangements, and develop support networks.

In addition, an early diagnosis provides people with more opportunities to participate in clinical trials or studies testing possible new treatments for Alzheimer's.

For more information, visit *How Is Alzheimer's Disease Diagnosed*?

How is Alzheimer's disease treated?

Alzheimer's is complex, and it is therefore unlikely that any one drug or other intervention will successfully treat it in all people living with the disease. In ongoing clinical trials, scientists are developing and testing several possible treatment interventions.

While there is currently no cure for Alzheimer's, medications are emerging to treat the progression of the disease by targeting its underlying causes. There are also medications that may temporarily improve or stabilize memory and thinking skills in some people and may help manage certain symptoms and behavioral problems.

Additionally, people with Alzheimer's also may experience sleeplessness, depression, anxiety, agitation, and other behavioral and psychological symptoms. Scientists continue

to research why these symptoms occur and are exploring new medications and non-drug strategies to manage them. Research shows that treating these symptoms may make people with Alzheimer's feel more comfortable and also help their caregivers. Antidepressants, antipsychotics, and anti-anxiety drugs may be helpful for some people with Alzheimer's, but experts agree that these medicines should be used only after other strategies to promote physical and emotional comfort, such as avoiding stressful situations, have been tried. It's important to talk with a doctor about what treatment will be most effective in your situation.

For more information, visit *How Is Alzheimer's Disease Treated*?

Support for families and Alzheimer's disease caregivers

Caring for a person with Alzheimer's can have significant physical, emotional, and financial costs. The demands of day-to-day care, changes in family roles, and decisions about placement in a care facility can be difficult. NIA supports efforts to evaluate programs, strategies, approaches, and other research to improve the quality of care and life for those living with dementia and their caregivers.

Becoming well-informed about the disease is one important long-term strategy. Programs that teach families about the various stages of Alzheimer's and about ways to deal with difficult behaviors and other caregiving challenges can help.

Good coping skills, a strong support network, and respite care are other things that may help caregivers handle the stress of caring for a loved one with Alzheimer's. For example, staying physically active provides physical and emotional benefits.

Some caregivers have found that joining a support group is a critical lifeline. These support groups enable caregivers to find respite, express concerns, share experiences, get tips, and receive emotional comfort. Many organizations sponsor in-person and online support groups, including groups for people with early-stage Alzheimer's and their families.

For more information, see *Alzheimer's Caregiving*.

For more information about Alzheimer's disease

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center
800-438-4380
adear@nia.nih.gov
www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Alzheimers.gov
www.alzheimers.gov

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

Eldercare Locator
800-677-1116
eldercarelocator@USAging.org
https://eldercare.acl.gov

MedlinePlus
National Library of Medicine
www.medlineplus.gov

Alzheimer's Association
800-272-3900
866-403-3073 (TTY)
info@alz.org
www.alz.org

Alzheimer's Foundation of America
866-232-8484
info@alzfdn.org
www.alzfdn.org

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Content reviewed: April 5, 2023

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https://alzheimer.ca/en/about-dementia/other-types-dementia/vascular-dementia

8.7 Vascular Dementia

How does **vascular dementia** happen?

- A network of blood vessels, called the vascular system, supplies the brain with oxygen. This network allows the brain to function properly.
- If these vessels are blocked, diseased or bleeding, blood is prevented from reaching the brain.
- With no oxygen and nutrients provided by the blood, the affected cells in the brain die, leading to dementia.

Researchers estimate that vascular dementia accounts for 15% to 25% of all dementia cases.

This can lead to **stroke** symptoms that may cause vascular dementia. Stroke symptoms may include paralysis and loss of speech. Read more about stroke below.

Types

Different kinds of conditions affecting the brain's blood supply can lead to different types of vascular dementia. Two common types are **subcortical dementia** and **cerebral amyloid angiopathy**.

SUBCORTICAL DEMENTIA

Subcortical dementia is caused by **small vessel disease**, where the small vessels in the brain become stiff and twisted. This results in reduced blood flow to the brain.

CEREBRAL AMYLOID ANGIOPATHY

Cerebral amyloid angiopathy happens when a protein called **amyloid** builds up in the brain blood vessels. Amyloid can form plaques, disrupting brain function. This often occurs with Alzheimer's disease.

Symptoms

The symptoms of vascular dementia are:

- Changes in the ability to make decisions, plan or organize, and
- Difficulties with movement, such as slow gait and poor balance.

Symptoms tend to appear slowly. Specific impairments may occur in steps, where abilities deteriorate, stabilize for a time and then decline again.

Diagnosis

There is no one specific test that can diagnose vascular dementia. If vascular dementia is suspected, your doctor will likely perform a number of physical and cognitive tests.

A combination of the physical and cognitive test results, along with a detailed medical history, will provide your doctor with the evidence she or he needs to make a diagnosis.

For more details about how dementia diagnosis processes often work, *visit our webpage about what to expect while getting your diagnosis*.

Risk factors

Note: Some content in this section has been adapted with permission from the Heart and Stroke Foundation's 2016 Stroke month report Mind the Connection.

STROKE

Stroke is a common cause of vascular dementia.

How does stroke occur?

A stroke occurs when blood flow in an artery stops, either because the artery is blocked (an **ischemic stroke**) or bursts (a **hemorrhagic stroke**).

This blockage or damage means brain cells aren't receiving oxygen and nutrients, leading to brain cell death. This may lead to vascular dementia.

Having a stroke more than doubles the risk of developing dementia

Strokes can be large or small, and can have a cumulative effect (each stroke adding further to the problem).

Can you recognize the symptoms of a stroke?

Recognizing the signs of stroke and acting quickly can make a difference in recovery and in lowering the risk of dementia. A stroke can:

- ✦ Affect your ability to walk,
- ✦ Cause weakness in your arms or legs,
- ✦ Cause you to slur your speech,
- ✦ Cause changes in your behaviour, such as having emotional outbursts and

Impact your cognitive abilities such as memory and abstract thinking, holding conversation and processing visual information.

THERE ARE DIFFERENT TYPES OF STROKE

COVERT STROKE

Covert strokes occur when a small blood vessel in the brain becomes permanently blocked.

While overt strokes have recognizable symptoms such as weakness and speech difficulties, covert strokes are subtler and can occur silently without any visible symptoms.

Since covert strokes don't cause immediate physical changes that are obvious, most people who have had this type of stroke don't know it.

TRANSIENT ISCHEMIC ATTACK

Transient ischemic attacks, sometimes called "warning strokes," are caused by a small clot that briefly blocks an artery.

Transient ischemic attacks and strokes have similar symptoms, but transient ischemic attacks only last a few minutes or hours and cause no lasting damage.

Transient ischemic attacks are an important warning that a more serious stroke may occur. **Anyone who experiences a transient ischemic attack should seek medical help immediately.**

OTHER RISK FACTORS

Other than stroke, risk factors for vascular dementia include:

- Atrial fibrillation (Afib)
- Diabetes
- Heavy alcohol intake
- Heavy drug abuse
- High blood pressure
- High cholesterol
- Physical inactivity
- Sleep apnea
- Smoking
- Stress
- Unhealthy diet
- Unhealthy weight

For more information about risk factors for dementia, *visit our risk factors webpage*.

Treatment

There are currently no medications that can reverse brain damage brought on by vascular dementia.

However, treating the risk factors for stroke significantly reduces the risk of vascular dementia:

- High blood pressure (or hypertension) is the single most important risk factor for stroke and vascular dementia that can be controlled.
- High blood pressure can be managed through physical activity, eating well and by taking the right medication. Talk to your doctor about the appropriate medication to treat high blood pressure.
- Medications may also help control other risk factors for vascular dementia, like diabetes, cholesterol and heart disease.

In general, living a brain-healthy lifestyle will reduce the risk of vascular dementia, delay its onset or slow its progression.

More links, downloads and resources

Vascular dementia. Alzheimer Society of Canada, last updated March 2018. Our information on vascular dementia is also available in a downloadable, print-friendly PDF.

Vascular Cognitive Impairment And Genetics Explained. A one-page infographic on the topic of Vascular Cognitive Impairment and Genetics developed by researchers at the University of Montreal.

Risk factors. Alzheimer Society of Canada, last updated March 2021. Read about risk factors for dementia in our downloadable, print-friendly PDF infosheet. This sheet also contains strategies and lifestyle changes that can help you reduce your risk of developing dementia.

Stroke risk and prevention. Heart and Stroke Foundation of Canada. On this page, learn more about health conditions that can contribute to stroke as well as the risk factors for stroke that you can and cannot change.

Understanding the Vascular Contributions to Dementia. brainXchange in partnership with the Alzheimer Society of Canada and the Canadian Consortium of Neurodegeneration in Aging (CCNA). This webinar discusses the vascular system in the brain and presents new research findings that maintaining good cardiovascular health may be an important strategy to delay the onset of dementia or slow its progression. Presented by Dr. Cheryl Wellington, Professor in the Department of Pathology and Laboratory Medicine at the University of British Columbia.

Rare Dementia Support Canada. Provides a free specialist Information and support service for people living with, or affected by, a diagnosis of rare or young onset dementia.

This webpage was last updated on June 9, 2023. If you have comments, concerns or questions about this webpage, please email publications@alzheimer.ca.

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https://www.caregiver.org/resource/vascular-dementia/

Testing and Diagnosis

Concerns about vascular dementia should be raised with a physician. Early diagnosis is important, as it provides access to treatment, advice regarding planning for the future, and possible recommendations for lifestyle changes that may slow down the progression of the underlying disease. Recommended lifestyle changes may include following a healthier diet, getting physically active, quitting smoking, and quitting or decreasing alcohol consumption. Depression frequently coexists with vascular dementia and can contribute to, or worsen, vascular-based cognitive symptoms. Medical conditions that may present symptoms similar to depression (fatigue, irritability, insomnia, decreased appetite, anxiety) caused by vascular disease should first be ruled out. A thorough medical examination for vascular dementia can include a variety of different tests and studies. A physician will conduct a full medical history and likely order blood tests to rule out reversible causes of cognitive decline, such as low Vitamin B12 or hypothyroidism. Often individuals are referred to a neurologist for more specialized examination of motor functioning, as well as reflexes, sensation, and gait (manner of walking). A brain scan (e.g., CT, MRI, MRA) is often ordered in the examination stage to identify the presence of strokes or disease in the blood vessels.

Some individuals may also be referred for a carotid ultrasound if there is concern about blockages in these specific arteries. Referral to a specialist for evaluation of thinking skills, such as memory and processing speed, is typical and an important component of the evaluation. The specialist consulted may be a psychiatrist or neuropsychologist. Evaluating independent function is important to determine if the cognitive difficulties are impacting day-to-day activities enough to indicate a diagnosis of dementia. Patients who have cognitive decline but intact daily functioning might instead be given a diagnosis of Mild Cognitive Impairment (MCI).

If the medical examination indicates the person has dementia or MCI due to vascular disease of the brain, the diagnosis will be made and discussion about the next steps will be provided.

Vascular dementia can be difficult to differentiate from other forms of dementia because there is frequently an overlap in symptoms. Also, many individuals with dementia have both vascular disease and another brain disease such as Alzheimer's or Lewy Body Dementia, and therefore have a "mixed dementia."

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https://www.lbda.org/facing-lewy-body-dementia-together-an-introduction-to-lbd/

8.8 Lewy Body Dementia

Lewy Body Dementia: Causes, Symptoms, and Diagnosis

Lewy body dementia (LBD) is a complex and challenging brain disorder. On this page, you can learn about LBD, including common symptoms and how it is diagnosed.

Lewy body dementia basics

LBD is a disease associated with abnormal deposits of a protein called alpha-synuclein in the brain. These deposits, called Lewy bodies, affect chemicals in the brain. These changes, in turn, can lead to problems with thinking, movement, behavior, mood, and other body functions.

Diagnosing LBD can be challenging. Early LBD symptoms are often confused with similar symptoms found in other brain diseases like Alzheimer's disease. Some early symptoms of LBD can include changes in mood, vision, sleep, and bowel movements. LBD can occur alone or along with other brain disorders.

LBD typically begins at age 50 or older, although sometimes younger people may have it. LBD appears to affect slightly more men than women.

LBD is a progressive disease, meaning symptoms start slowly and worsen over time. The disease lasts an average of five to seven years from the time of diagnosis to death, but it can range from two to 20 years. How quickly symptoms develop and change varies greatly from person to person, depending on overall health, age, and severity of symptoms

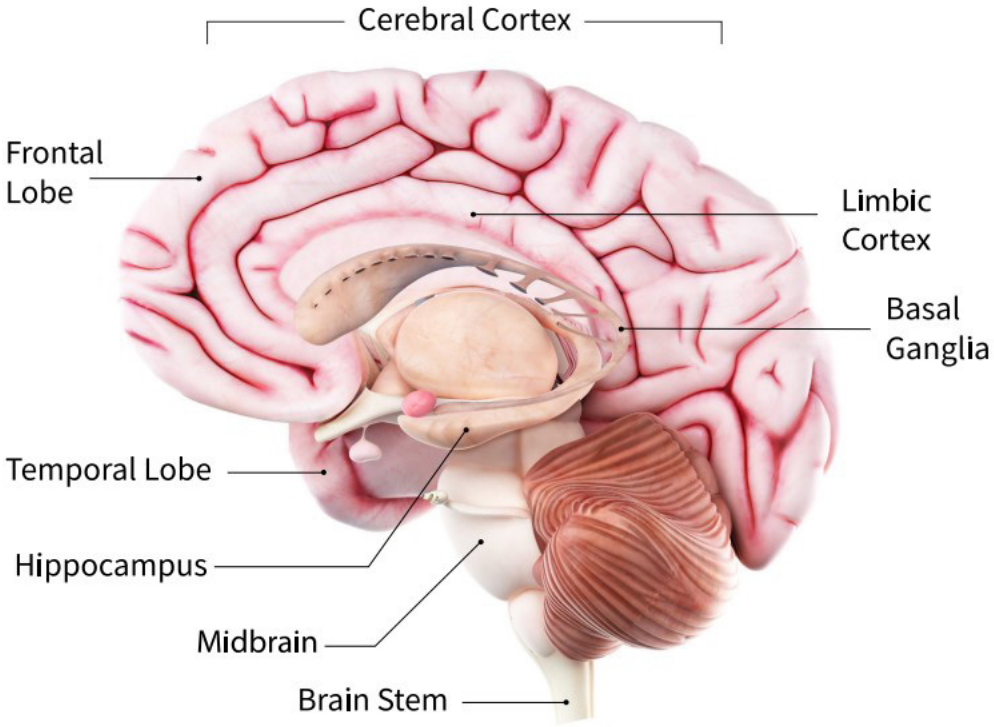
In the early stages of LBD, sometimes before a diagnosis is made, symptoms can be mild and have less impact on daily functioning. As the disease worsens, people with LBD require more and more help with daily activities due to a decline in thinking and movement abilities. In the later stages of the disease, people may depend entirely on others for assistance and care.

Some LBD symptoms may respond to treatment, though responses vary. Currently, there is no cure for the disease. Research is improving our understanding of LBD, and advances in science may one day lead to better diagnosis, improved care, and new treatments.

What are Lewy bodies?

Lewy bodies are named for Dr. Friedrich Lewy, a German neurologist. In 1912, he discovered abnormal protein deposits that disrupt the brain's normal functioning in people with Parkinson's disease. These abnormal deposits, called Lewy bodies, are named after him.

Lewy bodies are made of a protein called alpha-synuclein. In the healthy brain, alpha-synuclein plays a number of important roles in neurons (nerve cells), especially at synapses, where brain cells communicate with each other. In LBD, alpha-synuclein forms into clumps inside neurons, starting in specific regions of the brain. This process causes neurons to work less effectively and, eventually, to die. The activities of certain brain chemicals important to brain function are also affected. The result is widespread damage to certain parts of the brain and a decline in abilities controlled by the affected



brain regions.

In LBD, Lewy bodies affect several different brain regions, including the:

- Cerebral cortex, which controls many functions, including information processing, perception, thought, and language
- Limbic cortex, which plays a major role in emotions and behavior
- Hippocampus, which is essential to forming new memories
- Midbrain and basal ganglia, which are involved in movement
- Brainstem, which is important in regulating sleep and maintaining alertness
- Olfactory pathways, which are important in recognizing smells

Nervous system tissue outside the brain, including nerves in the intestines, heart, sex organs, and salivary glands, can be affected by LBD as well. This may lead to symptoms such as constipation, dizziness with changing position, sexual dysfunction, or drooling.

What are the causes and risk factors of Lewy body dementia?

The precise cause of LBD is unknown, but scientists are learning more about its biology and genetics. For example, they know that an accumulation of Lewy bodies is associated with a loss of certain neurons in the brain that produce important neurotransmitters, which are chemicals that act as messengers between brain cells.

One of these messengers, acetylcholine, is important for memory and learning. Another messenger — dopamine — plays an important role in behavior, thinking ability (cognition), movement, motivation, sleep, and mood.

Scientists are also learning about risk factors for LBD. Age is considered the greatest risk factor, with most people developing the disorder over age 50. A higher number of men are also affected by LBD.

Other known risk factors for LBD include the following:

- **Diseases and health conditions.** Certain diseases and health conditions, particularly REM sleep behavior disorder and loss of smell, are linked to a higher risk of LBD.
- **Genetics.** While having a family member with LBD may increase a person's risk, LBD is not typically considered a hereditary disease. A small percentage of families with dementia with Lewy bodies (a form of LBD) have certain genetic variants that may be associated with disease risk. However, in most cases, the

cause of LBD is unknown. At this time, no genetic test can accurately predict whether someone will develop LBD. Future genetic research may reveal more information about causes and risk.

- **Lifestyle.** No specific lifestyle factor has been proven to increase one's risk for LBD. However, some studies suggest that a healthy lifestyle, including regular exercise, mental stimulation, and a healthy diet, might reduce the risk of developing age-associated dementias.

What are common symptoms of Lewy body dementia?

People with LBD may not have every LBD symptom, and the severity of the symptoms can vary greatly from person to person. Throughout the course of the disease, any sudden or major change in functional ability, symptoms, or behavior should be reported to a doctor.

The most common symptoms of LBD include changes in cognition, movement, sleep, behavior, and body functions that happen without you thinking about them (autonomic functions), such as dizziness on standing (caused by low blood pressure) and constipation.

Cognitive symptoms

LBD causes changes in thinking abilities. These changes may include:

- **Dementia:** Loss of thinking abilities that interferes with a person's capacity to perform daily activities. Dementia is a primary symptom of LBD and usually includes trouble with attention, visual and special abilities (judging distance and depth or misidentifying objects), reasoning, and executive memory functioning (multitasking and problem solving). Memory problems may not be evident at first, but they often become more apparent over time. Dementia can also include changes in mood and behavior, poor judgment, loss of initiative, confusion about time and place, and difficulty with language and numbers.
- **Cognitive fluctuations:** Unpredictable changes in concentration, attention, alertness, and wakefulness from day to day and sometimes throughout the day. A person with LBD may stare into space for periods of time, seem drowsy and lethargic, or sleep for several hours during the day despite getting enough sleep the night before. Their flow of ideas may be disorganized, unclear, or illogical at times. The person may seem better one day, then worse the next. These

cognitive fluctuations are common in LBD but are not always easy for a doctor to identify.

- **Hallucinations:** Seeing or hearing things that are not present. Visual hallucinations occur in most people with LBD, often early in the disease. They are typically realistic and detailed, such as images of children or animals. Hallucinations based in other senses, such as hearing, are less common than visual ones but may also occur. Hallucinations that are not disruptive may not require treatment. However, if they are frightening or lead to a dangerous behavior (for example, if the person attempts to fight a perceived intruder), then a doctor may prescribe medication.

Movement symptoms

Some people with LBD may not experience significant movement problems for several years. Others may have them early on. Some people with dementia with Lewy bodies may never develop movement symptoms. At first, signs of these problems may be very mild and easily overlooked. Movement symptoms may include:

- Slowness of movement
- Muscle rigidity or stiffness
- Shuffling walk or frozen stance
- Tremor or shaking, most commonly at rest
- Balance problems and falls
- Stooped posture
- Loss of coordination
- Smaller handwriting than was usual for the person
- Reduced facial expression
- Difficulty swallowing
- Weak voice

Sleep disorders

Sleep disorders are common in people with LBD but are often undiagnosed. A sleep specialist can play an important role on a treatment team, helping to identify and treat

sleep disorders. Sleep-related disorders seen in people with LBD may include:

- **REM sleep behavior disorder:** A condition in which a person seems to act out dreams. It may include vivid dreaming, talking in one's sleep, violent movements, or falling out of bed. The dreams often involve the perception of being chased or attacked by something or someone. This can be challenging for both the person with LBD and the caregiver. REM sleep behavior disorder appears in some people years before other LBD symptoms.
- **Excessive daytime sleepiness:** Sleeping two or more hours during the day.
- **Insomnia:** Difficulty falling or staying asleep or waking up too early.
- **Restless leg syndrome:** A condition in which a person, while resting, feels the urge to move their legs to stop unpleasant or unusual sensations. Walking or moving usually relieves the discomfort temporarily, but the sensations return when at rest.

Behavioral and mood symptoms

Changes in behavior and mood are possible in LBD and may vary from person to person, depending on their level of cognitive decline. These changes may include:

- **Depression:** A persistent feeling of sadness, inability to enjoy activities, or trouble with sleeping, eating, and other everyday activities.
- **Apathy:** A lack of interest in normal daily activities or events; less social interaction.
- **Anxiety:** Intense apprehension, uncertainty, or fear about a future event or situation. A person may ask the same questions over and over or be angry or fearful when a loved one is not present.
- **Agitation:** Restlessness, including pacing, hand-wringing, an inability to get settled, constant repeating of words or phrases, or irritability.
- **Delusions or misperceptions:** Strongly held false beliefs or opinions not based on evidence. For example, a person may think their spouse is having an affair or that relatives long dead are still living. Capgras syndrome, in which the person believes a relative or friend has been replaced by an imposter, may also occur.
- **Paranoia:** An extreme, irrational distrust of others, such as suspicion that people are taking or hiding things.

- **Hallucinations:** Seeing, hearing, or feeling things that are not there.

Other symptoms of Lewy body dementia

People with LBD can also experience significant changes in the part of the nervous system that regulates automatic functions, such as involuntary activities of the heart, glands, and muscles. The person may have:

- Problems with blood pressure
- Difficulty regulating body temperature
- Fainting
- Frequent falls
- Constipation
- Urinary incontinence
- Sensitivity to heat and cold
- Sexual dysfunction
- Poor sense of smell

Types of Lewy body dementia and diagnosis

It's important for people with the symptoms of LBD to get an accurate diagnosis, both to tailor treatment to particular symptoms and to understand what to expect with the disease. It may take more than one visit with a clinician to diagnose a person with LBD.

LBD includes two related diagnoses — dementia with Lewy bodies and Parkinson's disease dementia.

Dementia with Lewy bodies

People with dementia with Lewy bodies (DLB) have a decline in thinking ability, especially in the areas of attention, visual perception, and planning and organization (executive function). Over time, they will also develop other distinctive symptoms that distinguish this form of dementia from others. These may include:

- Visual hallucinations early in the course of dementia
- Fluctuations in cognitive ability, attention, and alertness
- Slowness of movement, tremor, difficulty walking, or rigidity (parkinsonism)
- REM sleep behavior disorder, in which people appear to physically act out their dreams by yelling, flailing, punching, kicking, and falling out of bed
- More trouble with complex mental activities — such as multitasking and problem solving — than with memory

Dementia with Lewy bodies is often hard to diagnose because its early symptoms may resemble those of Alzheimer's or a psychiatric illness. As a result, it is often misdiagnosed or missed altogether. As additional symptoms appear, it is often easier to make an accurate diagnosis.

Parkinson's disease dementia

Another form of LBD is known as Parkinson's disease dementia. Some people with Parkinson's disease — a disorder that causes unintended or uncontrollable movements, such as shaking, stiffness, and difficulty with balance and coordination — may experience changes in their cognitive function over time. If this happens more than a year after movement symptoms appear, then Parkinson's disease dementia may be diagnosed.

Not all people with Parkinson's develop dementia, and it is difficult to predict who will, though this is an area of active research. Being diagnosed with Parkinson's later in life is a risk factor for Parkinson's disease dementia.

People with either form of LBD eventually develop similar symptoms due to the presence of Lewy bodies in the brain. But there are some differences. For example, the symptoms of dementia with Lewy bodies may worsen more quickly than those of Parkinson's disease dementia.

What are the benefits of getting diagnosed?

Receiving an accurate diagnosis may be a long process, but the good news is that doctors are increasingly able to diagnose both forms of LBD earlier and more accurately as researchers identify which symptoms help distinguish them from similar disorders.

Difficult as it is, getting an accurate diagnosis of LBD early on is important so that a person:

- Can get the right medical care and avoid potentially harmful treatment
- Has time to plan for medical care and arrange legal and financial affairs
- Can build a support team to maximize quality of life
- Can consider enrolling in clinical research to find new ways to diagnose, treat, and manage LBD.

Having a diagnosis of LBD is also important for the person's caregivers and for others who care about and support them. Not only does it allow them to better understand and prepare for what will happen with the disease, it also enables them to plan for how to take care of themselves throughout the process.

While a diagnosis of LBD can be distressing, some people are relieved to know the reason for their troubling symptoms. It is important to allow time to adjust to the news. Talking about a diagnosis can help shift the focus toward developing a care plan.

How is Lewy body dementia diagnosed?

Doctors perform physical and neurological examinations and various tests to distinguish LBD from other illnesses. An evaluation may include:

- **Medical history and physical examination:** A review of previous and current illnesses, medications, and current symptoms and tests of movement and memory give the doctor valuable information.
- Medical tests: Laboratory analysis of blood samples and other tests can help rule out other diseases, hormonal problems, and vitamin deficiencies that can be associated with cognitive changes. Undergoing a sleep study can help diagnose and identify sleep disorders, which can be treatable.
- **Brain imaging:** Different types of brain imaging — such as CT scans and MRIs, along with certain types of PET (positron emission tomography) scans, can detect brain shrinkage and structural abnormalities and can help rule out other possible causes of dementia or movement symptoms.
- Neuropsychological tests: These tests are used to assess memory and other cognitive functions and can help identify affected brain regions.

No single brain scan or medical test can definitively diagnose LBD. Currently, LBD can be diagnosed with certainty only by a brain autopsy after death. However, the development of new diagnostic tests is an ongoing priority.

Talking with your doctor

It is important for the person seeking a diagnosis and their care partners to tell the doctor about:

- Any symptoms involving thinking and memory
- Changes or concerns with movement, sleep, behavior, or mood
- Other health problems
- All medications and supplements that the person is currently taking, including prescriptions, over-the-counter drugs, vitamins, and supplements. Certain medications can worsen LBD symptoms, so it is important to pay attention to responses to medications as well.

Patients and their care partners should bring up any concerns they have with the doctor. The more information a doctor has, the more accurate a diagnosis can be.

Scientists are exploring many avenues to develop better ways to diagnose and treat LBD. Some researchers are trying to identify biomarkers (biological indicators of disease) that may improve screening tests to aid diagnosis. Other scientists are working to discover the specific differences in the brain between the two forms of LBD. Still other researchers are looking at the disease's underlying biology, genetics, and environmental risk factors.

Scientists hope that new knowledge about LBD will one day lead to more effective treatments and even ways to cure and prevent the disorder. Until then, researchers need volunteers with and without LBD for clinical studies.

NIH and other groups help people learn about clinical trials and studies and find research opportunities near them. Visit the following websites for details:

- *Alzheimers.gov Clinical Trials Finder* (search using the category "Related Dementias")
- *Lewy Body Dementia Association*
- *ClinicalTrials.gov*

For more information about Lewy body dementia

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center
800-438-4380
adear@nia.nih.gov
www.nia.nih.gov/alzheimers
The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Alzheimers.gov
www.alzheimers.gov
Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

National Institute of Neurological Disorders and Stroke (NINDS)
800-352-9424
www.ninds.nih.gov

Lewy Body Dementia Association
404-935-6444
800-539-9767 (LBDA Lewy Line)
www.lbda.org

Lewy Body Dementia Resource Center
833-LBDLINE
norma@lbdny.org
https://lewybodyresourcecenter.org

MedlinePlus
National Library of Medicine
www.medlineplus.gov

Michael J. Fox Foundation for Parkinson's Research
212-509-0995
www.michaeljfox.org

Parkinson's Foundation
800-473-4636
helpline@parkinson.org
www.parkinson.org

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Content reviewed: January 27, 2025

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https://www.nia.nih.gov/health/frontotemporal-disorders/what-are-frontotemporal-disorders-causes-symptoms-and-treatment

8.9 Frontotemporal Disorders

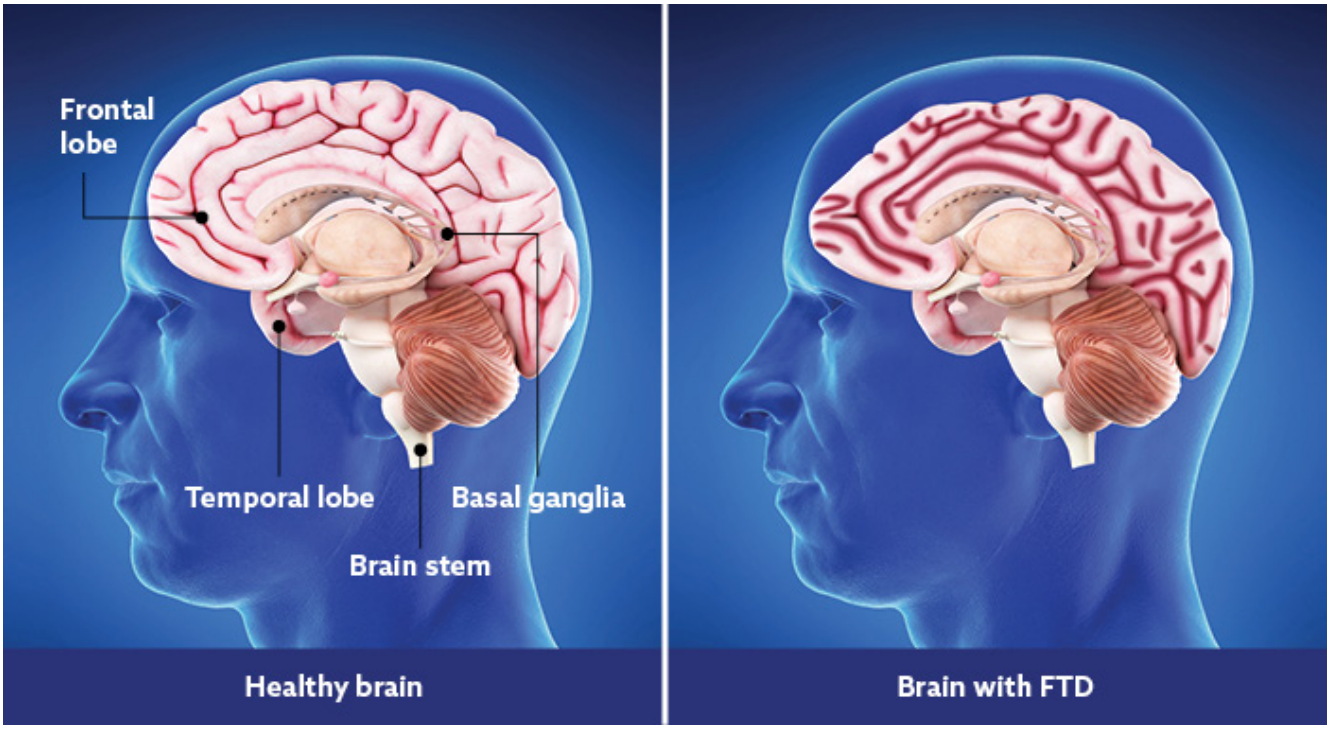
Causes, Symptoms, and Diagnosis

The symptoms of frontotemporal dementia (FTD) and other frontotemporal disorders gradually rob people of basic abilities — thinking, talking, walking, and socializing — that most of us take for granted. FTD and other frontotemporal disorders are a common cause of early-onset dementia. They often strike people in the prime of life when they are working and raising families. Families suffer, too, as they struggle to cope with the person's daily needs as well as changes in relationships and responsibilities.

There is currently no cure for FTD or related disorders, and no treatments to slow or stop the progression of the disease, but there are ways to help manage the symptoms. Research is improving our awareness and understanding of these challenging conditions. This progress is opening doors to better diagnosis, improved care, and eventually, new treatments.

Frontotemporal disorders result from damage to neurons primarily in the frontal and temporal lobes of the brain. As neurons die in these regions, the frontal and temporal lobes atrophy, or shrink. Gradually, this damage causes difficulties in thinking and behaviors normally controlled by these parts of the brain. Many possible symptoms can result in unusual behaviors, emotional problems, trouble communicating, difficulty with work, or difficulty with movement and walking. FTD and related disorders are rare and tend to occur at a younger age than other forms of dementia. Roughly 60% of people with FTD are 45 to 64 years old.

Frontotemporal disorders are progressive, meaning symptoms get worse over time. In the early stages, people may have just one type of symptom. As the disease progresses, other symptoms will appear as more parts of the brain are affected. It is difficult to predict how long someone with FTD will live. Some people live more than 10 years after diagnosis, while others live less than two years after they are diagnosed.



How frontotemporal disorders affect the brain

Frontotemporal disorders affect the frontal and temporal lobes of the brain. They can begin in the frontal lobe, the temporal lobe, or both. Initially, frontotemporal disorders leave other brain regions unaffected, including those that control short-term memory.

The frontal lobes, situated above the eyes and behind the forehead, direct executive functioning. This includes planning and sequencing (thinking through which steps come first, second, third, and so on), prioritizing (doing more important activities first and less important activities last), multitasking (shifting from one activity to another as needed), and monitoring and correcting errors.

When functioning well, the frontal lobes also help manage emotional responses. They help people avoid inappropriate social behaviors, such as shouting loudly in a library or at a funeral. They aid in making decisions that make sense for a given situation. When the frontal lobes are damaged, people may focus on insignificant details and ignore important aspects of a situation.

The frontal lobes are also involved in language, particularly linking words to form sentences, and in motor functions, such as moving the arms, legs, and mouth. The temporal lobes, located below and to the side of each frontal lobe on the right and left sides of the brain, contain essential areas for memory and play a major role in language and emotions. They help people understand words, speak, read, write, and connect words with their meanings. They allow people to recognize objects and to

relate appropriate emotions to objects and events. When the temporal lobes aren't working properly, people may have difficulty recognizing and responding appropriately to emotions.

Which lobe — and which part of the lobe — is affected first determines which symptoms appear initially. For example, if the disease starts in the part of the frontal lobe responsible for decision-making, then the first symptom might be trouble managing finances. If it begins in the part of the temporal lobe that connects emotions to objects, then the first symptom might be an inability to recognize potentially dangerous objects — a person might reach for a snake or plunge a hand into boiling water, for example.

In rare cases, frontotemporal disorders can begin in a different part of the brain. For example, when a person has early movement problems, such as falls, swallowing difficulties, or muscle stiffness, the disease may be beginning in the movement parts of the brain, such as the basal ganglia or brainstem.

What do the terms mean?

One of the challenges shared by people living with these disorders, families, clinicians, and researchers is confusion about how to classify and label frontotemporal disorders. A diagnosis by one doctor may be called something else by a second, and the same condition or disorder may be referred to by a different name by a pathologist who examines the brain after death.

Here, we use the term frontotemporal dementia and the abbreviation FTD to refer to frontotemporal dementia. We also cover other frontotemporal disorders, including corticobasal syndrome, progressive supranuclear palsy, and primary progressive aphasia.

Frontotemporal disorders are not a single brain disease but rather a family of neurodegenerative diseases. FTD is perhaps the most commonly used term, but other widely used terms include frontotemporal lobar degeneration, frontal lobe disorders, and frontotemporal degeneration. FTD also used to be referred to as Pick's disease, and some doctors still use the term. It's important to note that with some frontotemporal disorders, the primary symptoms are problems with speech or movement, rather than dementia symptoms. Physicians and psychologists diagnose the different forms of FTD based on a person's symptoms as well as the results of brain scans and genetic tests.

What are the types and symptoms of frontotemporal disorders?

Frontotemporal disorders can be grouped into three types, defined by the earliest symptoms. In the early stages, it can be hard to know which type of frontotemporal disorder a person has because symptoms and the order in which they appear can vary from one person to another. Also, the same symptoms can appear across different disorders and vary from one stage of the disease to the next as different parts of the brain are affected.

In general, changes in the frontal lobe are associated with behavioral symptoms, while changes in the temporal lobe affect language and emotions. Because it is rare and not well understood, FTD is sometimes misdiagnosed as Alzheimer's disease or other types of dementia.

Symptoms of FTD and related disorders are often misunderstood. Family members and friends may think that a person is misbehaving, leading to anger and conflict. It is important to understand that people with these disorders cannot control their behaviors and other symptoms and (before they are diagnosed) lack any awareness of their illness.

Behavioral variant frontotemporal dementia

The most common FTD, behavioral variant frontotemporal dementia (bvFTD), involves changes in personality, behavior, and judgment. People with bvFTD can act strangely around other people, resulting in embarrassing social situations. Often, they don't know or care that their behavior is unusual and don't show any consideration for the feelings of others. People with this disorder may or may not have problems with cognition or memory.

Symptoms can include:

- Problems planning and sequencing
- Difficulty prioritizing tasks or activities
- Repeating the same activity or saying the same word over and over
- Acting impulsively or saying or doing inappropriate things without considering how others perceive the behavior
- Becoming uninterested in family or activities they used to care about
- Displaying flat, exaggerated, or improper emotions that seem disconnected from the situation

- Difficulty reading social signals, seeming to lack empathy
- Compulsive eating or taking food from others' plates

Over time, language and/or movement problems may occur, and the person living with bvFTD will need more care and supervision.

Primary progressive aphasia

Primary progressive aphasia (PPA) involves changes in the ability to communicate — to use language to speak, read, write, and understand what others are saying. This includes difficulty using or understanding words (aphasia) and difficulty speaking properly (e.g., slurred speech). People with PPA may have one or both of these symptoms. They may eventually become unable to speak.

Many people with PPA develop symptoms of dementia. Problems with memory, reasoning, and judgment are not apparent at first but can develop over time. Some people with PPA may experience significant behavioral changes, similar to those seen in bvFTD, as the disease progresses.

There are three types of PPA, categorized by the language problems that appear first.

- **Semantic PPA:** A person slowly loses the ability to understand single words and sometimes to recognize the faces of familiar people and common objects.
- **Agrammatic PPA:** A person has more and more trouble speaking and may omit words that link nouns and verbs (such as to, from, and the). Eventually, the person may no longer be able to speak at all. The person may later develop movement symptoms similar to those seen in corticobasal syndrome (see below).
- **Logopenic PPA:** A person has trouble finding the right words during a conversation but can understand words and sentences. The person does not have problems with grammar. Logopenic PPA is usually accompanied by the hallmark brain changes seen in Alzheimer's.

Researchers do not fully understand the biological basis of the different types of PPA. But they hope one day to link specific language problems with the changes in the brain that cause them.

Movement disorders

Two rare neurological movement disorders associated with FTD, corticobasal syndrome and progressive supranuclear palsy, occur when the parts of the brain that control

movement are damaged. The disorders may affect thinking and language abilities, too.

- **Corticobasal syndrome (CBS)** can be caused by corticobasal degeneration — a gradual atrophy (shrinking) and loss of nerve cells in specific parts of the brain. This causes progressive loss of the ability to control movement, typically beginning around age 60. The most prominent symptom may be apraxia, the inability to use the hands or arms to perform a movement despite normal muscle strength. Apraxia leads to problems such as difficulty fastening buttons or operating small appliances. Other symptoms can include muscle rigidity and difficulty swallowing. Symptoms may appear first on one side of the body, but eventually both sides are affected. Occasionally, a person with corticobasal syndrome first has language problems or trouble orienting objects in space and later develops movement symptoms. Not everyone who has corticobasal syndrome has problems with memory, cognition, language, and behavior in addition to the loss of their ability to control their movements.

- **Progressive supranuclear palsy (PSP)** typically causes problems with balance and walking. People with the disorder often move slowly, experience unexplained falls, lose facial expression, and have body stiffness, especially in the neck and upper body. These symptoms are similar to those of Parkinson's disease. A hallmark sign of this disorder is trouble with eye movements, particularly looking down. These symptoms may give the face a fixed stare. Problems with behavior, language, problem solving, and judgment can also develop.

Other movement-related types of FTD include frontotemporal dementia with parkinsonism and frontotemporal dementia with amyotrophic lateral sclerosis (FTD-ALS).

- **Frontotemporal dementia with parkinsonism** is usually caused by CBS or PSP, and in rare cases can be an inherited disease. Symptoms are similar to those of Parkinson's and include slowed movement, stiffness, balance problems, and changes in behavior or language.

- **FTD-ALS**, also called FTD with motor neuron disease, is a combination of bvFTD and amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. In addition to the behavioral and/or language changes seen in bvFTD, people with FTD-ALS experience the progressive muscle weakness, fine jerks, and wiggling in muscles (fasciculation) seen with ALS. Symptoms of either disease may appear first, with other symptoms developing over time.

What causes frontotemporal disorders?

Scientists are beginning to understand the biological and genetic basis for the changes observed in brain cells that lead to FTD.

Scientists describe FTD using the patterns of change in the brain seen in an autopsy after death. These changes include loss of neurons and abnormal amounts or forms of proteins called tau and TDP-43. These proteins occur naturally in the body and help cells function properly. When the proteins don't work right, for reasons not yet fully understood, neurons in specific brain regions are damaged.

People can have changes in their brain associated with multiple forms of dementia. For example, people with corticobasal syndrome or logopenic PPA may also have beta-amyloid plaques in their brain, which are associated with Alzheimer's.

In most cases, the cause of FTD is unknown. Individuals with a family history of the disease are more likely to develop FTD.

FTD that runs in a family is often related to variants (permanent changes) in certain genes. Genes are basic units of heredity that tell cells how to make the proteins the body needs to function. Even small changes in a gene may produce an abnormal protein, which can lead to changes in the brain and, eventually, disease. An estimated one-third of FTD cases are inherited, meaning the genetic variant is passed from parent to child. These genetic variants can often be identified through genetic testing.

Scientists have discovered several different genes that, when changed or mutated, can lead to FTD. These include:

- **MAPT gene** — A change in this gene causes abnormalities in the tau protein, which can then form tangles inside neurons and ultimately lead to the destruction of brain cells. Inheriting a variant in this gene means a person will almost surely develop a frontotemporal disorder, usually bvFTD, but the exact age of onset and symptoms cannot be predicted.
- **GRN gene** — A change in this gene can lead to lower production of the protein progranulin, which in turn causes another protein, TDP-43, to go awry in brain cells. This can lead to frontotemporal disorders, with bvFTD being the most common. A change in the GRN gene can cause different symptoms in different family members, and the disease can begin at different ages.
- **C90rf72 gene** — An unusual variant in this gene appears to be the most common genetic abnormality in familial frontotemporal disorders and familial ALS. This variant can cause a frontotemporal disorder, ALS, or both conditions.

In recent years, researchers have discovered several other genetic changes that lead to rare familial types of frontotemporal disorders. These other variants account for less than 5% of all cases of FTD.

Scientists are continuing to study these genes and to search for other genes and proteins, as well as nongenetic risk factors, that may play a role in FTD. They are trying

to understand, for example, how variants in a single gene can lead to different types of FTD in members of the same family. Environmental factors that may influence risk for developing the disorders are also being examined.

How are frontotemporal disorders diagnosed?

FTD can be hard to diagnose because the symptoms resemble those of other conditions. For example, bvFTD is sometimes misdiagnosed as a mood disorder, such as depression. To make matters more confusing, a person can have both FTD and another type of dementia, such as Alzheimer's. Also, because these disorders are rare, physicians may be unfamiliar with the signs and symptoms.

To help diagnose FTD, a doctor may:

- Perform an exam and ask about symptoms
- Review personal and family medical history
- Use laboratory tests to help rule out other conditions, including Alzheimer's
- Order genetic testing
- Conduct evaluations to assess behavior, memory, thinking, language skills, and physical function
- Order imaging of the brain

A psychiatric evaluation can help determine if depression or another mental health condition is causing or contributing to the condition. A diagnosis of FTD can only be confirmed by genetic tests (in familial cases) or a brain autopsy after death.

Brain imaging and FTD

Different types of brain imaging may be used to determine the cause of a person's symptoms. A magnetic resonance imaging (MRI) scan shows changes in the size and shape of the brain, including the frontal and temporal lobes. It may reveal other potentially treatable causes of the person's symptoms, such as a stroke or tumor. In the early stages of disease, the MRI may appear normal. Other types of imaging, such as positron emission tomography (PET) may be useful. PET scans measure activity in the brain by monitoring blood flow, glucose usage, and oxygen usage. Other PET scans can help rule out a diagnosis of Alzheimer's.

Getting the wrong diagnosis can be frustrating. Without an accurate diagnosis, people with FTD and related disorders may not get appropriate treatment to manage their symptoms. Families may not get the help they need. Learn about medical centers that can help people with FTD get diagnosis and treatment.

Read more about how *FTD is treated and managed*.

Researchers are studying ways to diagnose FTD earlier and more accurately, and to distinguish these conditions from other types of dementia. One area of research involves biomarkers, such as proteins or other substances in the blood or cerebrospinal fluid, which can be used to help diagnose FTD and measure disease progression. Results from biomarker tests also can help rule out other causes of dementia. For example, a blood test for Alzheimer's could help establish whether the cause of dementia is likely to be Alzheimer's or something else. Researchers are also exploring ways to improve brain imaging and neuropsychological testing.

For more information

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center
800-438-4380
adear@nia.nih.gov
www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Alzheimers.gov
www.alzheimers.gov

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

National Institute of Neurological Disorders and Stroke (NINDS)
800-352-9424
www.ninds.nih.gov

MedlinePlus
National Library of Medicine
www.medlineplus.gov

Eldercare Locator
800-677-1116
eldercarelocator@USAging.org
https://eldercare.acl.gov

Association for Frontotemporal Degeneration
866-507-7222
info@theaftd.org
www.theaftd.org

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

Content reviewed: January 22, 2025

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https://alzheimer.ca/en/about-dementia/other-types-dementia/mixed-dementia

8.10 Other Dementias

Mixed Dementia

It's possible for someone to have more than one type of dementia. When this happens, it's known as mixed dementia.

What is mixed dementia?

Because different types of dementia can have different causes, it's possible for a person to have more than one type of dementia. When this happens, that person has **mixed dementia**.

A person living with mixed dementia will show symptoms of at least two different types of dementia. Usually, mixed dementia consists of the two most common types: **Alzheimer's disease** and **vascular dementia**.

For example, a person with mixed dementia may show symptoms of both Alzheimer's and vascular dementia. Because many symptoms overlap between different types of dementia, it can be hard to figure out if someone has mixed dementia.

However, it's important that we are aware whether someone has mixed dementia, because the combination of two or more dementias will likely have a greater impact on their brain than experiencing one disease alone. This can affect how a person progresses through the stages of dementia.

How many people have mixed dementia?

Researchers don't know exactly how many people currently diagnosed with a specific type of dementia actually have mixed dementia. However, autopsy studies indicate that mixed dementia may be much more common than previously realized.

Why do we perform autopsy studies? Autopsy studies play a key role in shedding light on mixed dementia because scientists can't yet measure most dementia-related brain changes in living individuals.

Some experts recommend suspecting mixed dementia whenever a person has both evidence of cardiovascular disease and dementia symptoms that get worse slowly over time. Evidence like this may indicate the presence of both Alzheimer's disease and vascular dementia.

How can I find out if I have mixed dementia?

Because of its nature, mixed dementia is difficult to diagnose. List the symptoms that you notice and discuss them with your doctor or a qualified healthcare provider.

How can mixed dementia be treated?

Like any other dementia, the best way to treat the effects of mixed dementia is to follow a brain-healthy lifestyle. This also holds true for reducing the risk of mixed dementia.

Depending on the symptoms experienced, someone living with mixed dementia may find relief with medications approved to treat Alzheimer's disease as well as certain alternative treatments. Before starting any treatment, however, the Alzheimer Society strongly recommends checking with a doctor or a qualified healthcare provider first.

SUGGESTED RESOURCES

Websites

Alzheimer's Disease International	
Helpful resources, including how to find a clinical trial	*alzheimers.gov*
Risk Factors for Dementia	*www.alzint.org/about/risk-factors-risk-reduction/*
Mixed Dementia	*alzheimer.ca/en/Home/About-dementia/Dementias/Mixed-dementia*
Alzheimer's Society of Canada	
Vascular Dementia	*alzheimer.ca/sites/default/files/documents/other-dementias_vascular-dementia.pdf*
Association for Frontotemporal Degeneration	
A nonprofit organization that provides information, education and support to those affected by frontotemporal dementia and their care partners	*www.theaftd.org/*
Cleveland Clinic Foundation	
Dementia	*my.clevelandclinic.org/health/diseases/9170-dementia*
Frontotemporal Dementia	*my.clevelandclinic.org/health/diseases/21075-frontotemporal-dementia*
Lewy Body Dementia	*my.clevelandclinic.org/health/diseases/17815-lewy-body-dementia*
Dementia UK	
Young Onset Dementia	*www.dementiauk.org/information-and-support/young-onset-dementia/*

Family Caregiver Alliance	
Caregiver's Guide to Understanding Dementia Behaviors	*www.caregiver.org/resource/caregivers-guide-understanding-dementia-behaviors/*
Dementia, Caregiving, and Controlling Frustration	*www.caregiver.org/resource/dementia-caregiving-and-controlling-frustration/*
Dementia: Is This Dementia and What Does It Mean?	*www.caregiver.org/resource/is-this-dementia-what-does-it-mean/*
Vascular Dementia	*www.caregiver.org/resource/vascular-dementia/*
Lewy Body Dementia Association	
Supports those affected by Lewy body dementia by raising awareness and promoting scientific advances	*www.lbda.org/*
Mayo Clinic	
Alzheimer's Disease	*www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447*
Dementia	*www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013*
Frontotemporal dementia	*www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/symptoms-causes/syc-20354737*
National Institute on Aging	
Alzheimer's Disease Fact Sheet	*www.nia.nih.gov/health/alzheimers-and-dementia/alzheimers-disease-fact-sheet*
Next Steps After an Alzheimer's Diagnosis	*www.nia.nih.gov/sites/default/files/2020-09/next-steps-after-alzheimers-diagnosis.pdf*

What Are Frontotemporal Disorders? Causes, Symptoms, and Treatment	*www.nia.nih.gov/health/frontotemporal-disorders/what-are-frontotemporal-disorders-causes-symptoms-and-treatment*
What Causes Alzheimer's Disease?	*www.nia.nih.gov/health/alzheimers-causes-and-risk-factors/what-causes-alzheimers-disease*
What Is Lewy Body Dementia? Causes, Symptoms, and Treatments	*www.nia.nih.gov/health/lewy-body-dementia/lewy-body-dementia-causes-symptoms-and-diagnosis#:~:text=Lewy%20body%20dementia%20(LBD)%20is,movement%2C%20behavior%2C%20and%20mood.*
Understanding Different Types of Dementia	*www.nia.nih.gov/sites/default/files/understanding-types-dementia_0.pdf*
Schlegal – University of Waterloo, Research Institute of Aging	
Young Onset Dementia — An inspirational guide for people living with dementia	*the-ria.ca/wp-content/uploads/2018/11/BUFU_Young-Onset-Dementia_eversion_A.pdf*
The Young Dementia Network, hosted by Dementia UK	
A community of people living with young onset dementia, their family and friends, as well as professionals who work in the field of health and social care and voluntary sector.	*www.youngdementianetwork.org/*

VISIT
Demetia Action Alliance
www.daanow.org

ADDITIONAL RESOURCES

Alzheimer's Association, *Legal and Financial Worksheet* — A useful financial and legal worksheet to help you organize important papers and information. If you fill out any information in the worksheet, be sure to store it in a secure place so only people you trust have access to the information.	*www.alz.org/getmedia/1867c02d-b631-4cf0-b1a3-0dfd1e73640e/worksheet-financial-legal.pdf*
Alzheimer Society of Canada, *All About Me* — This booklet helps record information that describes your background and history, likes and dislikes, and what's important to you. The completed information can be given to people who are supporting and caring for you if you are not able to articulate this information yourself. Knowing the person is fundamental to person-centered and directed support.	*alzheimer.ca/sites/default/files/documents/All-about-me-Alzheimer-Society.pdf*
Alzheimer Society of Canada, *Long-Term Care Home Checklist* — This checklist can be used as you and your care partner(s) consider and conduct site visits to select a residential care community.	*alzheimer.ca/sites/default/files/documents/Long-term-care-home-checklist-Alzheimer-Society_0.pdf*
Alzheimer Society of Canada, *Preparing for Your Doctor's Visit* — This document will guide you and your care partner(s) to gather information about the changes you have been experiencing and have you consider things you want to discuss during your doctor's visit.	*alzheimer.ca/sites/default/files/documents/tipsheet_preparingforyourdoctor_e.pdf*
Alzheimer Society of Canada, *Signs and Symptoms of Young Onset Dementia, A Personal Checklist* — This is a checklist intended to help people be aware of the signs and symptoms of young onset dementia. It is a tool that you could use to start a conversation with your doctor if you are concerned about symptoms you are experiencing.	*alzheimer.ca/sites/default/files/documents/young-onset-dementia-personal-symptom-checklist.pdf*

Alzheimer's Society UK, *Living with Dementia My Life, My Goals* — A practical guide full of hope to help you set and reach your goals. This guide has been created with people living with dementia to help you think about and decide what is important to you.	*www.alzheimers.org.uk/sites/default/files/2021-09/my-life-my-goals-workbook.pdf*
Alzheimer's Society UK, *Making your home dementia friendly* — This booklet provides information and things to consider to make your home dementia friendly.	*www.alzheimers.org.uk/get-support/publications-factsheets/making-your-home-dementia-friendly*
Alzheimer's Society UK, *My Checklist for Possible Dementia Symptoms* — This checklist is helpful for people who suspect they or someone they care about have symptoms of dementia.	*www.alzheimers.org.uk/sites/default/files/2023-04/dementia-symptoms-checklist.pdf*
Dementia Action Alliance, *Important Questions to Ask your Doctor About a Dementia Diagnosis* — This is a list of questions that people living with dementia developed and found useful when being diagnosed with dementia.	*daanow.org/wp-content/uploads/2024/12/Final-Important-Questions-to-Ask-Your-Doctor-About-a-Dementia-Diagnosis-3-1.docx*
Dementia Action Alliance, *What Matters to Me* — This storybook formatted resource was developed by people living with dementia and care partners as an easy-to-use tool to fill out about what matters to them. *What Matters to Me* can be provided to care partners of an individual living with advanced symptoms of dementia so they can get to know the person and what is important to them.	*daanow.org/wp-content/uploads/2024/12/What-Matters-to-Me-TOOL.pptx*
Dementia Action Alliance, *Words Matter* — This document was developed by people living with dementia and care partners to heighten awareness and understanding about the impact words can have on the well-being and lived experience of people living with dementia.	*daanow.org/wp-content/uploads/2020/05/WORDS-MATTER-Revisions.pdf*
Dementia Friendly America Toolkit — The DFA toolkit guides communities through a step-by-step process to help communities implement dementia friendly practices.	*www.dfamerica.org/toolkit-getting-started*

Dementia Toolkit, *Guide to the Living with Dementia Toolkit* — This toolkit was developed as part of the UK's IDEAL research program that has been finding since 2014 what helps people living well with dementia. It was prepared by people living with dementia, care partners and researchers.	*livingwithdementiatoolkit.org.uk/wp-content/uploads/2022/04/Dementia-Toolkit-English-Guide_April-2022.pdf*
Dementia Understand Together, At Home Activities: A selection of meaningful activities for people living with dementia and care partners — This booklet, developed by the Alzheimer's Society of Ireland/Dementia Together, provides meaningful activities that can be done together at home.	*www.understandtogether.ie/training-resources/helpful-resources/understand-together-resources/leaflets/at-home-activities-booklet.pdf*
The Eden Alternative – Dedicated to improving the well-being of Elders and their care partners through transformative support, education, and consultation.	*www.edenalt.org*
Jewish Family & Children's Service Memory Café Toolkit and Virtual/Hybrid Supplement — This resource provides step-by-step instructions to help you launch and sustain a Memory Café and includes templates you can download and adapt to fit your own program. The Toolkit was developed as a public service by Jewish Family & Children's Service Alzheimer's/Related Disorders Family Support with support from the Massachusetts Association of Councils on Aging (MCOA).	*www.jfcsboston.org/our-services/services-for-older-adults/home-community-supports/alzheimers-related-dementias-family-support/memorycafetoolkit*
Lewy Body Dementia Association, *Comprehensive LBD Symptom Checklist* — LBDA has created a helpful checklist that will assist people diagnosed with LBD or care partners with collecting new or concerning LBD symptoms they should discuss with their physician.	*www.lbda.org/comprehensive-lbd-symptoms-checklist/*
National Institute on Aging, *Tips for Advance Care Planning* — A helpful checklist for advance care planning developed by the National Institute on Aging.	*https://order.nia.nih.gov/sites/default/files/2024-07/tip-sheet-advance-care-planning.pdf*

National Institute on Aging, *Legal and Financial Planning for People with Alzheimer's Disease Fact Sheet* — This fact sheet from the National Institute on Aging provides helpful considerations for legal and financial planning.	*www.cooleydickinson.org/wp-content/uploads/2019/09/Legal-and-Financial-Planning-for-People-with-Alzheimers-Disease.pdf*
The Conversation Project, *Your Conversation Starter Kit* — This starter kit helps individuals have honest and open conversations about what matters most to them at the end of life.	*theconversationproject.org/wp-content/uploads/2015/09/TCP_StarterKit_Final.pdf*
The Conversation Project, *Your Conversation Starter Guide For Caregivers of People Living with Alzheimer's or Other Forms of Dementia* — The guide helps care partners understand what matters to someone living with dementia and how to help them have a say in their healthcare.	*theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf*
The Conversation Project, *Your Guide to Choosing a Health Care Proxy* — This guide will help you think about and determine who would be a good healthcare advocate for you.	*theconversationproject.org/wp-content/uploads/2020/12/ChooseAProxyGuide.pdf*
The Conversation Project, *Your Guide for Talking with a Health Care Team* — This guide will help you talk to your health team to create a care plan that is right for you and your needs.	*theconversationproject.org/wp-content/uploads/2020/12/HealthCareTeamGuide.pdf*
The Hartford Center for Mature Market Excellence, *At the Crossroads Family Conversations About Alzheimer's Disease, Dementia & Driving* — This guidebook is a helpful resource should the need arise to discuss driving safety with a person living with dementia.	*ewcstatic.thehartford.com/thehartford/the_hartford/files/CMME/cmme-crossroads.pdf*

ABOUT DEMENTIA ACTION ALLIANCE

Dementia Action Alliance is an outreach mission of The Eden Alternative
www.edenalt.org

At **Dementia Action Alliance**, we're creating a world ***without*** stigma and misperceptions, and ***with*** accommodations for changing abilities. Through advocacy, education, empowerment, and support, we want to create a society where people living with dementia don't just survive, **they live and thrive**.

Our virtual programs provide people living with dementia or MCI, and/or their direct care partners, opportunities to learn and share strategies for living a purpose-filled life. They are designed to **Educate, Engage**, and **Encourage** people through their journey.

Dementia Action Alliance's website is full of **resources and information** about living well with dementia: podcasts about important topics, videos of people living well with dementia, advocacy projects, information about timely topics and engagement… and more.



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Demetia Action Alliance
www.daanow.org

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Dementia Action Alliance
www.daanow.org/donate

Dementia Action Alliance

Dementia Action Alliance
ENHANCING LIVES
CONNECTING PEOPLE
INCREASING UNDERSTANDING

I believe that one of the biggest and most ignored human rights for people living with dementia is the right to have hope, to be able to live positively, meaningfully, and as fully as possible.

Allen Power, MD, Contributor



JOIN OUR VIRTUAL COMMUNITY OF PEER SUPPORT AND ENGAGEMENT

- Dementia Discussions
- Faith, Hope, and Love
- Drop in with DAA
- Dementia Men/Dementia Women
- Music Beat & Trivia
- Literature and Art
- Peer-to-Peer Buddy System
- And much, much more!

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