

# **PALLIATIVE AND THERAPEUTIC HARMONIZATION (PATH)**

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## **DEVELOPING KNOWLEDGE TRANSLATION TOOLS FOR CAREGIVERS OF FRAIL ADULTS WITH DEMENTIA**

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## Background

The need for programs which address end of life care for frail older adults is identified in the Strategy for Positive Aging in Nova Scotia<sup>1</sup> and is “a main focus” of the Continuing Care Strategy for Nova Scotia<sup>2</sup> but this need has not yet been translated into clinical programs. In an effort to deliver appropriate and sustainable health care to the growing population of frail older adults, the Palliative and Therapeutic Harmonization (PATH) model of care has been developed and implemented in the Capital District Health Authority (CDHA) since early 2009.

In 2008, the Principal Investigators (PM and LM) combined the results of an extensive literature review with their clinical experience to understand the requirements for an effective model for improving end-of-life care for frail older adults. This initial phase of the project culminated in the development of the PATH model and its principles.

The PATH model serves inpatient and outpatient populations of frail older adults with chronic health issues (often including dementia) where families or caregivers have questions about prognosis and future care planning, and where the benefit of aggressive medical or surgical interventions may be questioned. The model has been piloted within the CDHA and is being modified for community and long-term care settings in the South Shore Health District and Guysborough Antigonish Strait Health District.

### ***Description of PATH***

The PATH (Palliative and Therapeutic Harmonization) was developed to purposefully consider how frailty and dementia impacts medical decision-making.<sup>3,4</sup> PATH focuses attention on the final chapter of life, using a structured methodology using 3-steps that endeavor to:

1. Obtain a complete understanding of health status through comprehensive geriatric assessment;
2. Exchange information with patients/caregivers and health care workers to promote understanding of overall health status and the expected trajectory of decline based on underlying health conditions; and
3. Empower patients/caregivers and health care workers to use their new understanding of frailty in decision-making.

Greater understanding of health allows people to make well-informed decisions that will help ensure a comfortable life and, eventually, a dignified death. Using this process and

when provided with detailed information about frailty and its implications, health care workers, patients and caregivers usually choose less aggressive care. Preliminary experience with the PATH program indicates a 76% reduction in the demand for healthcare services and interventions. PATH received a Gold Quality Team Award from the Capital Health District in Nova Scotia and has been recognized as a leading practice by Accreditation Canada.

### ***The Need for Knowledge Translation***

One of the identified requirements of an effective model is that it include patient and caregiver information kits that combine state of the art clinical information about frailty and its composite diseases (including dementia) with practical tips on how to approach decision making. Thus, the next phase of program expansion involved the development of tools for information provision for patients and caregivers as well as integration of previously validated tools for information collection from patients and caregivers. Content for print materials were assembled into a PATH Care Planning Manual through funding received from a CDHA Innovation Grant. Given the high prevalence of dementia in the frail elderly, many of the materials directly address the clinical presentation and progression of dementia.

Preliminary feedback from participants in the PATH process indicates that print materials foster understanding of prognosis and facilitate care planning decisions, but experience from the PATH clinic indicates that the hard copy format has its limitations. For example, information packages or contact information etc. may be misplaced once participants have left the clinic. Also, participants may wish to share PATH resources with others. The need for consistent accessibility of resources during and after participation in the PATH process has become evident. Therefore, we requested and received funds to create a basic, stand alone website aimed at caregivers (aged 50 and older) to make PATH materials easily available online. This online resource will be crucial to the growth of our satellite sites and to increasing accessibility to PATH resources across the province.

### **PATH Collateral**

The CDKTN grant helped us to develop the following knowledge translation materials:

#### **1. The PathClinic.ca Website**

It is often questioned whether those 50+ are interested in or capable of using such technology, however, according to a 2009 report,<sup>5</sup> seniors are the fastest growing

group of internet users. According to the “Rural Communities Impacting Policy Project”<sup>6</sup> approximately 60% of Nova Scotia’s population lives in rural areas, and 21% of this rural population is over the age of 65. Urban seniors in Nova Scotia have access to broad band, and the Government of Nova Scotia has an ongoing project to supply broadband access to all rural Nova Scotians with a completion date of Spring 2010.

We engaged a local firm (HiThere) to develop a website to serve as a hub, from which to communicate the details of the PATH process and provide access to PATH resources. This firm assisted us with determining the most appropriate and effective way to present online information, including appropriate text size for older users and fluid site navigation. The firm adopted graphics and design elements currently used to brand the PATH Clinic and incorporated them in the design. The firm also arranged website hosting and domain name acquisition through a reliable Canadian third party host.

The website went live on July 4, 2011. A screen shot of the home page, including acknowledgement of support from the CDKTN, is shown in Appendix A.

The website was developed with the following information pages:

**About PATH:** This section of the website addresses commonly asked questions about the PATH program, including: What is PATH? Who is it for? What can I expect? There are subpages that describe why the PATH approach is needed and the fundamental principles of the program. Under this section, we also recognize the achievements of the PATH program and active research initiatives.

**The PATH Process:** This section of the website includes subpages that explain what happens at each of the three clinical PATH visits and provides resources for dealing with decision making when a medical crisis occurs.

**The PATH Team:** This section provides information about the co-founders of the PATH program and where the program is currently offered.

**Physician Information:** This page offers a concise summary of the PATH model and provides links to referral forms for a PATH consult.

**Resources:** This section provides links to PATH resource materials, including selected information sheets and presentations delivered by the Principal Investigators (video, PowerPoint and other formats). Subpages link users to news

articles and other PATH-relayed media, peer-reviewed publications of the PATH program, and other non-PATH specific resources.

## **2. Promotional Magnets**

To promote site traffic and awareness among current and potential PATH participants, we worked with CDHA Audio Visual Services to design and print (2500) refrigerator magnets that prominently display the website address and clinic contact information. Since they became available in April 2011, the magnets have been distributed in-clinic to participants as part of the standard PATH orientation package (first visit). In addition, magnets have been distributed at relevant provincial conferences and events, to referral sources (physicians and Continuing Care coordinators) and to other senior serving organizations such as the Alzheimer Society of Nova Scotia, Caregivers Nova Scotia, the Department of Seniors, and The Nova Scotia Hospice and Palliative Care Association.

A sample magnet has been enclosed with this submission.

## **3. Understanding Frailty Information Sheet**

The funding received from CDKTN allowed us to hire a writer to translate peer-reviewed evidence and the Principal Investigators' clinical experience about understanding and managing frailty into an easy to read information sheet targeted at caregivers of older frail adults. The information sheet explains what frailty is, how it can be recognized, how it is measured, how it progresses, and identifies common risk factors. The information is comprehensive, but is provided in short, manageable sections and includes narratives that help readers understand the impact of frailty in a practical manner. The *Understanding Frailty* information sheet is now a key piece of the information exchange (step 2) component of the PATH model (see Appendix B).

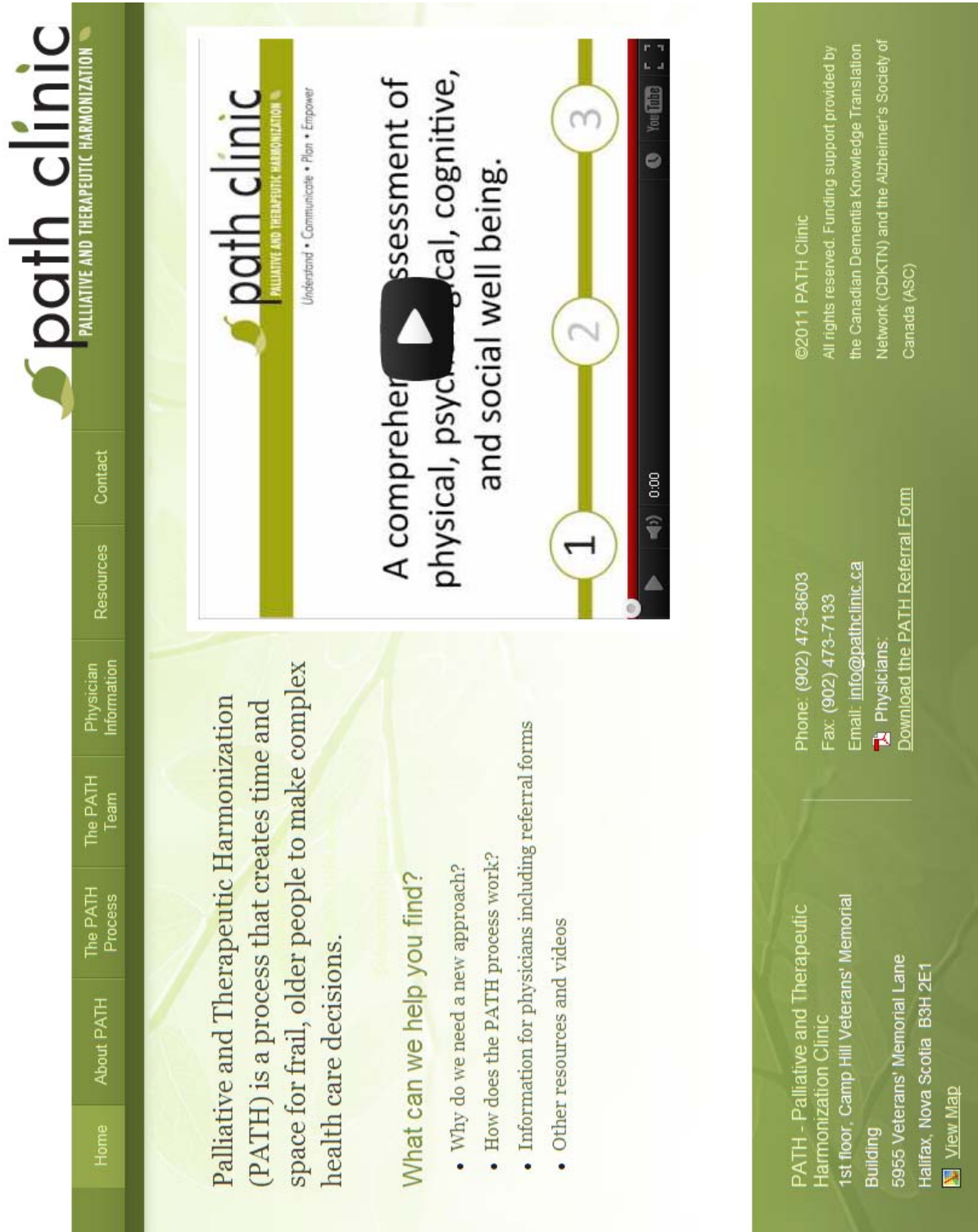
With funding from the CDKTN, our website and knowledge translation materials increase access to knowledge and skills for caregivers of frail older adults who have to make decisions about care planning. By improving accessibility to the PATH materials, this project has helped position the PATH program for larger scale feasibility testing and expansion to satellite sites.

## References:

1. Nova Scotia Department of Health Strategy for Positive Aging.  
<http://www.gov.ns.ca/scs/positiveaging.asp>
2. Continuing Care Strategy for Nova Scotia: Shaping the Future of Continuing Care, Nova Scotia Department of Health, May 2006. Seniors Statistical Profile 2005, p. 76.  
<http://www.gov.ns.ca/news/details.asp?id=20030722001>
3. Mallery LH, Moorhouse P. Respecting frailty. J Med Ethics. 2011 Feb;37(2):126-8. Epub 2010 Nov 21
4. Moorhouse P, Mallery LH. PATH: A new approach to end-of-life care. Canadian Review of Alzheimer's disease and Other Dementias. May 2010.
5. Statistics Canada. 2009. Accessed online at: <http://www.statcan.gc.ca/pub/11-008-x/2009002/article/10910-eng.htm#a5>
6. Atlantic Health Promotion Research Centre. Rural Communities Impacting Policy Project. 2003 Dalhousie University. Accessed online at: <http://www.ruralnovascotia.ca/RCIP/PDF/Acknowledgements.pdf>

## Appendix A

Website Home Page Screen Shot (<http://pathclinic.ca/>)



The screenshot shows the path clinic website home page. At the top left is the path clinic logo with the tagline 'PALLIATIVE AND THERAPEUTIC HARMONIZATION'. Below the logo is a navigation menu with links: Home, About PATH, The PATH Process, The PATH Team, Physician Information, Resources, and Contact. The main content area features a large video player. The video title is 'A comprehensive assessment of physical, psychological, cognitive, and social well being.' The video player shows a play button and a progress bar with three numbered steps (1, 2, 3). Below the video player, there is a text block that reads: 'Palliative and Therapeutic Harmonization (PATH) is a process that creates time and space for frail, older people to make complex health care decisions.' Below this text is a section titled 'What can we help you find?' followed by a bulleted list: 'Why do we need a new approach?', 'How does the PATH process work?', 'Information for physicians including referral forms', and 'Other resources and videos'. At the bottom of the page, there is a footer with contact information: 'PATH - Palliative and Therapeutic Harmonization Clinic, 1st floor, Camp Hill Veterans' Memorial Building, 5955 Veterans' Memorial Lane, Halifax, Nova Scotia B3H 2E1'. There is also a 'View Map' link. On the right side of the footer, there is a 'Physicians' link and a 'Download the PATH Referral Form' link. At the very bottom right, there is a copyright notice: '©2011 PATH Clinic. All rights reserved. Funding support provided by the Canadian Dementia Knowledge Translation Network (CDKTN) and the Alzheimer's Society of Canada (ASC)'.



**Appendix B**  
**Handout: Understanding Frailty**

## Understanding Frailty

### What is frailty?

Frailty is a fragile state of health that makes a person vulnerable to illness and injury. When a person is frail, he or she may lack vitality, strength and resilience to withstand physical and emotional stress.

A person can be frail at any age, but frailty is more common in older people. As people age, many lose muscle mass and bone density. They may feel less stable on their feet and begin to move more slowly. They may feel weak and tired and find that shopping and housework are getting more difficult. As their ability to think and remember declines with the aging of their brains, older people who are becoming frail may also find it harder to keep track of the details of their daily lives.

When a frail person is injured or sick, he or she is slow to recover and may never regain his or her previous level of health. As more health problems develop over time, the person becomes increasingly frail and requires more help from others with the tasks of daily living, such as cooking, shopping and banking. Eventually, he or she may need help with personal care, such as bathing or dressing.

### How do we recognize and measure frailty?

You can probably picture a frail person easily in your mind—you may imagine someone with a slight build and stooped posture who walks slowly. But how do you know what makes this person frail, and what that means to his or her daily function and quality of life? How can you predict how he or she will fare in the future?

Researchers at the QEII Health Sciences Centre and Dalhousie University have developed ways to better answer these questions. They have developed a *frailty index*\* to accurately measure the extent of a person's frailty.

Simply put, the frailty index counts the number of health issues a person has, and compares this to the number of health issues typically experienced by people the same age. These could be any type of health issue, from heart disease, to osteoporosis, to confusion, to living without family support. The key is not the type of health problem but the overall number and their severity. The more health issues a person accumulates, the frailer they become.



### Age is only part of the frailty equation

There are vast differences in how people age, depending on a wide range of genetic, lifestyle and other factors. Not everyone will become frail, or as frail as other people their age.

Look at Sandra and Joseph, for example:

Sandra is 82 and suffers from osteoarthritis of the knee, but she continues her habit of walking briskly for 30 minutes each day, in spite of the discomfort in her knees. Although she has macular degeneration (a disease of the eye that causes vision loss), she can still drive. She is active in her local gardening club, does her own housework and shopping, and cooks nutritious meals for herself and her husband.

In contrast, Joseph is 74 and being treated for type 2 diabetes, high blood pressure and angina (chest pain due to heart disease). Nerve damage in his feet from the diabetes makes standing and walking uncomfortable, so Joseph spends most of his time sitting. As a result, he feels unsteady and moves slowly. He is afraid of falling and gets his daughter to help him to and from appointments and with errands. A widower, Joseph relies on hired help to clean house and tends to eat frozen dinners.

Although Sandra is considerably older than Joseph, she is fit and he is frail. Clearly, age is only part of the frailty equation.

## Measures of frailty

To measure an older person's frailty, a physician conducts what is known as a 'comprehensive geriatric assessment,' or CGA. The CGA involves taking a detailed medical history, examining the patient, evaluating their physical and cognitive function, and assessing social factors that impact health.

Healthcare professionals examine the following areas to assess frailty:

**Memory and thinking:** Is the person showing signs of forgetfulness, confusion, delirium, or dementia?

**Mood:** Is the person unmotivated or depressed?

**Communication:** Do they have any problems with vision, hearing, or speech that affect their ability to communicate?

**Mobility:** Can they stand easily from a sitting position? Are they able to walk or do they shuffle?

**Balance:** How stable are they? Have they fallen or is there a high risk of falling?

**Strength:** Is strength diminished?

**Bowel and bladder function:** Have they control of these functions, or are they incontinent?

**Nutrition:** Does the person eat enough nutritious food? Are they losing weight?

**Activities of daily living:** What can they do for themselves, and with what do they need help?

**Social supports:** Does the person live alone? If so, are friends or family nearby to help and keep them company?

**Health problems:** What chronic or acute health problems does this person have? What medications do they take? Have they experienced any adverse side effects of their medications?

**Trajectory:** How will the above issues progress?

## Degrees and progression of frailty

Frailty is not 'all or nothing.' A person can be mildly, moderately, severely or very severely frail (see *Clinical Frailty Scale*, back page).

Progress from one degree of frailty to the next can be fast or slow. A mildly or moderately frail person could live comfortably and independently that way for many years. However, illness—such as a stroke, a bout of influenza, or cancer and its treatment—can cause a mildly frail person to decline rapidly to a severe state of frailty. He or she may recover to some extent, but is likely to remain more frail than before the illness.

Some of the physical problems that signal a person is becoming frail are difficulty walking and doing heavier chores, loss of vision, loss of control of bowel or bladder function (incontinence), and a new tendency to fall. Problems with mental function that indicate a person is becoming frail include confusion, loss of short term memory, and difficulty understanding complex information. When frail older people become ill, these complex functions are usually the first to decline. They are also the first to improve as a person recovers.

As a person accumulates health problems—such as acute illness on top of chronic disease—they become more frail. Any one problem on its own may not shorten life expectancy. However, health problems tend to accumulate as a person ages. And, taken together, the effects of multiple problems magnify each other. This increases overall frailty, increases the risk of being admitted to a long-term care institution, and reduces life expectancy.

## Risk factors for frailty

What makes some people frail in their 70s, while others are hardy into their 80s and even beyond?

Researchers have identified factors that increase a person's risk of becoming frail, including: increasing age, overweight or underweight, low physical activity, inadequate nutrition, depression, smoking, chronic health problems, and acute illness. Social factors contributing to frailty include isolation, lack of financial resources, and lack of mental stimulation.

People who stay physically active, eat healthy foods, drink alcohol moderately, don't smoke, suffer few ailments, have adequate financial resources, and enjoy good mental health and satisfying social lives, are less prone to frailty.



**The impact of frailty on medical decisions**

It is very important for health care professionals to assess a person’s degree of frailty and discuss what it means with that person and their family members. This is because the degree of a person’s frailty predicts how well he or she will respond to treatment in the event of a new illness. Frailty also predicts how long a person might expect to live.

It is very important for people to understand that frail older people do not respond to treatment—such as drugs or surgery—in the same way that younger, stronger people do. In fact, aggressive treatments can often do more harm than good when the patient is frail. Such treatments may cause unnecessary pain and distress and reduce quality of life. In fact, people who are frail are 60 per cent more likely to experience complications during a hospital stay, and 10 times less likely to be able to return home.

Surgery, in particular, can lead to major problems. Anesthesia drugs, and the experience of being hospitalized, can cause delirium in frail older people. Delirium is a state of confusion that, once triggered, often does not fully resolve in frail older people.

Understanding frailty helps frail people and their families decide what kind of medical care they will accept when illness arises in the future. Knowing how frail they are—and thus how well they are likely to fare with treatment—allows frail people and their families to make informed decisions about what kinds of treatment to consider and what kinds of treatment to avoid. When someone is frail, it is best to make decisions that will preserve quality of life, rather than length of survival.

Please consult the *PATH Guide to Making Medical Decisions* for a detailed discussion about care planning.

**The brain’s role in frailty**

Diseases of the brain and nervous system have a big impact on frailty. Neurodegenerative diseases like Parkinson’s disease and Alzheimer’s disease cause the body to lose strength and muscle mass faster than it would if the person did not have the disease. Stroke can lead to physical disabilities and cognitive problems that contribute to frailty. Mental health problems can also cause overall health to decline, for example by reducing motivation or ability to be socially engaged or physically active. Illnesses affecting the brain limit a person’s ability to function in their lives and shorten life span.



**Tales of frailty**

How did Sandra and Joseph fare as they got older and encountered new health problems?

Joseph contracted influenza, which led to pneumonia. Because of his frailty, the pneumonia had a big impact on his ability to walk, to think clearly and carry out his daily tasks. He was admitted to hospital because of his confusion and difficulty walking. Antibiotics cleared up the infection, and his ability to think. Joseph was able to return home, but he never regained his previous level of health. When he was diagnosed with colon cancer the following year, he became delirious after the surgery and had to be admitted to a nursing home.

Sandra contracted pneumonia after knee replacement surgery. Because she was fit, her cough cleared up quickly after a course of antibiotics. She recovered well from the surgery and resumed her habit of daily walking. Sandra continued to live independently into her early 90s, although her eyesight gradually got worse. Her health began to decline faster after her husband died and she found keeping house too much to handle on her own. At that point, she moved into a senior’s home where she had lots of social interaction and support with daily living.

**Signs of frailty**

Markers of frailty include exhaustion, muscle weakness, unintentional weight loss, slow walking speed, falls, incontinence, low mood and motivation, confusion, inability to perform complex tasks, increasing difficulty with the activities of daily living, multiple illnesses, and multiple medications.



## Clinical Frailty Scale



1. **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



2. **Well** – People who have no active disease symptoms but are less fit than Category 1. Often, they exercise or are very active occasionally, e.g. seasonally.



3. **Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.



4. **Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up,” and/or being tired during the day.



5. **Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



6. **Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.



7. **Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



8. **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.



9. **Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy < 6 months, who are not otherwise evidently frail.

### Where dementia is present, the degree of frailty usually corresponds to the degree of dementia:

- **Mild dementia** – includes forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.
- **Moderate dementia** – recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.
- **Severe dementia** – they cannot do personal care without help.

K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. *CMAJ* 2005;173:489-495.

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Dalhousie University, Halifax, Canada

## Selected references

The information in this guide is based on extensive research by researchers at Dalhousie University in Halifax, NS, who have made a major impact on the understanding of frailty, how to assess and measure it, and how to approach health care decisions in the context of frailty. Key publications include:

- ‘Respecting frailty,’ Mallery L, Moorhouse P., *Ethics*, 2011; 37:126-128.
- ‘Evaluation of a frailty index based on comprehensive geriatric assessment in a population-based study of elderly Canadians,’ Jones D, Song X, Mitnitski A, Rockwood K, *Aging: Clinical and Experimental Research*, 2005;17:465-71.
- ‘A standard procedure for creating a frailty index,’ Searle SD, Mitnitski A, Gahbauer EA, Gill TM, Rockwood K., *BMC Geriatrics*, 2008; 8:24.
- ‘Frailty defined by deficit accumulation and geriatric medicine defined by frailty,’ Rockwood K, Mitnitski A, *Clinical Geriatric Medicine*, 2011; 27:17-26.
- ‘Comprehensive geriatric assessment: Helping your elderly patients maintain functional well-being,’ Rockwood K, Silvius JL, Fox RA., *Postgraduate Medicine*, 1998;103:247-9.

## About the PATH Clinic

The PATH clinic is an innovative health care service for older people in Nova Scotia who have chronic health conditions. PATH provides assessment and consultation to help these people and their families understand their true health status and outlook for the future. The PATH Clinic aims to help people understand the potential risks and benefits of the options before them, so that they can make health care decisions that support overall health and quality of life.

### Contact us:

By telephone: (902) 473-8603  
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### Visit our website:

[www.pathclinic.ca](http://www.pathclinic.ca)

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