

"There was a sense of relief that I was able to name what was going on, but also it was a shock because I wasn't expecting that my entire life was going to change within a few moments."

Early Dementia

Middle Dementia

Late Dementia

Actively Dying

The Patient

Signposts

Good Questions

Our Tasks

Memory loss of recent events
 Repetition of questions or stories
 Disorientation

- to time - forgetting the day or month, day/night reversal
- to place - getting lost, initially in unfamiliar (airports, freeways) then in familiar places (shopping mall)

Loss of instrumental activities of daily living (IADLs)

- paying bills, taxes
- driving
- shopping, following recipes, safely using stove

Loss of interest in hobbies; apathy, social withdrawal

Mood changes; anxiety, depression, irritability, paranoia, suspicion

Acute confusional event; "spell"
 Post op delirium – after surgery, with an infection, medications, or dehydration
 Loss of driver's license
 Fall or fracture, especially if unable to call for help
 Unable to manage medications, meals, the phone or stove
 Needing help to dress, wash, shave, brush teeth
 Wandering or lost
 Unsafe alone
 Night problems
 Incontinence of bladder, then bowel

Safety

- Is (s)he safe driving, with the stove, wandering, with falls, or at night?
- Do your loved one's behaviours sometimes make you feel unsafe?

Dependency

- How much support does (s)he need?
- How long can you leave him/her alone for?

Burnout

- How are you coping with this?
- Are you getting any support?

1. Make the diagnosis and treat what we can
 - Delirium
 - Depression
 - Dementia – identify type if possible: Alzheimer's, vascular, Lewy Body, frontotemporal, or Parkinson's
2. Reduce medication burden
3. Focus on comfort and quality of life
 - Pain, Bowels, Sleep, Mood / behavioural challenges (anxiety, depression, delusions)
4. Support caregivers, and actively assess and monitor for caregiver burnout
5. Prepare patient and family for the future
 - Information on dementia and trajectory
 - Start care planning discussions
6. Put affairs in order
 - Finances
 - Joint accounts
 - Enduring power of attorney, representative agreements/committeeship
 - Will/estate planning
 - Health
 - Appoint substitute decision maker or representative
 - Discuss goals of care

"Every month, there's a little less of my Ted there to see. They call it the disease of a thousand good-byes. Now I know why."

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Progressive loss of activities of daily living (ADLs)

- Dressing
- Bathing and grooming
- Managing bowel and bladder
- Ability to speak and express needs
- Walking safely
- Feeding

Able to do these ADLs initially, but progressively lose them all as they transition to late dementia

Wandering, pacing, or restlessness

Signposts

Loss of continence
 Walking unsafely and risk of falls
 Admission to residential care
 Unable to dress, wash or shave
 Becoming wheelchair bound
 Choking and feeding problems

Good Questions

Function: How much help does (s)he need?

- Dressing/grooming
- Managing bathroom
- Walking safely

How much has this changed recently? (trajectory and rate of change)

Cognition

- Is (s)he able to:
 - Find her/his room?
 - Name family members?
 - Express needs in words, or only non-verbally?
- What is the longest sentence (s)he would say?

Our Tasks

1. Focus on person-centred, relationship-centered, personhood-preserving care; Meaningful human relationships
2. Treat boredom, social isolation, loneliness, grief and loss reactions, and loss of personhood.
3. Provide impeccable comfort care
 - Pain, bowels, sleep
 - Mood/ behavioural challenges (responsive behaviours, delusions, anxiety)
4. Reduce medication burden
 - Pills only for comfort, in seniors-friendly doses
 - Reduce cardiac meds to 1-2 to manage symptoms
 - Stop preventative therapy
 - Reconsider blood thinners if falling or bleeding
 - Simplify Diabetes Management
 - No dietary restrictions – eat for enjoyment
 - Fasting glucose < 10 and after meals < 20
 - A1c target < 8. < 9 if frailty. Reduce meds if < 7
 - Reduce glucometers to BID weekly or twice monthly
 - No sliding scale insulin in residential care
 - Longer acting insulins once or twice daily
5. Connect / Communicate / Form a team with families
 - Prepare families for the future
 - Have conversations about dementia trajectory:
 - current situation, recent changes, rate of change
 - At each signpost, about what's coming next
 - Prepare them for upcoming choices about:
 - Avoiding hospitalization (MI / CVA / Pneumonia)
 - Falls and hip fracture
 - Feeding issues (choking, eating at risk, chest congestion, pneumonia, feeding tube)

"He turns his head. He looks at me. I know he hears me. 'Hi, Dad, I'm here.' I repeat. 'How are you today?!' He looks at me and smiles weakly. Maybe he recognizes me today - I can't really tell."

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Total care with all ADLs
 Incontinent of bowel and bladder - often unaware
 Decreased mobility; progression from walking unsafely →to wheelchair-bound →unable to stand up →lift transfer →unable to sit up, roll over or move in bed
 Muscle spasticity, decreased ROM, and pain (often unable to smile or laugh)
 Pressure wounds on back, tailbone, heels (decreased healing)
 Risk of pneumonia (decreased mucus clearance and immunity)
 Risk of bladder infection (drinking little and decreased immunity)
 Assistance feeding with progression to choking risk →pocketing →agnosia (no longer recognizing food) →loss of interest →then refusing feeding
 Sleeping much of the day
 Changes are occurring more rapidly now

Signposts

Becoming wheelchair-bound
 Feeding difficulties
 →coughing →then choking
 →microaspiration
 Delirium
 Febrile episodes / infections (UTI, pneumonia, skin)
 Refusing food

Good Questions

What percentage of the day is (s)he sleeping?
 How interested is (s)he in food?
 Is there choking or chest congestion?
 Is (s)he losing weight?
 Does (s)he recognize family?
 Are family aware of approaching end of life?

Our Tasks

1. Impeccable comfort care
 - Pain, bowels, sleep
 - Pressure reduction / wound care
 - Mood symptoms and behavioural challenges (taper meds as able)
2. Reduce medications and doses
3. Prepare family
 - Anticipate transitions
 - Clarify goals of care
4. Avoid hospital transfers for:
 - Hip fracture (death by orthopedic surgeon)
 - IV hydration, unless for an acutely treatable, reversible cause. Is resident actually actively dying?
 - Feeding tubes (do not prevent weight loss, choking, or pneumonia and do not prolong life in late stage dementia)
 - IV antibiotics for pneumonia (in late dementia they do not change outcome and IV route makes no difference to survival). Pneumonia was known as the "old man's friend", because it is often a comfortable and quiet way to die. Focus on comfort.

“When the moment came that she was released from this life, I felt loss the depth of which I’ve never experienced. I knew I should feel thankful that she was whole again and that her suffering had finally ended. And I did feel that, but it didn’t dull the pain of this final loss.”

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As people are dying a natural death, they generally stop eating, then drinking, and often refuse when offered. The dehydration makes them sleepy and comfortable, and much less aware of discomforts in their body. They get sleepier and sleepier, and often slip away easily and quietly.

Often subtle changes initially

- Difficulty to awaken for meals
- Sleeping 90% of the day
- Turning away from food
- “(S)He’s changing; something’s different”, “(S)He’s less present
- Recurring chest congestion or pneumonia
- Palliative wounds, or progressive ischemic changes in legs and feet

Terminal delirium

Eating poorly → only drinking fluids → sips only → taking nothing by mouth → mostly sleeping → unresponsive periods → pauses in breathing → mottling of arms and legs as circulation shuts down → natural death

What percentage of the day is (s)he sleeping?

Are you getting him/her up anymore?

Is (s)he interested in food?

Is (s)he still drinking?

Is (s)he comfortable?

1. Notify family early (say “Your mother / father may be dying”)
2. Communicate effectively with family and within the care team to provide coordinated, responsive, seamless care
3. Stop the pills (difficulty swallowing or barely eating)
4. Provide excellent comfort care
 - Pain and bowels
 - Anxiety and restlessness
 - shortness of breath
5. Have conversations with family about “dehydration” as a comfortable part of the natural dying process
6. Support family to “say good-bye” to their loved one in the best way possible
7. Support care staff and fellow residents to acknowledge and honour the loss of their friend
8. Debrief as a care team to improve on quality and process