

Items still to be covered

ACP. Medical SDM and financial planning.

Goals of care conversations and MOST

Resources for aging in place

Transitions and supports available in Supported Housing, AL, Complex Care

Hydration at end of life.

Dying at home pros/cons/ resources

Driving

A Frailty Roadmap For Families

Welcome to the Frailty Roadmap. You're reading this because you or someone you love is becoming increasingly frail, and is starting to need more help. This guide helps you to understand more about frailty, and gives you ways you can support yourself or your loved one, so we can "Live as well as we can, with the time we have left."

Becoming frail

As we all age and become more frail, we gradually lose some of our ability to cope with everyday and acute stresses. With aging, our physical abilities gradually decrease;

- Our heart, lungs, muscles, and even our brain, are no longer able to do their jobs quite as well as when we were young,

- We have less reserve, mentally and physically

- We can't do as much as we used to; we're more tired, and we have to slow down.

- We spend more of the day sitting on the couch, or napping.

- We also are more vulnerable to illness or injury, and take longer to recover.

All of these are signs of increasing physical frailty. We may also have some early problems with memory, or making good decisions, that can make us less able to look after ourselves.

Our ability to function and manage in the world depends on four things; our physical abilities, our medical diagnoses, our ability to think clearly and remember (our cognition), and our social network of connections and support. Any one of these four can limit our ability to live independently.

Physical Frailty

People with physical frailty can often manage independently if they have the right social supports to keep them safe, and they're clear enough to ask for help when they need it.

These are some indicators of **physical frailty**;

Slow or unsteady gait, or falls

General muscle weakness (stairs, lifting, getting up from a low chair)

Unintentional weight loss (we're losing muscle)

Fatigue or exhaustion

Low level of physical activity (sitting all day)

The more of these we have, the more physically frail we are, and the more likely we are to lose function more quickly over time.

Medical Frailty

The more of these diseases we have, the more our function is limited and the more medically frail we are.

-Brain (stroke, TIAs, Parkinson's Disease, Multiple Sclerosis)

-Heart (hypertension, heart attacks, atrial fibrillation, pacemaker)

-Diabetes

-Lungs (COPD, chronic bronchitis, emphysema, asthma)

-Digestion (stomach ulcers, reflux, colitis, constipation, gallstones)

-Kidney (stones, bladder infections, prostate, renal failure)

-Joints (Osteoarthritis in our neck, back, hips, and knees, rheumatoid arthritis, chronic backache, pinched nerves).

-Loss of hearing and vision (glaucoma, macular degeneration, cataracts)

Each of these diseases and the multiple medications used to treat them result in more limitations to our function, balance, stamina, and overall resilience.

The effects of all these diseases and medications are additive. The more we have, the more frail we become, and the more likely we are to experience poor outcomes from any further challenge to our health.

Thinking and Memory

With increasing age or frailty, there can sometimes be challenges with our ability to think clearly, remember, find our way around, or manage money. A little bit of forgetfulness is very common as we get older, but if we're having trouble remembering what happened today, we're missing appointments or forgetting what we needed to do frequently, we may be developing early dementia.

Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that is severe enough to interfere with daily life. Alzheimer's is the most common cause of dementia. Vascular dementia, due to hardening of the arteries, is the second most common, and they often overlap. Less common forms of dementia are Lewy Body Dementia, which can come with Parkinson's Disease, and Frontotemporal Dementia, which can cause problems with language, social skills, or motivation.

Frailty is not dementia

Let's be very clear about keeping physical and medical frailty separate from memory problems. We may have some frailty, or memory problems, or sometimes a bit of both. Many people who are physically frail can be very clear mentally, and physical frailty does not in any way imply dementia.

And, since we need both physical strength and mental abilities to function in the world, a problem with either can limit our functional ability. Often there can be both, with some people being more physically or medically frail, and some having more memory problems.

Early Signs of Dementia

- Not remembering recent events

- Repeating the same stories or asking the same questions over and over

- Trouble managing purse, wallet, or phone

- Getting mixed up about people or places

- Having more trouble with driving, managing money, shopping, or cooking.

- Needing more help with dressing, washing, bathing, or meals.

- Needing supervision to keep safe, and trouble managing problems alone.

- Behavioural problems; refusing help or personal care

Early dementia often affects mood, with some people becoming more withdrawn from family, friends, or hobbies. Some may be sad, anxious, depressed, or apathetic. It is common for people with early dementia to become easily irritable and frustrated when outside their comfort zone.

People with dementia very soon need a social support network, spouse, or live-in caregiver to help keep them safe.

Safety concerns about driving, the stove, medications, money, wandering or getting lost, being up at night, or falls are all common. If the person doesn't have the ability to recognize they're in trouble and know how to call for help, they need even more support, and may no longer be safe to live alone.

Caring for a person with memory problems or dementia can be exhausting, and spouses often struggle. They tell me this is the hardest thing they've ever done in their life. It often becomes impossible for them when their loved one can no longer get in and out of bed or off the toilet even with help, or starts wandering, is up at night, develops incontinence, or is angry or scared, or refuses needed care.

People with moderate dementia eventually need facility care when it's no longer possible to manage them at home safely. At that point their caregiver is exhausted, and their own health and well-being is often failing. Their loved one often does better in the very social environment of a care home, with more stimulation, activities, and human interaction. Their spouse can enjoy quality time with them, then go home and rest, and regain some health and quality of life. Their spouse would not want them to suffer because of their dementia.

See "A Dementia Roadmap For Families" for more information and support.

Frailty and Functional Status: What Can I do For Myself?

Our **overall frailty** is the sum total of our physical frailty, our medical frailty, and our ability to think clearly and remember. One of the best ways to assess our overall frailty is to look at functional status. The more help I need to do these things, the more frail I am. I may need help because I'm too tired or weak, or because I can't remember how to do it.

Basic activities of daily living (ADLs)

Grooming (hair, shaving, make-up)

Dressing

Bathing

Toileting (continence of bladder and bowel)

Mobility (ability to walk safely and get up from bed or toilet)

Eating

Advanced activities of daily living

Using the telephone

Getting around town (driving, buses, taxi)

Shopping

Preparing meals

Housekeeping and laundry

Managing medications

Handling bills and finances

How Frail Am I?

I have Mild or Early Frailty. I feel tired every day, and I sometimes have trouble walking alone outside the house, even with my walker. I need help with getting around town, shopping, meal preparation, and managing my pills or money. I may be able to live on my own if I have the right supports and I remember to call when I need help.

I will do my best and feel safest when my needs are well supported, in a place where I can have bad days or minor disasters (like dizzy spells, falls, bladder infections or a chest cold), without causing a crisis, or winding up in hospital. I'm vulnerable to falls, especially when I take too many pills, and I don't want to break a hip like my friend. If I wound up in hospital, I might not get strong enough to get back to my home again. My doctor says we need to consider very carefully before embarking on surgery or other major medical interventions, because he says complications and poor outcomes are very common. I want to hang on to my function and quality of life for as long as possible.

(Adapted to first person narrative. Is this effective, or sounds contrived?)

(My spouse has moderate frailty...)

People living with **Moderate Frailty** need help with all activities outside the house, and with preparing meals, managing stairs, and bathing. They can't stand for long periods, and often nap in the day. They need someone to support all their advanced ADLs of money, getting around, shopping, and housekeeping.

They are very vulnerable to over medication, and will decompensate quickly with even minor sleep deprivation, dehydration or poor feeding, minor colds, or bladder infections. They frequently have 'bad days', dizzy spells, unresponsive episodes, falls, or injuries leading to emergency visits and hospitalizations.

We should only consider very limited medical interventions that have a high likelihood of improving quality of life. They do badly with surgery, and frequently suffer delirium (severe confusion and agitation) and other complications after even minor medical interventions. They suffer significant loss of function with any hospitalization or period of immobility, and will not regain their previous level of function after a setback. We can mitigate or stabilize their loss of function, but not reverse it.

They are often in their last year or two of life, and could have a heart attack, stroke, pneumonia, fall and hip fracture, or other serious event without warning.

(My mother has severe frailty...)

People living with **Severe Frailty** are completely dependent for personal care, are in a wheelchair and may be too weak to stand up. They need help with dressing, washing, eating, and may be incontinent of bladder and bowel. Some are too weak to sit up by themselves in bed, or even roll over without help. They are too tired to be up for long periods, and spend more and more of the day sleeping as their frailty progresses. They may have difficulty communicating, and expressing their personal needs (hungry, cold, wet, tired...). They may be too weak or forget how to swallow, and foods start going down the wrong way, causing coughing and choking.

They are in the last months to year of their life, and the best indicator of how much time they have left is how quickly their function is changing. If they are changing from month to month, they likely have months left, and are **approaching end of life** (He's sleeping so much more in this last couple months). If they've declined a lot in the last weeks, they are in their last weeks, (He's less and less interested in eating this last week). If they're changing from day to day, they're in their last days (For two days now, he's doesn't even want to drink when I offer it to him), or last hours (cold mottled hands and feet, longer pauses in breathing).

Quality of Life

As we become more frail, diagnostic tests and surgical procedures are much more likely to cause unintended harms, and may even worsen our overall quality of life. If we are moderately or severely frail, and suffer a significant medical setback, we may be offered medical intervention without considering our

underlying frailty and our approaching end of life. Because of our frailty, a failure in one system leads to a cascade of failures in all the others. We experience complications, and are offered more burdensome medical interventions. Our last few weeks or months are spent in the hospital bedbound and with very limited quality of life. This approach can prolong the dying process, and lead to considerable unnecessary suffering.

Most of the seniors I talk to want to live well for as long as they can, but once they're tired and weak and sick, they don't want to linger. They don't want to be a burden to the ones they love, and would like to go with some respect and dignity. Once they're unable to get up off the couch, or walk around in the house, or feed and dress themselves, or be able to recognize and talk to the people they love, they don't want to live like that. They would like us to let them go, quietly and peacefully.

Choosing Wisely

For all of us as we become more frail, we need to choose very carefully how much medical intervention we want. Some people are willing to go through quite a bit of medical intervention if it means they might live a little longer. For others, it's much more about quality of life than quantity, and they would rather avoid medical interventions, stay home as long as possible, and be allowed to go when it's their time.

Anytime a procedure is being considered, we need a careful assessment of our level of function, our overall level of fitness or frailty, the clarity of our thinking, and our preferences about quality of life. With that understanding, we then need a frank conversation with our family doctor and specialist about our options and best choices.

Questions to ask include

Can my problem be fixed easily?

Can I be made comfortable without this procedure?

How much will this treatment cost me? (In time stuck in the hospital,, discomfort, side effects, travel, etc.)

Will this treatment affect my function or memory?

What is the best quality of life I can hope for if the procedure goes well, and how likely is that?

Given my overall condition, what complications might come if things go badly?

How many more good quality years might I get, especially at home?

PATH, a Canadian program specifically designed to have these conversations, found that patients and families consistently decline more than three quarters of the proposed tests and procedures once they understand the pros and cons for their own medical situation and level of frailty.

(First Draft fragments)

Getting Help

As we become more frail, our ability to do these activities of daily living (ADLs) can be limited by our physical frailty, or our ability to think and remember. If I have a social network of connections and support who can help with the parts I can't do, I can still manage at home. Family and friends are often able to step in and provide support with drives to the mall, doctor's appointments, and help with bills and taxes. These are advanced activities of daily living, and if we have a large circle of friends and family, we can often organize the support we need. We can sometimes hire people to provide these services to allow us to live independently.

Interestingly when we live as a couple, my deficits can be balanced by my spouse's strengths, and vice versa. If my spouse has memory problems, and my arthritis makes it hard to get around, we can still manage at home. I can be the brains of the operation, and my partner can be the hands and feet. We can shop together with me in my wheelchair and my partner pushing the shopping cart. As long as both of us together have the necessary skills, we can manage, but if either one loses abilities or has to go to hospital, both of us will need more support, and may no longer be able to live independently.

When I Need Help Every Day

When we start needing help with basic activities of daily living (ADLs), on a weekly or more frequent basis, we often need to get help from home support for baths and personal care, or hire a caregiver. As long as we have the ability to make good decisions and direct our care, we can still live independently even though we need a lot of physical assistance.

If we are relying on a spouse or family member for basic ADLs, we know that their strength, energy, time, and goodwill are not unlimited, their health will be challenged by the burden of providing care, and that caregiver burnout will come. We don't want to cause harm to those we love, and will need to make choices to get the support we need in a way that's healthy for everyone involved. We may need to move into a supported housing or assisted living apartment where caregivers can provide support with meals, personal care, medications, or mobility.

If I or my partner has memory problems or dementia, this can be much harder to manage. With dementia, many people experience behavioural changes, and may become unwilling to accept care or direction. This can be very challenging for the spouse or caregiver, and often medications are needed. It often becomes too challenging to manage at home when incontinence of urine or bowel starts to happen, or the spouse is up in the night and the caregiver

stops getting enough sleep. At this point we need much more full time help, and may eventually need facility care for everyone's wellbeing. See "A Dementia Roadmap For Families" for more information and support.