

A Dementia Roadmap for Families

Say "goodbye" to your loved one in the best way possible

- Share 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



When Your Loved One Has Dementia

A Roadmap for Families

A Dementia Roadmap for Families

Dear Reader,

Dementia is known as the disease of a thousand goodbyes. It 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. Many 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.

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 breath
 - Morphine does not hasten death. In tiny doses it can bring comfort and ease distressYour 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



A Dementia Roadmap for Families

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

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
 - Sleeping 90% of the day
 - "He's changing; something's different". "He's less present"
 - Recurring chest congestion or pneumonia
 - Palliative wounds, or progressive skin breakdown in legs and feet as circulation and healing slows
- Terminal delirium (confusion, disorientation, restlessness)
- Turning away from food. Their metabolism is shutting down. If we force food it may cause discomfort or bloating
- 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 he sleeping?

Are you getting her up in her chair anymore?

Is he interested in food?

Is he still drinking?

Is she comfortable?

Who in the family do we need to talk to?

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

What religious or spiritual observances or rituals would be meaningful for her right now?

How would she have wanted the last days of her life to look?

“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.”

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

Longterm Care Medical Director
Interior Health East Nelson, BC

Useful Resources and Links

Alzheimer Society Canada:

Living with dementia

<http://bit.ly/living-with-dementia>

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

Treating disruptive behaviour in people with dementia: *Antipsychotics usually not the best choice*

<http://bit.ly/no-antipsych>

Please share this document with family and friends.

This document has been developed by Dr. Trevor Janz with support from the Kootenay Boundary Division of Family Practice. Please do not adapt or revise without permission. Contact kdoctors@divisionsbc.ca.

This document has been reproduced by the Vancouver Division of Family Practice. For questions about Frail Elder Care in Vancouver please contact Jaimie Ashton, jashon@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 - forgetting the day or month, mixing up days and nights
- to place - getting lost, initially in unfamiliar places (airports, freeways) then in familiar places (shopping mall)

Loss of abilities

- 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

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, the phone, or stove

Needing help to dress, wash, shave, brush teeth

Wandering or lost

Unsafe alone

Night problems

Good Questions

Safety

- Is 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 she need?
- How long can you leave her alone for?

Burnout

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

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

“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.”



A Dementia Roadmap for Families

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

Our Loved One

- Needs total care with feeding and dressing
- Incontinent of bowel and bladder - often unaware
- Decreased mobility; progression from →walking unsafely →to using a wheelchair →unable to stand up →mechanical lift transfer →unable to sit up, roll over or move in bed
- Muscle stiffness, pain, decreased range of motion. May be unable to smile or laugh
- Increased risk of 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, then →pocketing food in cheek sometimes →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)
- Fever or infections (bladder, pneumonia, skin)
- Refusing food at times

Good Questions

What percentage of the day is she sleeping?

How interested is he in food?

Is there choking or chest congestion?

Is he losing weight?

Does she recognize you?

Are all family members aware of approaching end of life?

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
 - Ask your doctor to connect you with a home care case manager to talk about home support, respite care, and adult day program options
6. **Put affairs in order**
 - Finances
 - Joint accounts
 - Enduring power of attorney, representative agreements
 - Will/estate planning
 - Healthcare
 - Appoint substitute decision maker or representative
 - Discuss goals of care with your doctor

“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.”



A Dementia Roadmap for Families

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

Our Loved One

Progressive loss of basic activities of daily living

- Dressing
- Bathing and grooming (hair, teeth, shaving)
- Managing bowel and bladder
- Ability to speak and express needs
- Walking safely
- Feeding

Able to do these activities initially, but progressively lose them all over 1-3 years

Reliving their past: "I have to go to work."; "I need to go home and cook supper."

Repetitive speech or actions:

"Where am I?"; "I want to go home."; "What do I do now?"

Wandering, pacing, or restlessness

Signposts

Admission to residential care

Needing help to dress, wash or shave

Incontinence of bladder, then bowel

Walking unsafely and risk of falls

Becoming wheelchair bound

Choking and feeding problems

Good Questions

Function: How much help does he need?

- Dressing/grooming
- Managing bathroom
- Walking safely

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

Thinking and orientation

- Is she able to:
 - Find her room?
 - Name family members?
 - Express needs in words, or only non-verbally?
- What is the longest sentence she can say?

Our Tasks

1. Focus on person-centred, relationship-centred, personhood-preserving care; Meaningful human relationship is the most important part of quality of life
2. Look for ways to ease 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
4. Focus on comfort
 - Pain, bowels, sleep
 - Mood/ behavioural challenges (responsive behaviours, delusions, anxiety)
5. Connect / Communicate / Work together 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, bladder or skin infections)
 - 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 goodbyes. Now I know why.”