

## When Your Loved One Has Dementia

# *A Roadmap for Families*

## *A Dementia Roadmap for Families*

Dear Reader,

Known as the disease of a thousand goodbyes, dementia affects about 1 in 7 Canadians over the age of 70 (alzheimers.org). While different kinds of dementia vary in their initial presentation and rate of progression, there are features of the dementia journey common to all. This brochure is a basic roadmap of the territory, to help families orient themselves on the journey they are traveling, and see what's coming farther along the road.

The dementia journey can be roughly divided into early, middle, and late stages, then actively dying. This guide outlines the features of each stage, the signposts that tell you where you are on this road, and what may be coming up next. Included are questions that can help you clarify where you are, and suggestions about things we can do as a family and care team to give your loved one the best possible quality of life where they are right now.

By reflecting together on how quickly your loved one is changing, we can get an idea how long this journey might be. Our trajectory, or how fast things are changing, is the best predictor of how fast things may progress in the future. In the early stages people often change slowly, from year to year. In the middle and especially later stages things start changing faster. When you find that your loved one has changed quite a bit in the last few months, we are likely approaching the last months or perhaps year of the journey. As we transition to actively dying, things change more quickly, from week to week, and then day to day in the last days.

At all stages of the journey we can focus on providing comfort and improving quality of life, working with what we are still able to do and things we can still enjoy together.

Please be gentle with yourself as you read through this roadmap. Loving someone with dementia is a bittersweet journey, that asks a great deal of us as caregivers. All of us will feel guilty; about not giving enough, or losing our patience, or dealing with the inevitable feelings of anger and frustration. We need to give ourselves time and permission to grieve, and adjust to all the losses and changes. We need to acknowledge all the things we are doing, and give ourselves permission to care for ourselves too.

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Your loved one knows at some level the toll their illness is taking on you, and doesn't want to be a burden on you. More than anything else, they want you to be happy, and care for yourself, both now and when they're gone.

Please give them the gift of being kind to yourself.

Sincerely,

*Trevor Janz*

Dr. Trevor Janz  
Residential Care Medical Director  
Interior Health East

### **Useful Resources and Links**

Alzheimer Society Canada:  
*Living with dementia*  
<http://bit.ly/living-with-dementia>

Alzheimer Society Canada:  
*BC's Dementia Helpline,*  
Province-wide: 1-800-936-6033  
<http://bit.ly/dementia-help-line>

HealthLinkBC: *Dementia*  
<http://bit.ly/hlbc-dementia>

Advance Care Planning:  
*Making Future Health Decisions*  
<http://bit.ly/advance-care-bc>

*Care for an older adult who needs help today; Representation Agreements*  
<http://bit.ly/nidus-care-planning>

Alzheimer's or Other Dementia:  
*Should I Move My Relative Into Long-Term Care?*  
<http://bit.ly/move-into-care>

*Care Giver Tips*  
<http://bit.ly/caregiver-quicktips>

Long Term Care:  
*Six Things Physicians and Patients Should Question*  
<http://bit.ly/ltc-6things>

Feeding Tubes for people with Alzheimer's disease:  
*When you need them—and when you don't*  
[http://bit.ly/feedtubes-do\\_dont](http://bit.ly/feedtubes-do_dont)

Treating disruptive behaviour in people with dementia:  
*Antipsychotics usually not the best choice*  
<http://bit.ly/no-antipsych>

Please share this document freely with family and friends.  
A PDF is available online at [www.kbdivision.org/selfcare](http://www.kbdivision.org/selfcare)

This document has been developed by Dr. Trevor Janz with support from the Kootenay Boundary Division of Family practice. You can contact us at [kbdoctors@divisionsbc.ca](mailto:kbdoctors@divisionsbc.ca)

# A Dementia Roadmap for Families

• **Early Dementia** • Middle Dementia • Late Dementia • Actively Dying

## Our Loved One

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 episode of confusion;"spell"

**Delirium** (confusion, disorientation and often restlessness) 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, or stove

Needing help to dress, wash, shave, brush teeth

Wandering or lost

Unsafe alone

Night problems

Incontinence of bladder, then bowel

## Good Questions

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?

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## Our Tasks

1. Get a clear diagnosis and treat what we can.

- Delirium
- Depression
- Dementia – identify type if possible: Alzheimer's, vascular, Lewy Body, frontotemporal, or Parkinson's.

2. Reduce the burden of too many pills.

3. Focus on comfort and quality of life.

- Pain
- Bowels
- Sleep
- Mood / behavioural challenges (anxiety, depression, delusions)

4. Get support, and regularly check in with yourself about your stress level and signs of burnout.

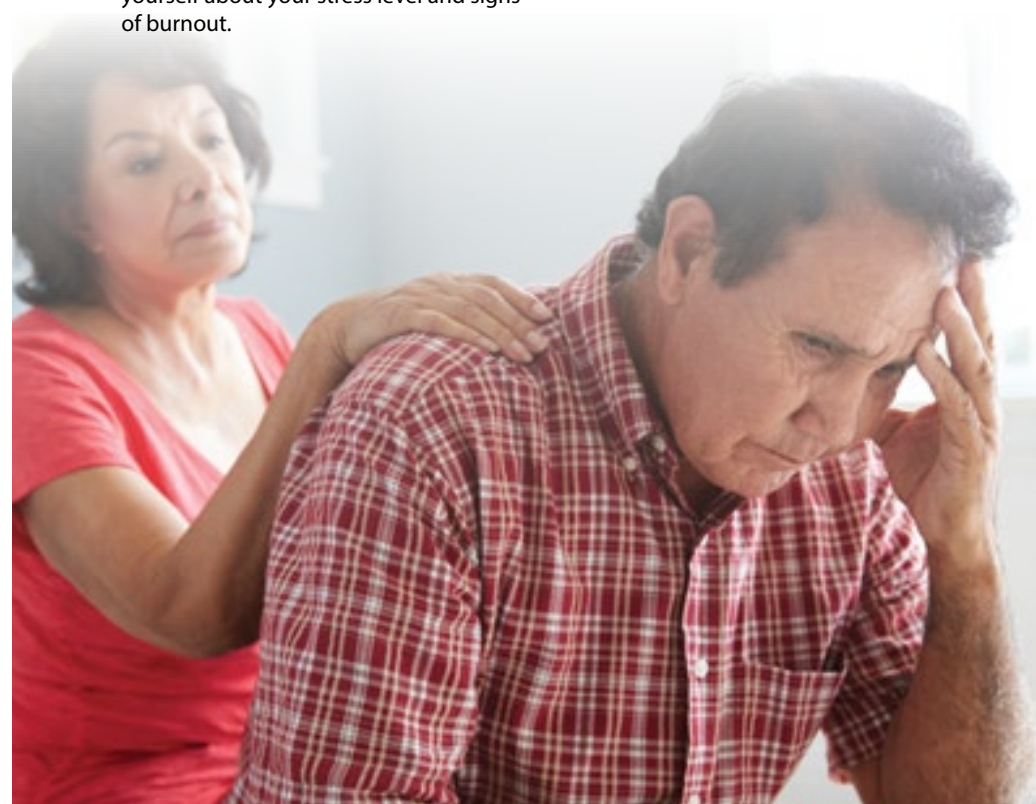
5. Prepare for the future.

- Get information on dementia and future changes coming
- Start care planning discussions

6. Put affairs in order.

- Finances
  - Joint accounts
  - Enduring power of attorney, representative agreements, committee ship
  - Will/estate planning
- Health
  - Appoint substitute decision maker or representative
  - Discuss goals of care

“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.”



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## Our Loved One

### Progressive loss of basic activities of daily living (ADLs)

- Dressing
- Bathing and grooming (hair, teeth, shaving)
- Managing bowel and bladder
- Ability to speak and express needs
- Walking safely
- Feeding
- Able to do these ADLs initially, but progressively lose them all over 1-3 years

## Signposts

Loss of continence

Walking unsafely and risk of falls

Admission to residential care

Needs help 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)

### Thinking and orientation

- 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 can say?

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## 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. Talk to your doctor about reducing medications.
  - Pills only for comfort, in seniors-friendly doses
  - Stop preventative medications
  - 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 weekly or twice monthly
    - No sliding scale insulin in residential care
    - Longer acting insulins once or twice daily
4. Focus on comfort.
  - Pain, bowels, sleep
  - Mood/ behavioural challenges (responsive behaviours, delusions, anxiety)
5. Connect / Communicate / Form a team with your doctor and care team.
  - Prepare for changes to come by having conversations:
    - about current situation, recent changes, and rate of change
    - At each signpost, about what's coming next
  - Prepare for upcoming choices about:
    - Avoiding hospitalization (heart attack, stroke, pneumonia)
    - Falls and hip fracture
    - Feeding issues (choking, eating at risk, chest congestion, pneumonia, feeding tube)

*“Every month, there’s a little less of Mom there to see. They call it the disease of a thousand good-byes. Now I know why.”*



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## Our Loved One

- Needs 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, roll over or move in bed
- Muscle stiffness, pain, decreased range of motion. Often unable to smile or laugh.
- Pressure wounds on back, tailbone, heels (decreased healing)
- Risk of pneumonia (unable to breath deeply or cough to clear mucus)
- Risk of bladder infection (drinking little and decreased immunity)
- Needing more and more assistance feeding with gradual progression to choking risk → pocketing → no longer recognizing food → loss of interest → then refusing feeding
- Sleeping more and more of the day
- Changes are occurring more rapidly now; from month to month. We are approaching the end.

## Signposts

- Becoming wheelchair-bound
- Feeding difficulties → coughing → then choking → aspirating food into the lungs causing chest congestion
- Delirium (acute confusion, disorientation, restlessness)
- Febrile episodes/ infections (bladder, 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 you?

Are all family members aware of approaching end of life?

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## Our Tasks

### 1. Focus on comfort care

- Pain, bowels, sleep
- Pressure reduction for bony places with weight loss and immobility
- Mood symptoms and behavioural challenges

### 2. Reduce medications and doses

### 3. Prepare as a family

- Anticipate coming changes (infections, feeding problems, choking)
- Clarify goals of care

### 4. Avoid burdensome medical interventions that will not improve quality of life

### 5. Avoid hospital transfers for:

- Hip fracture if very frail and eating poorly
- IV hydration, unless for an acutely treatable, reversible cause. If your loved one is dehydrated because of drinking poorly, are they actually actively dying?
- Feeding tubes (they 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.

“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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## Our Loved One

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.

- Changes are often subtle initially:
  - Difficult to awaken for meals
  - "less present", or "He's changing; something's different"
  - Chest congestion or pneumonia
  - Palliative wounds, or progressive skin breakdown in legs and feet as circulation slows
- Terminal delirium (confusion, disorientation, restlessness)
- Turning away from food. Their metabolism is shutting down.
- Eating poorly → only drinking → sips only → taking nothing by mouth → mostly sleeping → unresponsive periods → pauses in breathing → mottling of arms and legs as circulation shuts down → natural death

## Signposts

## Good Questions

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?

Who in the family do we need to talk to?

Who will have a hard time with this, and needs our support?

*“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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## Our Tasks

1. Notify all family members early (say "Mum/ Dad may be dying").
2. Communicate with other family members and the care team to keep everybody in the loop.
3. Stop the pills (difficulty swallowing or barely eating)
4. Focus on comfort care. Medications can ease:
  - Pain
  - Anxiety and restlessness
  - Shortness of breathYour loved one does not need to suffer. Dying can be comfortable and peaceful.
5. Dehydration is a comfortable part of the natural dying process. Moisten their lips and tongue for comfort.

## Say "good-bye" to your loved one in the best way possible

- Tell the great stories of who this dear one was, and the things they did that they were most proud of.
  - Share what this person gave to you, and what they meant to you in your life.
  - What did you most respect in them, and what did you learn from them about how to be as a person?
  - What parts of them will you carry with you, and make a part of who you are as a way of remembering and honouring them?
- Loving someone can be sweet, and doesn't need to stop when they're gone.**

