

The Dementia Journey

A Roadmap for Residents and their Families



This brochure gives you a basic roadmap of the dementia journey. We hope this helps you to see and prepare for what is coming down the road. We know that every person's journey will be different. You might see some of these changes or none of these.

Dementia is a disease of the brain that gets worse over time. It causes problems with memory, thinking, and behaviour. Over time, dementia affect more than the brain, it affects the entire body. There is no cure.

With dementia, knowing the journey can help you and your family know what to expect so you can plan ahead.

If you have any questions, please ask us.

Stages of the Dementia Journey

Dementia basically has 4 stages: early, middle, late, and actively dying. Over the next few pages, we outline each stage, the possible signs that help tell where you are on the journey, things you can do, and what to expect next.

In the early stages, changes often happen over years. In the later stages, things start changing from month to month, or even faster.

Dementia Stages and Possible Signs

Early Stage

- Change in memory (cannot remember recent events)
- Repeating questions or stories
- Hard time learning new things
- Trouble paying attention and focusing (such as making meals, taking medicines)
- Get lost easily or wander
- Sometimes change in mood, such as feeling depressed or not taking part in (withdrawing from) social occasions

Middle Stage

- Begin to forget how to do every day activities and need help with eating, bathing, getting dressed, shaving, etc.
- Live in the moment, maybe only focus on what is in front of you
- Relive your past, saying things like “I have to go to work” or “I have to go home”
- Trouble deciding or making choices, such as following direction or understanding conversations
- Changes in mood that come and go, maybe anxious, sad, angry, frustrated, or paranoid then back to your usual self
- Changes in behaviour that come and go, such as wandering or pacing if restless or uncomfortable (might forget where your room is one time then remember at another time)
- Trouble controlling bowel and bladder
- Unsteady on your feet and when walking

The Dementia Journey

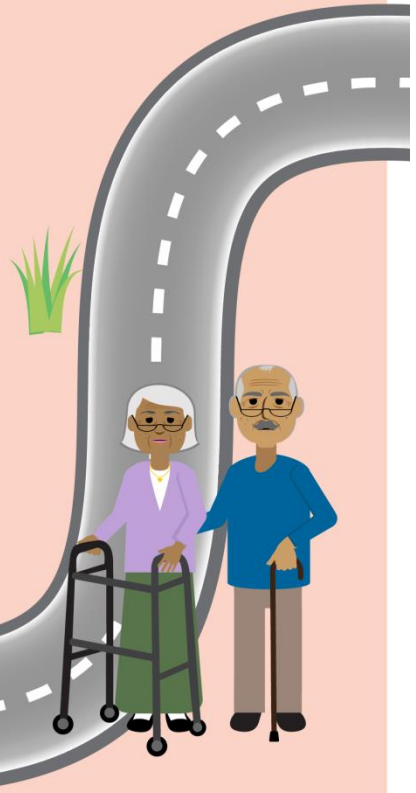
Early



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- Forget things
- Wander or get lost easily
- Trouble making meals
- Trouble managing medicines

Middle



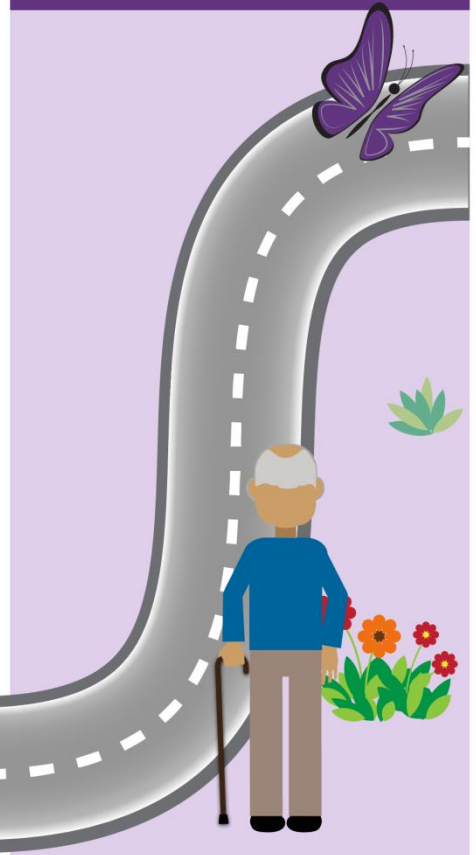
- Might forget where my room is
- Forget what or when I last ate
- Feel anxious or restless
- Wander or restless when bored, uncomfortable, or confused
- Need help to eat, bath, get dressed

Late



- Not recognize family and friends
- Forget how to walk
- Need help to eat and/or forget how to eat
- Problems swallowing (choking, coughing)
- Trouble controlling bladder and bowels

Actively Dying



- Not interested in food
- Losing weight
- Withdrawn or 'less present'
- Sleep most of the day
- Stop eating and drinking

Dementia Stages and Possible Signs

Late Stage

- Need help with all care and everyday activities (brushing teeth, eating, bathing, getting dressed, shaving)
- Problems swallowing (might notice coughing when eating)
- Cannot control bladder and bowel, and eventually do not notice
- Not recognize family members or friends
- Forget how to walk without help or how to sit up without support
- Sleep more during the day
- More fragile skin
- Less able to move in bed or chair (could cause pressure sores on back, tailbone, and heels that are slow to heal)
- Not able to tell others what you want or need
- Trouble finding the right words to tell people what you want or feel

Actively Dying

- Changes happen more quickly
If changes are happening week to week, there may be weeks left.
- Often the changes may not be obvious at first
- Sleep most of the day (80%-90% of the day)
- Trouble waking up for meals, lose interest in food, and losing weight - eventually will stop eating and drinking
- 'Seem different' and withdrawn or 'less present' to those around you
- Feel pain, short of breath, or be restless

Ways to help on The Journey

What you can do

- Connect with the world around you through your senses: touch, smell, vision, and hearing.
- Do activities that are meaningful and important to you.
- Play music you like.
- Go out and enjoy the outdoors.
- Talk with your family and care providers about your goals and wishes for future medical care, and what you would like and not like regarding your care.

What your family can do

- Fill a box with items that represent your interests, past work, and happy memories.
- Look at photographs or movies of past events with you.
- Tell you stories about past celebrations and enjoyable times.
- Play your favorite music or music that has special meaning to you.

What we will do

- Focus on your comfort, dignity, what you need, what is important to you, and what you prefer.
Our approach is about giving you care that gives you the best quality of life. We ask everyone *“What do we need to know about you as a person to give you the best care possible?”*
- Identify and manage pain, shortness of breath, restlessness, and any other discomforts you have so you are as comfortable as possible.
- Support you to have meaningful routines, symbols, music, practices, and rituals that can trigger happy memories and give your life meaning.
- Offer options to support your spiritual, emotional, social, and mental health needs.

Where to learn more about dementia

Fraser Health

- Dementia and Alzheimer's disease



fraserhealth.ca
bit.ly/2BrH9tD



- Advance Care Planning



1-877-825-5034



fraserhealth.ca/acp



advancecareplanning@fraserhealth.ca

HealthLinkBC

- Dementia Overview, Frequently Asked Questions, and Resources



bit.ly/2nUBhQe



Alzheimer Society of Canada

- Ambiguous Loss and Grief in Dementia: A Resource for Individuals and Families



bit.ly/2Mng5km



- Dementia and End of Life Care



bit.ly/2waMb82



- First Link® Dementia Helpline



1-800-936-6033
604-681-8651

Acknowledgements

This brochure is based on the booklet *A Dementia Roadmap For Families*, developed by Dr. Trevor Janz and the Kootenay Boundary Division of Family Practice. The original is available (with translations in development) from www.divisionsbc.ca/kb/resourcesformembers. Please contact www.divisionsbc.ca/kb for permission to adopt or share the original resource. Fraser Health Authority created this brochure and adapted with permission from the authors. Please contact Fraser Health for permission to adopt or adapt this brochure.

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This information does not replace the advice given to you by your healthcare provider.

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