Kootney Boundary Division of Family Practice
A GPSC initiative

Shuswap North Okanagan Division of Family Practice
A GPSC initiative

Dementia Trajectory Tool: Practitioners

"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

- Memory loss of recent events
- Repetition of questions or stories
- Disorientation
  - to time - missed appoints, 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
- Problems with balance & walking
- Loss of interest in hobbies; apathy, social withdrawal
- Mood changes; anxiety, depression, irritability, paranoia, suspicion

Signposts

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

Good Questions

1. Safety
   - Is (s)he safe with the stove, wandering, with falls, or at night?
2. Dependency
   - How much support does (s)he need?
   - How long can you leave him/her alone for?
3. Burnout
   - How are you coping with this?
   - Are you getting any support?

Our Tasks

1. Make the diagnosis and treat what we can
   - Delirium
   - Depression
   - Dementia
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
     - Discuss goals of care

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"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."

Early Dementia | **Middle Dementia** | Late Dementia | Actively Dying

The Patient

- 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, progressively lose all

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

1. Function: How much help does (s)he need?
   - Dressing/grooming
   - Managing bathroom
   - Walking safely
2. How much has this changed recently? (trajectory and rate of change)
3. 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 once falling
   - Simplify Diabetes Management
     - A1c target < 8. < 9 if frailty. Reduce meds if < 7
     - Fasting glucose < 10 and after meals < 20
     - Reduce glucometers to BID weekly or twice monthly
     - No sliding scale insulin in residential care
     - Longer acting insulins once or twice daily
     - No dietary restrictions
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)

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Dementia Trajectory Tool: Practitioners

"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."

Early Dementia | Middle Dementia | **Late Dementia** | Actively Dying

The Patient

- Total care with all ADLs
- Incontinent of bowel and bladder - often unaware
- Decreased mobility; progression from walking unsafely →wheelchair-bound →lift transfer →unable to sit up, unable to roll or move in bed
- Muscle spasticity, decreased ROM, and pain (often unable to smile or laugh)
- Pressure wounds (decreased healing)
- Risk of pneumonia (decreased mucus clearance and 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

Signposts

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

Good Questions

1. What percentage of the day is (s)he sleeping?
2. How interested is (s)he in food?
3. Is there choking or chest congestion?
4. Is (s)he losing weight?
5. Does (s)he recognize family?
6. 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)

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"When the moment came that she was released from this life, I felt loss the depth of which I've never experienced. It was only then that I fully understood – no matter how much advance warning I had or how much I thought I had grieved, I was now facing something distinctively different. 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."

Early Dementia | Middle Dementia | Late Dementia | **Actively Dying**

The Patient → Signposts → Good Questions → Our Tasks

As people are dying they universally 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 just go to sleep, and often slip away easily and quietly.

- Often subtle changes initially
  - Difficulty to awaken for meals
  - Turning away from food
  - "less present", or "He's changing; something's different"
- Chest congestion or pneumonia
- Palliative wounds, or progressive ischemic changes in legs and feet
- Terminal delirium
- Eating poorly →only drinking →sips only →NPO →mostly sleeping →unresponsive apneic periods →Cheyne-Stokes respirations →mottling →natural death

1. What percentage of the day is (s)he sleeping?
2. Are you getting him/her up anymore?
3. Is (s)he interested in food?

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