Improving access to palliative care in Ontario

STRENGTHENING CARE FOR FRAIL OLDER ADULTS IN CANADA

13 AUGUST 2016

EVIDENCE >> INSIGHT >> ACTION
The McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at the regional/provincial level and at national levels, the Forum harnesses information, convenes stakeholders and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions and communicate the rationale for actions effectively.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the view of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

About this brief

This brief was produced by the McMaster Health Forum to serve as the basis for discussions by the citizen panel on how to strengthen care for frail older adults in Canada. This brief includes information on this topic, including what is known about:

- the underlying problem;
- three possible options to address the problem; and
- potential barriers and facilitators to implement these options.

This brief does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.
Table of Contents

**Key Messages** ........................................................................................................................... 1

**Questions for the citizen panel** .................................................................................................. 4

**The context:** Why is strengthening care for frail older adults a high priority? ............................... 7

**The problem:** Why is strengthening care for frail older adults in Canada necessary but challenging? ....................................................................................................................................... 11

- Frailty is challenging to define and ‘diagnose’ .............................................................................. 12
- Frailty affects some Canadians more than others ........................................................................ 13
- Frail older adults have complex needs which often leads to care that is fragmented ................. 14
- Frail older adults require considerable support from caregivers who also need support given increased demands placed on them. ................................................................. 15

**Elements of an approach to address the problem** ..................................................................... 18

- Element 1 – Engaging in efforts to prevent frailty or prevent the onset for those who are ‘pre-frail’ ..................................................................................................................................... 19
- Element 2 – Managing challenges faced by frail older adults...................................................... 21
- Element 3 – Supporting caregivers in their efforts to prevent, delay the onset of, and manage the burden of frailty ..................................................................................................... 23

**Implementation considerations** ................................................................................................. 25

**Acknowledgments** .................................................................................................................... 27

**References** .................................................................................................................................. 28
Key Messages

What’s the problem?
Many factors contribute to the challenges of strengthening care for frail older adults in Canada, including:
• frailty being challenging to define and ‘diagnose’;
• frailty affecting some Canadians more than others;
• frail older adults having complex needs, which often leads to care that is fragmented; and
• frail older adults requiring considerable support from caregivers who also need support given increased demands placed on them.

What do we know about elements of a potentially comprehensive approach for addressing the problem?
• **Element 1: Engaging in efforts to prevent frailty or prevent the onset for those who are ‘pre-frail’**
  o This could include: 1) using data and screening tools to proactively identify those at risk for becoming frail; 2) providing information and supports in different settings (e.g., seniors’ residences, healthcare facilities) for approaches that promote healthy aging and prevent frailty (e.g., supporting a physically active lifestyle and good nutrition); 3) using physical and occupational therapy to improve strength and functioning; 4) and enhancing home-based care and support to help older adults living at home for as long as possible.

• **Element 2: Managing challenges faced by frail older adults**
  o This could include making care more integrated and ‘person-centred’, which could involve: 1) ensuring patients receive care when they need it; 2) supporting the engagement of patients and their caregivers in their care; and 3) supporting seamless transitions between settings.

• **Element 3: Supporting caregivers in their efforts to prevent, delay the onset of, and manage the burden of frailty**
  o This could include: 1) addressing the economic security of caregivers through financial programs (e.g., flexible work arrangements); 2) engaging caregivers in decision-making about how care and support is organized; and 3) providing education and supports needed by caregivers to reduce their burden and to help them cope and build resilience.

What implementation considerations need to be kept in mind?
• Barriers to implementing these elements might include: 1) possible lack of adherence to health-promoting interventions by older adults to help them stay healthy; 2) systems of care not being set up to address complex conditions; and 3) hesitance of policymakers to pursue significant system-level change.

• Windows of opportunity for implementing these elements might include: 1) an aging population making it necessary to invest in new ways of doing things; 2) a growing desire within the health sector for pan-Canadian leadership and collaboration; and 3) difficult economic times forcing the creation of innovative approaches. (18)
Box 1: What is frailty?

Frailty is difficult to define, but most definitions consider it in terms of vulnerability,(3;5) which can relate to physical, emotional and social factors.(6;7)

In relation to physical factors, this often means:
- having a general lack of strength;
- being more vulnerable to disease (e.g., one or more chronic diseases) or disability (e.g., lack of mobility); and
- deteriorating in health more quickly as a result of diseases and disability (including cognitive deficits and/or dementia).(1)

Also, frailty, chronic disease and disability are related but not the same. This means that some older adults can be frail without having a chronic disease or disability. As a result, frailty can precede chronic disease or disability, or be the result of it.(6) In addition, Figure 1 outlines that frailty can be understood across a broad spectrum from being mostly healthy, to being vulnerable or at-risk for frailty (what is sometimes called ‘pre-frail’), to more severe forms of frailty (e.g., being completely dependent on others for personal care).

Emotional and social factors can relate to many things that lead to vulnerability (and eventually greater risk of functional impairments and disease), including lack of emotional and social support and social isolation.(5)

As outlined in this brief, there are opportunities for intervention at many stages in the process leading to frailty. Frailty should therefore be considered on a continuum where those who are not frail can become ‘pre-frail’ and later frail. This is not necessarily a one-way process with some who are frail being able to revert to a ‘pre-frail’ status and possibly to a non-frail state.
Figure 1: Clinical Frailty Scale (figure reproduced with permission)(21)

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 Severe 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.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In 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.

In severe dementia, they cannot do personal care without help.

*Note that IADLs in the figure refers to instrumental activities of daily living.
Questions for the citizen panel

>> We want to hear your views about a problem, three elements of a potentially comprehensive approach to addressing it, and how to address barriers to moving forward.

This brief was prepared to stimulate the discussion during the citizen panel. The views and experiences of citizens can make a significant contribution to finding the best ways to meet their needs. More specifically, the panel will provide an opportunity to explore the questions outlined in Box 2. Although we will be looking for common ground during these discussions, the goal of the panel is not to reach consensus, but to gather a range of perspectives on this topic. To help you better understand some of the terminology when considering these questions and reading through the brief, we provide a glossary of key terms in Box 3.
Box 2: Questions for citizens

Questions related to the problem

• What challenges have you faced in accessing care and other supports as:
  o someone who is frail;
  o someone who is at risk for becoming frail; or
  o someone who provides care to a frail older adult.
• What challenges do you see for supporting someone who takes care of (i.e., caregivers) frail older adults?
• What do you think is needed to recognize frailty as an issue that warrants attention and effort to address?

Questions related to the elements of a potentially comprehensive approach to address the problem

• An overarching question for the elements: What would you like to see done differently as part of efforts towards strengthening care for frail older adults?
• Element 1: Engaging in efforts to prevent frailty or prevent the onset for those who are ‘pre-frail’
  o What do you think is needed to help you or others from becoming frail?
  o Who do you think should provide information about preventing frailty (e.g., family physician, nurse practitioner or case manager)?
  o Where and how do you want to receive this information (e.g., during medical visits or in the community)?
• Element 2: Managing challenges faced by frail older adults
  o What would help you get the care you need when you need it to manage the burden of frailty?
  o What would be helpful to support you to: 1) take ownership of your health and promote your well-being; and 2) to understand how to manage your own care?
  o What would help you easily access the full range of care and support that you need?
• Element 3: Support caregivers in their efforts to prevent, delay the onset of, and manage the burden of frailty
  o What do you want and expect in terms of supports for caregivers?
  o What can be done to reduce:
    ▪ physical burden;
    ▪ economic burden;
    ▪ emotional burden; and
    ▪ social burden?

Question related to implementation considerations

• What do you see as the main challenges for achieving these expectations?
**Box 3: Glossary**

**Healthy aging**
Staying healthy, active and engaged as long as possible, so that older adults can actively participate in society and lead an independent and high-quality life.(2)

**Chronic health condition**
A health problem requiring ongoing management over a period of years or decades (e.g., arthritis, asthma, cancer, depression, dementia, diabetes and heart disease).(4)

**Integrated care**
The provision of patient-centred care in which all healthcare providers work together with patients. Integrated management ensures coordination, consistency and continuity of care over time and through the different stages of patients’ chronic health conditions.(8)

**Patient-centred care**
“Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”(9)

**Caregiver**
An individual who is providing unpaid and ongoing care or social support to a family member, neighbour or friend who is in need as a result of physical, cognitive or mental health conditions.(12)

**Primary care**
“Level of a health service system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and co-ordinates or integrates care provided elsewhere by others.”(14)

**Home and community care**
Services to help people receiving “care at home, rather than in a hospital or long-term care facility, and to live as independently as possible in the community. Home and community care is delivered by regulated health care professionals (e.g., nurses), non-regulated workers, volunteers, friends and family caregivers.”(15)

**Self-management**
“An individual’s ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition.”(17) It empowers patients and prepares them to manage their health and healthcare.(19;20)

**Multimorbidity**
A term that refers to people living with multiple chronic health conditions.
The context: Why is strengthening care for frail older adults a high priority?

Provincial and territorial health systems in Canada are increasingly focusing on how to strengthen care for those with complex health needs. This includes frail older adults, people living with multiple chronic diseases, and/or people living with disabilities. The need to take action has become more pressing given that:

- the number of Canadians aged 65 years or older is expected to double in the next two decades;(22)
- the proportion of older adults (i.e., 65 years and older) over the age of 80 is expected to grow from 27.5% in 2012 to 32% in 2036;(23)
- in 2015, for the first time, there were more persons aged 65 years and older in Canada than children aged 0 to 14 years;(24)
- the older people get, the more likely they are to accumulate health problems (e.g., reduced mobility, disability and/or chronic diseases);(8)
- the number of frail older adults in Canada is expected to rise from 1.1 million to more than 2 million by 2035;(1)

“The number of frail elderly Canadians is today estimated at 1.1 million; rising to well over 2 million Canadians by 2035”(1)
• those who are frail are at greater risk for chronic illnesses (25;26) and disabilities in basic and instrumental activities of daily living;(25;27)
• as more people accumulate health problems, there is increased need for in-home services, hospital-based care and long-term care;(28;29)
• chronic disease costs the Canadian economy $100 billion annually in lost productivity and $90 billion in treatment costs (67% of all direct health care costs are related to chronic diseases);(30) and
• caregivers spend a considerable amount of time and resources caring for others, reducing their ability to work and engage in other activities.(31)

Given the cost of treatment and potential for increased number of frail older adults, maintaining the status quo in provincial and territorial health systems is not sustainable. As outlined in Figure 2, this means taking an approach that focuses on healthy aging, as well as better managing the challenges faced by frail older adults and their caregivers.

Efforts to strengthen health systems in this way represent an opportunity for:
• preventing or delaying the onset of frailty for those most at risk (and in doing so, helping to also prevent chronic disease and disability, and potentially bringing people back from the state of frailty);
• improving delivery of care and support; and
• improving the health and quality of life for individuals with complex health needs.

To do this, many provincial health systems have been focusing on strengthening primary care (the first point of contact for care for most), and enhancing coordination between primary, acute, home and community care and public health.(32) The goal is to enhance patient experience, improve health outcomes and keep costs manageable.(33)
Figure 2: Areas of focus for strengthening care for frail older adults

- Preventing frailty
- Managing the challenges of frailty
- Supporting caregivers
Box 4: Key features of provincial health systems in Canada

Key features of health systems

- Medical care provided in and with hospitals and by physicians is fully paid for as part of each publicly funded provincial health system.
- Care and support provided by other healthcare providers such as nurses, physiotherapists, occupational therapists and dietitians are typically not paid for by provincial health systems unless provided in a hospital or long-term care setting. Public coverage outside of these settings varies by province (e.g., services from occupational therapists working in the community are paid for in Quebec, but not in other provinces).
- Other healthcare and community services such as prescription drug coverage, community support services and long-term care homes may be partly paid for, but the extent of coverage varies across provinces, and any remaining costs need to be paid by patients or their private insurance plans.
- All provinces allocate responsibility for the planning and funding of healthcare in regions within a province (e.g., Local Health Integration Networks in Ontario).

Features most relevant to home and community care

- The extent of coverage for home and community care varies by province, and the coordination of services is often conducted at the regional level either by or in collaboration with the regional authorities responsible for planning and funding healthcare.
- A mix of not-for-profit and for-profit community support-service agencies deliver home and community care to residents in their province (e.g., more than 800 community support-service agencies provide care to more than 800,000 community-dwelling Ontarians, including older adults, and people with a physical disability and/or mental health issue, and addictions). The assistance can include personal support (e.g., for household tasks, transportation, meals-on-wheels, supportive housing and adult day programs).(8)

Features of public health

- At the national level, the role of the Public Health Agency of Canada is to promote health, prevent and control chronic diseases and injuries, prevent and control infectious diseases, prepare for and respond to public health emergencies, share Canada’s expertise internationally, apply research, strengthen intergovernmental collaboration, and facilitate national approaches to public health policy.(10;11)
- In Ontario, for example, public health units provide a range of health-promotion and disease-prevention programs, including those that inform the public about healthy lifestyles, provide communicable disease control, and support healthy growth and development.(13)

Features for specific populations (high-needs users of the health system)

- Some provinces provide specific resources for those with complex conditions. For example, 82 Health Links (of an anticipated total of 90) in Ontario support the delivery of integrated care (e.g., coordinating between different care providers and settings) for those with complex needs (typically those living with multiple chronic diseases).(16)

*We have provided a general description of the key features and provided examples from Ontario given that most panel participants are from Ontario.
The problem: Why is strengthening care for frail older adults in Canada necessary but challenging?

Several factors contribute to the challenges of strengthening care for frail older adults in Canada, which include:

• frailty being challenging to define and ‘diagnose’;
• frailty having more of an impact on some Canadians than others;
• frail older adults having complex needs, which often leads to care that is fragmented; and
• frail older adults requiring considerable support from caregivers who also need support given increased demands placed on them.

“Older seniors with multiple conditions want coordinated, person-centred care rather than to be treated as a collection of separately treated diseases.”(1;3)
Frailty is challenging to define and ‘diagnose’

There is a lack of consensus on how to define frailty, and whether it is distinct from chronic disease and disability, and the natural aging processes. For example, as briefly described earlier, most definitions consider it in terms of vulnerability,(6) which can be related to physical, mental, emotional and social factors.(21;34) Common ways of describing frailty include:

- limited physical performance or physical decline;(29)
- a medical condition;(30;32)
- an age-related syndrome;(33)
- accumulation of deficits in health;(35) and
- a model that combines many or all of these factors.(36;37)

The result is that frailty and approaches to screening for it have been defined with many different components.(38)

What we do know is that older adults make up the fastest-growing age group in Canada, and this trend is expected to continue for several decades. In 2011 there were five million Canadians aged 65 or older, and that number is expected to double by 2036.(39) As a result, the number of frail older adults will increase as these population trends continue.(39)

As described by Figure 1 earlier, frailty impacts people’s lives as they move along a spectrum from fit and active to very frail and in need of considerable support.(40) Those who are very frail will have greater difficulty recovering from illness (either acute or chronic) and may be completely dependent on others for their care. For example, a relatively minor event (e.g., developing a minor infection or a minor fall) can lead to a series of challenges resulting in increased disability and significant declines in health.(25)

The lack of agreement about how to define frailty makes it difficult for clinicians to ‘diagnose’ or identify frailty in their patients and clients. Different criteria have produced estimates across several countries (including Canada) of the number of frail older adults, ranging from a low of 4% to a high of 59%.(30;41-44) The lack of agreement makes it difficult to identify individuals at risk of becoming frail.(27) This is important because early detection is necessary to prevent or reverse frailty through targeted education and health-promoting activities (e.g., physical activity).(45;46) This includes identifying cognitive impairment, which can change the type of preventive approach that can be taken. Lastly,
the lack of clear criteria can make it difficult for care providers to monitor people who are already frail and prevent further deterioration, hospitalization and institutionalization.

Frailty affects some Canadians more than others

The combination of frailty and chronic disease (especially people living with multiple chronic diseases) greatly affects a person’s health. For example, as outlined earlier in Figure 1, the physical decline associated with frailty can lead to chronic disease or make them more difficult to manage. Also, the many effects of having multiple chronic conditions can make it more likely that an older adult will become frail.

Poverty has a significant impact on the health of older adults (e.g., on their ability to access needed care) and their caregivers (many of whom need to fully or partially leave paid employment to provide care). For example, people living in poverty tend to experience the effects of aging and the onset of frailty earlier than those with higher incomes. In addition, frail older adults living in poverty are less likely to be able to afford things they need to keep them healthy (e.g., healthy food), as well as medications, allied healthcare, and home care. In terms of chronic disease, people with low incomes and those living in poverty are affected more than others. Specifically, 40% of low-income Canadians have one or more chronic-health conditions, compared to 27% of high-income Canadians.

In general, older adults who are isolated experience worse health outcomes than those with strong social ties and who have a partner. Loneliness has been associated with frailty in community-dwelling elderly adults because of isolation. Those who are isolated lack access to support networks of family and friends (i.e., caregivers) who can help them. This help could include:

- supporting routine activities around the house;
- providing transportation to appointments; and
- monitoring changes in functioning and health, and communicating these changes to clinicians and other service providers who can intervene early and adjust care plans.
Frail older adults have complex needs which often leads to care that is fragmented

The complex needs of frail older adults require care providers to consider both medical and non-medical factors such as physical and mental functioning, symptom burden, survival and life expectancy, nutrition, social networks/supports, and housing. For example, providers and patients must find a balance between improving nutrition, living situation, function, severity of symptoms, survival and active life expectancy of a patient, as well as other health outcomes. This also means that a range of supports are needed to achieve this balance, and that providers, patients and families need to be aware of what is available.

However, provincial and territorial health systems in Canada have not typically considered this full spectrum of care needs. For example, most physicians recently surveyed in Canada feel they are not well prepared to manage the care of patients with complex needs.(21) This includes health professionals (e.g., physicians, nurses, social workers and pharmacists) not always working together in collaboration with a clinician that specializes in geriatrics to get people the care they need,(47) despite this being important for improving patients’ outcomes.(47-49;53-54) This may be the result of physicians and other care providers often not having the training and experience needed to work with frail older adults.(57-59) It could also be the result of a shortage of geriatricians who can be available to collaborate on teams.(60)

Also, a lack of electronic health records (i.e., a system enabling healthcare providers to access health information about individual patients) means that all the information about a patient is rarely in one place. As a result, frail older adults often report poor interactions with healthcare services and service providers.(61)

This fragmentation can increase the risk of medical error and poor coordination of services (e.g., being over- or mis-prescribed drugs).(62;63) It also often leaves people with complex conditions (such as frailty) and their caregivers to navigate the system on their own, where they have to see a family physician, set and attend appointments with several specialists in different settings, manage many medications, organize home-based care, and identify additional supports such as transportation that they may need.
Also, without an integrated and patient-centred approach that avoids fragmentation, patients, families and caregivers often lack the supports they need to help them to make informed decisions about their health and managing their care needs. It also means that they are not always engaged in policy development about the health system. Without such supports and engagement, it will be difficult to support integrated and patient-centred care. Also, policy developed to address health-system issues may not be based on citizens’ values and preferences, or be flexible enough to accommodate those values and preferences.

Frail older adults require considerable support from caregivers who also need support given increased demands placed on them.

Frail older adults have significant care needs, and often rely heavily on caregivers to support them. A caregiver may be an intimate partner, family member, friend, or volunteer who may also themselves be frail or at-risk of becoming frail. The roles of caregivers of frail older adults can be significant and may take various forms, such as:

- providing emotional support;
- transporting or accompanying patients to medical appointments;
- reporting or managing side effects;
- giving medicines;
- keeping track of interventions (e.g., for nutrition and exercise), medicines, test results and papers;
- providing physical care (e.g., feeding, dressing and bathing);
- coordinating care (including navigating the system and advocating on behalf of their loved ones);
- keeping family and friends informed; and
- making legal and financial arrangements.
In 2012, nearly half of Canadians aged 15 years and older (46%) provided some type of care to a family member, friend or neighbour with a chronic health condition, disability or aging needs. Canadians spend a considerable amount of time and resources caring for others, with one in 10 caregivers spending more than 30 hours a week (equivalent to a full-time job) providing some form of assistance. This time spent providing care reduces their ability to work and engage in other activities (see Figure 3). This heavy burden may generate stress and other health issues among caregivers (e.g., depression), who may neglect the management of their own health in favour of caring for others. Early research from 2009 estimated that the economic contribution of Canadian caregivers was between $25-$26 billion per year.

Despite their crucial role in supporting the health of older adults, practical, social, emotional, informational and financial support for unpaid caregivers is lacking or inconsistently available. This lack of support can have a negative impact on the physical and mental health of caregivers, on their personal and professional lives, and on the quality of care that they provide. As reported by a forum of cancer, mental health and caregiver groups: “Failure to recognize, acknowledge and support family caregivers heightens their risk of becoming ‘collateral casualties’ of the illness, compromises their health, reduces the efficacy of the help they can provide to their relatives, and increases costs to the health and social service systems.”
Figure 3: Role of caregivers in supporting older adults (figure reproduced with permission from the Canadian Institute of Health Information)(31)

**Informal caregiving**
Results from The Commonwealth Fund 2014 International Health Policy Survey of Older Adults (age 55+) show that Canadians generally spend more time as informal caregivers than people in other countries and don’t always get the support they need.

1 in 5 older Canadians provided care to someone with an age-related problem at least once a week. That’s about the same as the international average of 11 countries.

4 in 5 older Canadian caregivers provided care for their family members.

Almost half (47%) of older caregivers provided care for at least 10 hours a week, which is higher than the international average of 40%.

Canadian caregivers were more likely to experience distress, anger or depression if they provided 10 or more hours of informal care.

Almost one-quarter of Canadian caregivers needed help in the past year but didn’t receive it.

The main reasons caregivers didn’t get the help they needed were lack of services and not knowing where to go for help.
Elements of an approach to address the problem

To promote discussion about the pros and cons of potential solutions, we have selected three elements of an approach to strengthening care for frail older adults in Canada.

Many approaches could be selected as a starting point for discussion. We selected the three elements of a potentially comprehensive approach for which we are seeking public input:

1. Engaging in efforts to prevent frailty or prevent the onset for those who are ‘pre-frail’;
2. Managing challenges faced by frail older adults; and
3. Supporting caregivers in their efforts to prevent, delay the onset of, and manage the burden of frailty.

These elements should not be considered separately. Instead, each should be considered as contributing to a potentially comprehensive approach to addressing the problem. New elements could also emerge during the discussions. In considering these elements we would like you to think about what you would like to see done differently as part of efforts towards strengthening care for frail older adults.
Element 1 – Engaging in efforts to prevent frailty or prevent the onset for those who are ‘pre-frail’

Overview
This element is focused on how to engage in efforts to prevent frailty or prevent the onset of frailty for those who are pre-frail. This could include:

• using data and screening tools to proactively identify those at risk for frailty;
• providing information and supports in different settings (e.g., seniors’ residences, healthcare facilities) for approaches that promote healthy aging and prevent frailty (e.g., health-promoting activities such as supporting a physically active lifestyle and good nutrition that are embedded in daily routine);
• using physical and occupational therapy to improve strength and functioning; and
• enhancing home-based care and support (e.g., transportation) to help older adults live at home for as long as possible.

Evidence and questions to consider during your deliberations are provided below.

Evidence to consider
We found several systematic reviews (i.e., a synthesis of results from all the studies addressing a specific topic) that provide evidence about efforts to prevent frailty or its onset, which we summarize in Table 1.

Questions to consider
• What do you think is needed to help you or others from becoming frail?
• Who do you think should provide information about preventing frailty (e.g., family physician, nurse practitioner or case manager)?
• Where and how do you want to receive this information (e.g., during medical visits or in the community)?
<table>
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<tr>
<th>Area of focus</th>
<th>Key findings</th>
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| **Using data and screening tools to proactively identify those at risk for frailty** | • Currently available screening tools are not sophisticated enough to identify patients most at risk for frailty. A comprehensive, complete geriatric assessment is recommended instead. (51)  
• Some risk factors may predict a decline in functioning and risk of frailty in older adults, and could be used as an indicator to assess individuals. These include:  
  o slow gait speed;  
  o limited physical activity, reduced muscle strength, weight loss and reduced balance;  
  o cognitive impairment;  
  o depression  
  o anxiety. (70-72) |
| **Providing information about supports for approaches that promote healthy aging and prevent frailty** | • Interventions aimed at preventing disability among older adults generally have positive effects. (73)  
• No benefit was found for the use of hip protectors on rates of hip fractures (harms such as skin irritation and risk of falls while putting it on were also reported). (74)  
• No evidence was found about whether interventions to improve nutrition or lower extremity strength (e.g., strength training) improved levels of disability. (73)  
• Resistance training for those over 65 did help to prevent loss of muscle tissue, reduced risk of falling and improved mobility. (75)  
• Interventions that target multiple risk factors were more successful than those that targeted a single risk factor, but evidence is mixed on the impact on functional ability. (76)  
  Individualized assessments, case management and long-term follow-up were other predictors of program success. (73) |
| **Using physical and occupational therapy to improve strength and functioning** | • Physical-therapist led, group-based and home-based exercise programs were found to improve balance, fall rates and fear of falling. (77; 78)  
• Completing a geriatric assessment (e.g., by a clinician, including physical or occupational therapists) lowers the risk of older adults moving to long-term care. (79) |
| **Enhancing home-based care and support to help older adults live at home longer** | • Home-based occupational therapy has been found to be effective for improving client safety in the home, health-related quality of life and fear of falling. No improvements in long-term functional status or reduction in actual falls were found, but home-based occupational therapy did result in a decreased number of required hours of personal care. (80)  
• The combination of geriatric assessment, community care and a fall-prevention intervention improved care satisfaction and decreased return hospital visits. (79)  
• Care coordination, preventive health checks and having a care liaison were all effective at preventing admission to hospital among frail older adults. (81)  
• There is a lack of evidence on the effects of multi-component falls prevention, day hospital services, medication reviews or nutritional enhancement on hospital admissions. (81) |
Element 2 – Managing challenges faced by frail older adults

**Overview**

The focus of this element is on helping frail older adults manage the burden of frailty on their lives. This could include making care more integrated and ‘person-centred’, which may involve: 1) ensuring patients receive care when they need it; 2) supporting the engagement of patients and their caregivers in their care; and 3) supporting seamless transitions between settings. In Table 2, we summarize the types of activities that could be included in each of these areas of focus. We also provide evidence and questions below to consider during your deliberations.

**Table 2: Types of activities that could be included as part of ‘person-centred’ care (table adapted from Wilson et al. 2016)(34;82)**

<table>
<thead>
<tr>
<th>Area of focus</th>
<th>Types of activities</th>
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| Ensure patients receive care when they need it | • Providing patient-driven scheduling to ensure timely access (i.e., access to same- or next-day appointments, with priority for those who need it most)  
• Using team-based models to provide same- or next-day access to care  
• Using secure email and telephone encounters to enhance access, and to prepare for, follow up from, or substitute for in-person visits  
• Developing personalized care plans where patients and clinicians collaboratively develop a care plan to address the patients’ health issues  
• Conducting regular reviews of drugs prescribed to avoid taking too many prescription drugs that can lead to potentially harmful effects  
• Providing access to and promoting the use of resources (e.g., transportation), and providing skills development to help patients and their caregivers manage certain aspects of their care  
• Supporting shared decision-making with care providers, patients and their caregiver (e.g., through decision aids that can help weigh the pros and cons of decisions about the care and support they need)  
• Engaging patients and caregivers in their care through shared use of electronic health records that allow for laboratory and radiology test results review, online medication review and refills, and provision of “after-visit summaries” |
| Engage patients in their care               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| Support seamless transitions between settings | • Providing a single point of contact (e.g., a system navigator) for frail older adults (as well as other patients with complex conditions) who takes responsibility for ensuring patients are transitioned across providers, teams and settings  
• Having a central ‘hub’ to coordinate outreach and follow-up for discharges from hospital and emergency or urgent care visits  
• Ensuring effective communication between care providers |
Evidence to consider
Several systematic reviews (and some key studies) have found that using models of person-centred care has many benefits, including:
• increased access to specialists;
• improved patient satisfaction with care and clinician experience;
• better use of technology;
• improved coordination of care;
• enhanced delivery of preventive services; and
• reduced hospitalizations and emergency department visits. (31;60;67-69)

Also, evidence from systematic reviews points to several benefits for strengthening care for chronic diseases. For example, 27 reviews found that integrating care across settings (e.g., hospitals, primary care and care provided in the community) and between providers (e.g., between family physicians, specialists and other providers):
• reduced hospital admissions and re-admissions;
• improved the use of treatment guidelines to support delivery of appropriate care; and
• improved quality of life for patients. (81)

It has also been found that including case management in models of care for older adults led to:
• reduced hospital use;
• reduced use of nursing homes/long-term care homes;
• cost-effectiveness and cost savings; and
• increased client satisfaction and quality of life. (83)

Questions to consider
• What would help you get the care you need when you need it to manage the burden of frailty?
• What would be helpful to support you to: 1) take ownership of your health and promote your well-being; and 2) to understand how to manage your own care?
• What would help you easily access the full range of care and support that you need?
Element 3 – Supporting caregivers in their efforts to prevent, delay the onset of, and manage the burden of frailty

Overview
The focus of this element is on supporting the efforts of caregivers in the many types of activities they may provide for older adults. In general, this could include identifying what caregivers find most difficult in their role, and supporting their efforts as part of the previous two elements about preventing, delaying the onset of, and managing the burden of frailty. This could include:

- addressing the economic security of caregivers through financial programs (e.g., flexible work arrangements or tax deductions for caregivers);
- engaging caregivers in decision-making about how care and support is organized to ensure it is appropriate for their needs; and
- providing education and supports to reduce caregiver burden and to help them cope and build resilience.

Evidence to consider

We found several systematic reviews that provide evidence about these activities, which we summarize in Table 3.

Questions to consider

• What do you want and expect in terms of supports for caregivers?
• What can be done to reduce:
  o physical burden;
  o economic burden;
  o emotional burden; and
  o social burden?
# Table 3: Summary of evidence about element 3

<table>
<thead>
<tr>
<th>Area of focus</th>
<th>Key findings</th>
</tr>
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| **Addressing the economic security of caregivers** | • No reviews were found on employment arrangements or income supports for caregivers.  
• However, some policy proposals have recommended that there should be supports for employed caregivers to continue to work, and that assistance should be provided to those that are most in need.(60) |
| **Engaging caregivers in decision-making about needed care, and about how care and support is organized** | • Engaging caregivers was found to:  
  o create a more rewarding experience for healthcare staff;  
  o increase access for those with disabilities;  
  o simplify appointments;  
  o result in more efficient transportation between services; and  
  o increase organizational attitudes that support caregiver and patient involvement.(84)  
• One way to engage caregivers is to provide materials that help to make decisions (often called decision aids). These were found to increase the understanding of options, risks and outcomes, improve involvement, and support professionals in counselling and sharing information with patients and caregivers.(85-88)  
• Caregivers should be provided with training to better prepare them to participate and engage in policy and care-planning discussion, and to determine what they see as appropriate supports for their specific situations. However, any engagement or education should be tailored to local contexts and each policy issue.(89;90) |
| **Providing education and supports to reduce caregiver burden and to help them cope and build resilience** | • Mixed evidence was found about whether education and training reduced caregiver burden.(91-94) However, training in coping strategies was found to improve the mental well-being of caregivers.(95)  
• Providing assistance and emotional support to caregivers was found to improve their mental and physical health. It was also found to improve their engagement with social activities and reduce depression.(96)  
• When education and training about the health needs of the person they are caring for was provided alongside assistance and emotional support, caregivers were found to have a reduced level of burden and stress.(97;98)  
• Not enough evidence was found to determine whether respite care (i.e., services that provide a ‘break’ for caregivers) reduced caregiver burden.(99) |
Implementation considerations

It is important to consider what barriers we may face if we implement the proposed elements of a potentially comprehensive approach to address the problem. These barriers may affect different groups (for example, patients, citizens, healthcare providers), different healthcare organizations or the health system. While some barriers could be overcome, others could be so substantial that they force us to re-evaluate whether we should pursue that element. Some potential barriers to implementing the elements could include:

- a potential lack of adherence to activities that support healthy aging (e.g., health-promoting interventions such as those for living an active lifestyle and/or improving nutrition that can help to prevent frailty);

- systems of care not being setup for addressing complex conditions such as frailty, which means significant changes to provincial and territorial health systems may be needed; and

- provincial and territorial health-system leaders having different readiness for change and collaboration (although, as noted below under windows of opportunity, there is increasing interest in pan-Canadian leadership towards strengthening home and community care).
The implementation of each of the three options could also be influenced by the ability to take advantage of potential windows of opportunity. A window of opportunity could be, for example, a recent event that was highly publicized in the media, a crisis, a change in public opinion, or an upcoming election. A window of opportunity can facilitate the implementation of an option.

Examples of potential windows of opportunity

- **An aging population**: As the realities of an aging population emerge, there will be a need to invest in new ways of doing things to meet the care needs of older adults.

- **Innovations at the provincial level**: Some provinces such as Ontario, with newly introduced legislation to strengthen patient-centred care (including better access to and coordination with home and community care), are innovating with new ways to provide care to people with complex conditions. (16)

- **Interest in pan-Canadian leadership**: Following the election of a new federal government, collaboration among federal, provincial and territorial governments appears to have new momentum. Also, the use of evidence is now being prioritized in all of the thinking at the federal level, and making home care more available has been identified as a priority for the government. (100)

- **Difficult economic times**: Sometimes difficult economic situations force the development of innovative policy approaches for making tough decisions.
Acknowledgments

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the citizen brief. The funder played no role in the identification, selection, assessment, synthesis, or presentation of the research evidence profiled in the citizen brief.

Merit review

The citizen brief was reviewed by a small number of citizens, other stakeholders, policymakers and researchers in order to ensure its relevance and rigour.

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Strengthening Care for Frail Older Adults in Canada


