Empathic Transitions:
Embracing People with Dementia at the End of Life

EMPATHIC TRANSITIONS

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Second Wind Dreams/Empathic Transitions

2025 DOUBLING DOWN on Dementia DEMENTIA SYMPOSI

DYING WITH DEMENTIA IS DIFFERENT

They receive less healthcare in their final months than people without dementia.

Social Death
- The untouchables
- Little communication with the patient
- They are discounted
- There's nothing we can do

Healthcare has death anxiety around people with dementia

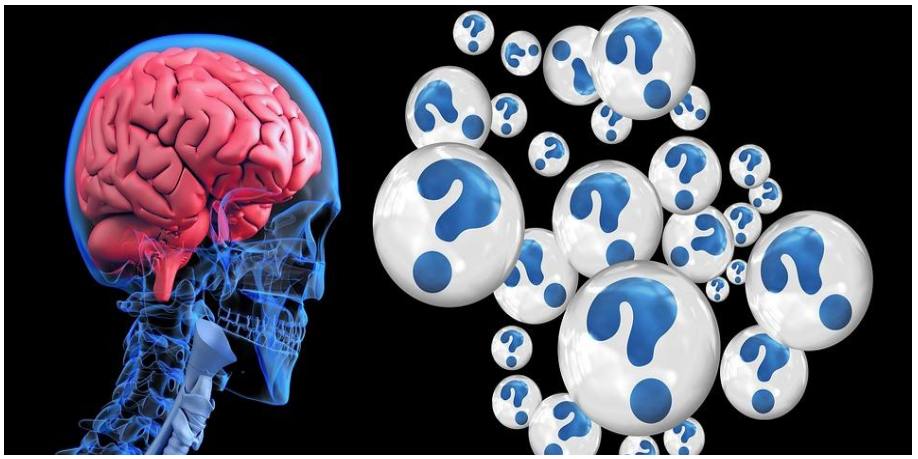
No guidance about dementia death

We have no frame of reference



DYING WITH DEMENTIA IS DIFFERENT

- Sensory Deprivation
- They can't tell us of any regrets or needs of forgiveness even reconciliation.
- We can't ask them their wishes in advanced dementia.
- They can't share memories therefore no legacy activities
- They can't tell us they are in pain
- They can't tell us if abuse or neglect has happened



FAMILY DYNAMICS ARE DIFFERENT

Families have been on a long journey

- Anticipatory grief
- Different dynamics than other terminal illnesses
- Might avoid the death because they feel the person is already dead
- Can’t see them that way
- No feedback from their loved one.
- No ability to share stories from their loved one.



EMOTIONAL CHARACTERISTICS OF ADVANCED DEMENTIA



Even though the limbic system is damaged, a person still has emotions

- FEAR
- Withdrawal
- Agitated
- Angry
- Acting out
- Existential Pain
  - Past and current Trauma
- Liminal space
- Visioning
- Inner work

PAIN IN ADVANCED DEMENTIA



Dementia Pain Assessment

- What it looks like
  - Decubitus
  - Agitation
  - Pacing
  - Can’t be still in the bed
  - Sweating
  - Clenched fists
  - Constipation
- The Rally

ADVOCACY

The ability to advocate for a person with dementia is one of the most important parts of End-of-Life care

- Seat of Power

Watch out for:

- Medication Management
- Pain
- Anxiety
- Clean Briefs
- Treatment by caregivers
- Bed sores



Why do we need Dementia Doulas?

- They embrace the dying with dementia
- They can prepare and sit vigil
- They are experienced in deathbed guidance
- THEY ARE PRESENT
- They are experienced in family dynamics before during and after death
- They are advocates
  - Pain management
  - Death care of the body
  - Environment



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