



Frailty Roadmap for Families

A guide to help ensure safety, provide comfort, and improve the quality of life for you or your loved one

A Frailty Roadmap for Families

Becoming Frail

You're reading this because you or someone you love is becoming more weak or tired, and is starting to need more help.

- Frailty is a natural and inevitable part of our aging. As we grow older, we all gradually lose some of our muscle mass and strength, have less energy and ability to exercise, and have decreased physical reserves
- We are more vulnerable to illness or injury, and take longer to recover
- We may have heart disease, strokes, diabetes, arthritis, hearing or vision problems, or other diseases that can all increase our frailty, and it is cumulative. The more chronic health conditions we have, the more frail we become
- We may also have some early problems with memory, or making good decisions, that can make us less able to look after ourselves
- Our frailty is a good predictor of how much strength and time we have left. We can't cure it, but can stabilize the rate of decline, and provide supports for safety and to improve quality of life

Welcome to the Frailty Roadmap for Families

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 frailty journey can be roughly divided into early, middle, and late stages, then end of life. 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 you or your loved one the best possible quality of life where they are right now.

How Much Time Do We Have?

By reflecting together on how quickly your loved one is changing, we can get an idea of 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 approach the end of life things change more quickly, from week to week, and then day to day in the last days.

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At all stages of the journey we can focus on ensuring safety, providing comfort, and improving quality of life. Preparing early and having good conversations with our loved ones about what's coming next will help us manage these changes more safely and gracefully.

For Caregivers

Please be gentle with yourself as you read through this roadmap. Loving and caring for a person with increasing frailty can be a very demanding and tiring task. Many of us may feel guilty; about not giving enough, not being patient enough, or dealing with the inevitable feelings of exhaustion and frustration. We need to give ourselves time and permission to grieve, and adjust to the losses and changes for our loved one, and for ourselves. We need to acknowledge all the things we are doing, and give ourselves permission to care for ourselves too.

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. Underneath it all, 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

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This document has been developed by Dr. Trevor Janz with support from the Vancouver Division of Family practice. Please do not adapt or revise without permission. You can contact us at vancouver@vancouverdivision.com

A Frailty Roadmap for Families

• **Early Frailty** • Moderate Frailty • Severe Frailty • End of Life

Our Loved One

Having Less Energy

- Moving more slowly
- Less steady walking
- Often feeling tired; needing to stop and rest
- Getting less done in a day
- Socializing less

Needing More Help With

- Getting around town
- Looking after the house and yard
- Doing taxes/paying bills
- Managing medications
- Shopping and making meals
- Managing dribbling or urinary incontinence

Concerns About Safety

- Driving
- Risk of falls, and unsafe walking outside alone
- Vulnerability to computer/phone scams and financial abuse

Signposts

Forgetting recent events, or repeating stories

Needing more help with meals, the stove, medications, or money

Losing the ability to walk or do stairs; needing a cane or walker

Acute “spells” of confusion, dizziness, or fainting

Fall or fracture, especially if unable to call for help

Needing more personal help with baths, hygiene, or incontinences

Good Questions

What things do I feel less confident about doing now?

Am I more anxious about managing things by myself?

How safe am I alone at home? Can I call for help when I need it?

Do I have family or a support network, for times when I need more help?

What supports do I need to stay at home safely?

What changes need to be made in my house to help me stay at home longer?

Is it time to talk about moving into a smaller place, supported housing or assisted living?

Am I making good choices about my safety?

Am I limiting my driving; at night, or outside my neighbourhood?

Do other people feel safe riding in the car with me?

Our Tasks

1. Optimize what we can

- Vision, hearing, nutrition
- Walking strength, balance, and safety
- Medical conditions, to avoid crisis trips to the ER
- Promote healthy socialization and avoid isolation

2. Reduce the burden of too many pills

- Talk to your doctor and pharmacist about simplifying medications to reduce side effects like confusion, fatigue, and stomach upset

3. Focus on comfort and quality of life

- Manage pain, bowels, sleep, and mood (anxiety, depression)
- Provide dignity-preserving help with incontinence

4. Get supports to improve safety and reduce stress

- Connect with a case manager or home support nurse to do a home assessment
- Consider home support for meals, help with medications, bathing or dressing

- Look into getting help for housework, yard, errands, or shopping
- Consider supports like a personal emergency call system, Meals on Wheels, auto-bill payments

5. Make home safer

- Handrails for stairs, toilet, and tub
- Bath chair, bathtub mat, hand shower nozzle, home support worker
- Removing tripping hazards like throw rugs and electrical cords
- Adding nightlights and motion sensor activated lights for stairs and doorways
- Moving to a main floor bedroom

6. Put affairs in order

Finances

- Joint bank accounts to allow family support managing bills and finances
- Enduring Power of Attorney; allows appointed person to manage finances/ pay bills and taxes if you or your loved one becomes unable
- Will and Estate Planning

Healthcare

- Appoint a substitute decision maker or representative to speak for you if you are no longer able to speak for yourself
- With your doctor, consider the risks and benefits of proposed medical interventions or surgery. As we become more frail and medically complex, our risk of complications or poor recovery is greater
 - Will this test/procedure help me maintain my abilities or quality of life if things go well?
 - What are the risks if things go badly, and how much might it cost me, in terms of time spent in hospital, loss of strength and abilities while bedbound, or other potential complications?

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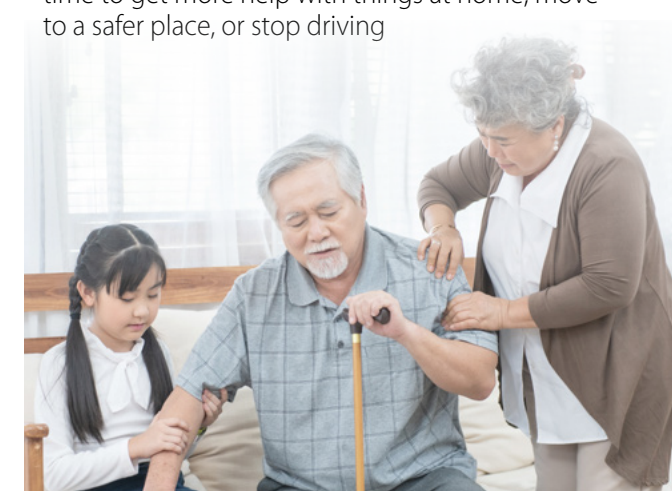
• **Early Frailty** • Moderate Frailty • Severe Frailty • End of Life

7. Have conversations now about what we would like the natural end of our life to look like

- Heart attack, stroke, pneumonia, or a fall/ hip fracture often come without warning. It's important to discuss our preferences with our loved ones and doctor now. We need to know:
 - Would I ever want to be kept alive on machines, short or long term, if my death was imminent with little chance of recovery?
 - If I was very sick and maybe dying, would I want to go to hospital, to the ICU to be put on a breathing machine or other 'life supports', or to surgery?
 - What things would be most important for me in my last weeks and days?
 - What are my hopes for the end of my life, and what are my biggest fears?
 - Where would I prefer to die; at home, in a hospice or long term care facility, or hospital?
 - Have conversations with your family and doctor about recording your wishes now, in a Medical Orders for Scope of Treatment (MOST) document, also sometimes called a Do Not Resuscitate (DNR) order.

8. Plan for the future

- Have conversations about when we'll know it's time to get more help with things at home, move to a safer place, or stop driving



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Our Loved One

Much Less Energy

- Much more tired; needing to rest more often in the day
- Muscle weakness; harder getting up from bed or chair, or lifting things
- Slow or unsteady gait, needing a cane or walker
- Less able to do stairs safely
- Mostly housebound
- Spending most of the day sitting

Needing More Help With

All activities outside the home like shopping and transportation
Money and finances
Using the phone or computer
Housework and cooking
Using stairs or the bathtub
Toileting, grooming (washing, hair, teeth, shaving)
Managing in the bathroom (dribbling, or needing help with clean up)

Concerns About Safety

Significant concerns about driving safety, with possible decreases in vision or awareness of things beside or behind the car, slowed reaction time and judgement, especially in busy crowded intersections
Loss of balance, strength, vision, or judgement all increase the risk of falls, especially in the dark or outside
Risk of burns or fires with cooking and the stove

Signposts

Unable to manage meals, money, dressing, or basic housework alone

Weakness and unintentional weight loss (loss of muscle mass)

Being unable to get up from a fall, or use the stairs alone
Needing help to stand up or transfer from a chair, bed, or toilet

Losing the ability to walk; requiring a cane, walker, or wheelchair

Dizzy spells, fainting, falls, or injuries, especially if unable to call for help or remember what happened

Less reserve; even minor events like sleep deprivation, dehydration, a cold, or bladder infection can cause loss of function

Unplanned trips to the ER for heart or breathing problems, weakness, confusion, or a fall

No longer safe alone at home without significant daily supports or a full-time caregiver present

Needing to move to receive a higher level of care

Good Questions

How long can my loved one be left alone at home without someone checking on them?

How well are they making safe choices for themselves, and how might they allow us to support them with this?

How much longer can my loved one live safely in their current home?

How is this affecting spouse or caregivers?

How much support can family or friends reasonably provide, without causing personal distress, or harm to their other relationships and responsibilities?

Am I as a caregiver getting the support I need, to allow me to keep going?

What's our Plan B, for when we meet our next setback, or lose more abilities?

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Our Tasks

Work together with your doctor and care team to:

1. Optimize what we can

- Hearing and vision
- Medical conditions
- Walking strength, balance, and safety
- Safety aids in the home, or a personal emergency call system
- Maintaining social contact with family & friends

2. Consider stopping medications that don't improve comfort or quality of life

- Many frail seniors feel and function much better when we reduce their pill burden
- We can taper or stop preventative medications, which have fewer benefits and more harms as we age
- Diabetes diet restrictions can be relaxed; eat what you want, for pleasure
- Keep only those pills that support comfort and the best possible quality of life
- Actively manage pain, bladder continence, bowel, sleep, and mood medications to get the best symptom relief at the lowest possible dose, with the fewest side effects
- Work with your doctor and pharmacist to do this safely

3. Communicate that now is the time to stop driving

- Get help from trusted health care team members if this is a difficult topic

4. Have conversations about where our loved one can live safely

- Work towards the best quality of life possible for their condition, knowing that their abilities will decline over time and that more help should be available without having to move again

5. Put affairs in order

- Put in place or review existing financial planning, including joint bank accounts, Enduring Power of Attorney, Wills, and Estate planning
- Appoint a substitute decision maker or representative to speak for you when you are no longer able to speak for yourself
- Discuss healthcare decision making including representative agreements and goals of care conversations. See Nidus.ca

6. Consider proposed medical investigations or interventions carefully

- With increasing frailty it's important to preserve quality of life by avoiding risky interventions
- Frail individuals are more fragile and less likely to recover fully after surgery. They are at higher risk of complications including infection and confusion, and seldom regain their previous level of function after a setback or even brief periods in bed or hospital
- CPR (cardio-pulmonary resuscitation) is an intervention where chest compressions and electric shocks may be administered when the heart stops. It is not recommended for frail individuals, because it doesn't work and causes harm
- Heroic medical interventions at end-of-life may slightly prolong life, but often prolong pain and suffering without any improved quality of life



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Our Loved One

Much Less Energy

- Mostly bedbound
- Needing a ceiling lift or assistance for transfers
- In a wheelchair and unable to mobilize by themselves
- May be too weak to sit up or even roll over in bed
- Too tired to be up in a chair for long, and may sleep more of the day

Completely Dependent For

- Dressing, washing, and toileting
- May be incontinent of bladder or bowel
- May need help with feeding
- Needing 24/7 care
- Unable to be left alone safely

Signposts

Becoming wheelchair bound
Admission to long term care

Periods of confusion;
unresponsive spells

Cognitive impairment and
dementia are common in
late frailty

Difficulties feeding or swallowing;
coughing or choking on foods

Less interested in eating; refusing
at times

Unintended weight loss

Sleeping more and more of the day

Fever and infections (bladder,
pneumonia, skin)

Skin breakdown and pressure
sores from poor healing

Less able to recover from even
minor illnesses

Good Questions

How much of the day are they
sleeping?

How interested are they in
food?

Is there choking or chest
congestion after meals?

Are they losing weight?

Are all family members aware
of approaching end of life?

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Our Tasks

1. Focus on comfort care

- Manage pain, bowels, and skin
- Pressure reduction for bony places with weight loss and immobility

2. Reduce medications and doses, focusing on comfort

- This can be a liberating time when your loved one can be freed from onerous medication routines and strict diabetes monitoring

3. Prepare as a family for sudden, acute medical event

- Infections, feeding problems, choking, dehydration, falls and hip fracture
- Clarify goals of care around use of hospital, surgery, and the ICU

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

- Very frail seniors generally do poorly in hospital or with surgery, are more likely to suffer complications, lose function quickly when bedbound, and almost never get back to their previous level of abilities

5. Avoid hospital transfers for:

- Hip fracture if very frail and already eating poorly. Most stop eating and slip away within days, with or without surgery. "It's far better for Mom" to spend her last days peacefully, in her own room, surrounded by those who know her well
- 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 severe frailty or dementia)
- IV antibiotics for pneumonia (in severe frailty they rarely 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 and quality of life



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Sign Posts For Our Loved Ones

As people are dying a natural death, they generally stop eating, then drinking, and often refuse when offered. The dehydration is a natural and unavoidable part of their dying. It makes them drowsy and comfortable, and much less aware of discomforts in their body. They get sleepier and sleepier, and often slip away easily and quietly. Palliative Care doctors think of dehydration as a comfort to the dying, to ease their journey.

- Changes are often subtle initially:
 - Difficult to awaken for meals
 - Sleeping 90% of the day
 - Too weak to be up in a chair for meals now
 - "He's changing; something's different, he's less present"
 - Recurring chest congestion or pneumonia
 - Palliative wounds, or progressive skin breakdown on tailbone, legs, or feet as circulation and healing slow down
- Terminal delirium (episodes of confusion, disorientation, or restlessness)
- Dying people often dream or speak about long dead family members, who have come to help them come home. This is often a comfort to them. Some call these visitors "the welcoming committee"
- Turning away from food. Their metabolism is shutting down. If we force food it may cause discomfort or bloating. We can offer, but let them choose if they want it right then, and respect their signals
- Eating poorly > mostly sleeping > only drinking fluids > sips only > unresponsive periods > nothing by mouth > pauses in breathing > coolness and mottling of legs then arms as circulation shuts down > natural death



Good Questions

What percentage of the day are they sleeping?

Are you getting them up in their chair anymore?

Are they interested in food?

Are they still able to swallow comfort medications?

Are they still drinking?

Are they comfortable?

Who in the family or support circle do we need to talk to?

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

Are there religious or spiritual rituals, or cultural observances that would be meaningful for them right now?

How would they have wanted us to honour and celebrate the last days of their life?

Our Tasks

1. Notify all family members or supports early (say "Mom/ Dad may be dying")

- False alarms are common, and they may stop eating, then start again several times as they approach their last goodbye
- Communicate regularly with family members and the care team to keep everybody in the loop

2. Check in with and support grieving caregivers. Communicate regularly with 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

Dehydration is a comfortable and inevitable part of the natural dying process. We all stop wanting to

eat, then drink as our body shuts down. Offer sips if your loved one is awake, and let them choose.

When less responsive, you can still moisten their lips and tongue with a wet swab for comfort

Medications can ease:

- Pain
- Anxiety and restlessness
- Shortness of breath

Morphine does not hasten death. In tiny doses it can bring comfort and ease distress. Your loved one does not need to suffer. Dying can be peaceful and comfortable

5. When death is near, consider calling the funeral home, especially if pre-arrangements have been made. They can help guide you through the steps needed at the time of your loved one's death

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 that sweetness doesn't need to stop when they're gone.

"Thank you for all you've given me"

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Resources

Family Caregivers of BC (FCBC) – supports caregivers by providing access to information, education, and supports that enable caregivers to feel more confident and successful in their role familycaregiversbc.ca / BC Caregiver Support Line 1-877-520-3267

Nidus – Advanced Care Planning nidus.ca

PATH Frailty App – rapidly identify frailty pathclinic.ca/app

BC211 – provide information and referral to a broad range of community, government, and social services that assist with support for seniors bc.211.ca / Phone: Dial 2-1-1 (1-888-484-3211)

Care BC – Meals on Wheels carebc.ca

Better at Home – Supporting the non-medical needs of older adults in B.C. betterathome.ca

Canadian Red Cross – equipment loans bit.ly/redcrossequipment

Handydart – TransLink's door-to-door, shared-ride service for people needing assistance to navigate conventional public transit.

Vancouver: bit.ly/handydartvan

Canada Virtual Hospice – virtualhospice.ca

Indigenous and Multicultural Resources – livingmyculture.ca/culture

Qmunity – QMUNITY engages and supports 2SLGBTQIA+ persons 55 years and older bit.ly/qmunityvancouver

VCH Home & Community Care Services – provide a range of health care and support services to people who have acute, chronic, palliative or rehabilitative health care needs bit.ly/homecarevan

Vancouver Community Palliative Access Line – Health care professionals are available to discuss an individual's needs and eligibility for Home Hospice Palliative Care services and refer to the closest Community Health Centre or suggest some alternative resources. Call at [\(604\) 263-7255](tel:6042637255)