



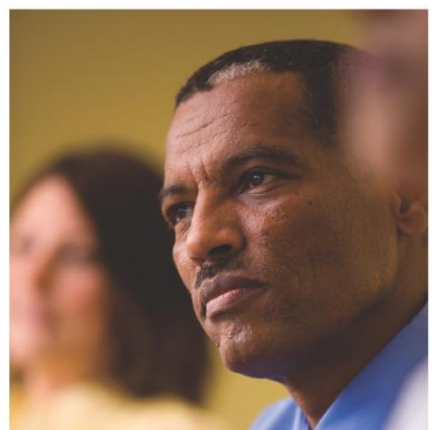
CITIZEN BRIEF



IMPROVING CARE AND SUPPORT FOR UNPAID CAREGIVERS IN ONTARIO



8 NOVEMBER 2014



EVIDENCE >> INSIGHT >> ACTION

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 regional/provincial levels 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 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views 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 a citizen panel about improving care and support for unpaid caregivers in Ontario. 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 implementing these options.

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

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Key Messages

What's the problem?

Providing care and support for unpaid caregivers in Ontario is challenging because:

- We have an aging and diverse population with significant need for unpaid caregivers;
- Unpaid caregivers are increasingly in need of support and care;
- Existing programs and services often don't fully meet the values, needs and preferences of unpaid caregivers; and
- Health-system arrangements (e.g., limited availability of financial aid) complicate the situation.

What do we know about three options for addressing the problem?

- **Option 1:** Addressing the economic security of unpaid caregivers
 - Improving housing conditions can help to improve health but there is a lack of evidence about flexible employment models or income supports
- **Option 2:** Engaging and supporting unpaid caregivers
 - A range of interventions were found to be beneficial for caregivers, including: engaging caregivers in decision-making about how care and support is organized; providing materials that help caregivers or the individuals they provide care to make decisions about their care; and providing education/training to caregivers
- **Option 3:** Providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions
 - Teaching coping strategies and communication skills helps to improve caregivers' psychological health, communication skills, knowledge and quality of life of people with dementia
 - Incorporating a mix of educational and supportive interventions in one package for caregivers helps to reduce their burden and stress

What implementation considerations need to be kept in mind?

- Barriers to implementing these options might include challenges to building consensus among many stakeholders about next steps, an unwillingness among decision-makers to make additional investments, and the difficulty of adapting services to many languages and cultures
- Facilitators to implementing these options might include the recent interest from the Federal government to identify how workplaces can better support caregivers, investments from the province of Ontario to improve home and community supports, and emerging and
- innovative approaches to providing coordinated care for people with complex needs



8.1 million Canadians provide care to a family member or friend with a long-term health condition or aging-related needs.

The context:

Why is improving care and support for unpaid caregivers a high priority?

>> Despite their crucial role in caring for older adults, support for unpaid caregivers can be lacking, inconsistently available or not aligned to their values, needs and preferences.

Consider the three scenarios on the following page that illustrate the types of challenges faced by caregivers.

Scenario 1

- **Mary, 48**, is a mother of two teenage girls and a primary school teacher. She lives with her husband who is a machinist in a local company. Mary's mother passed away this year and her father has been living on his own since. Her father has some difficulty with performing activities of daily living and increasingly needs Mary's help. As her father's health has deteriorated, Mary had to start working part-time, which has placed financial strain on her family.

Scenario 2

- **Syed, 50**, is divorced and lives in a small apartment with his mother who is 75. She has a history of arthritis, high blood pressure and mild asthma and increasingly requires help from Syed with activities of daily living. They have no immediate family in the country to provide support and Syed is unsure where to turn to get information and support when he needs help.

Scenario 3

- **Linh, 72**, is a married woman who is taking care of her husband at home. She has Type 2 diabetes and has suffered from depression in recent months. Her husband was diagnosed with mild Alzheimer's disease. He is increasingly unstable and falls frequently, and he is unable to adhere to his complex drug regimen.

The three scenarios described above illustrate just a few examples of challenges that unpaid caregivers are facing on a daily basis, such as those who are:

1. facing financial difficulties as a result of balancing work and caregiving responsibilities;
2. seeking information and support to help them provide care as well as a greater role in decision-making about how care and support is delivered; and
3. providing care to someone with complex care needs (e.g., dementia and Alzheimer's).

The need to identify how to improve care and support for unpaid caregivers has attracted a lot of attention from governments, media and the public, in part because of the increasing number of people who are acting as unpaid caregivers. In 2012, it was estimated that 8.1 million Canadians provided care to a family member or friend with a long-term health condition (most commonly cancer) or aging-related needs.⁽⁹⁾ In Ontario, about 20% of the population serve as a caregivers to family members and provide the majority of care needed.⁽¹¹⁾ As a report from the Canadian Medical Association pointed out that: “Much of the burden of continuing care falls on [unpaid] caregivers. More than one million employed people aged 45-64 provide informal care

to seniors with long-term conditions or disabilities and 80% of home care to seniors is provided by [unpaid] caregivers [in Canada].”(13)

Unpaid caregivers can play any of the following important roles:(15)

- providing emotional support;
- accompanying patients to medical appointments;
- reporting or managing side effects;
- giving medicines;
- keeping track of medicines, test results and papers;
- providing physical care (e.g., feeding, dressing and bathing);
- coordinating care;
- keeping family and friends informed; and
- making legal and financial arrangements.

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.(2;11;16) This lack of support can have a negative impact on the physical and mental health of unpaid caregivers, on their personal and professional lives, and on the quality of care that they provide.(18) As reported by a forum of Canada’s leading 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.”(18)

Glossary

Unpaid 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.(1)

Chronic health condition

A health problem requiring ongoing management over a period of years or decades (e.g., asthma, cancer, depression, diabetes and heart disease).(3)

Home and community care

Services to help people receive “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.”(5)

This brief was prepared to support a discussion by a citizen panel about improving care and support for unpaid caregivers in Ontario. More specifically, it examines the challenges facing unpaid caregivers, as well as what is known about potentially viable solutions to address these challenges. The input from the citizen panel will help to guide the efforts of policymakers, managers and professional leaders who make decisions about our health system.

Box 2: The health system in Ontario

- Medical care provided in hospitals and by physicians is fully paid for as part of Ontario's publicly funded health system.
- Care and support provided by other healthcare providers such as nurses, physiotherapists, occupational therapists and dietitians are typically not paid for by the health system unless provided in a hospital or long-term care setting, or in the community through Community Care Access Centres, Community Health Centres, Family Health Teams and other designated clinics.
- Other healthcare and community services such as prescription drug coverage, community support services and long-term care homes may be partly paid for by the health system, but any remaining costs need to be paid by patients or their private insurance plans.
- Fourteen geographically defined Local Health Integration Networks (LHINs) have responsibility for the planning and funding of healthcare in their respective regions, and for ensuring that the different parts of the health system in their respective regions work together.
- Fourteen Community Care Access Centres (CCACs) – one for each LHIN – have responsibility for connecting people with the care they need at home and in their community.
- 644 not-for-profit community support-service (CSS) agencies provide assistance to more than 800,000 community-dwelling Ontarians (most of whom are older adults). The assistance can include personal support (e.g., for household tasks), services provided as part of supportive housing, Meals on Wheels, transportation, and respite and adult day programs.(2)
- 54 Health Links (of an anticipated total of 90) support the delivery of integrated care for those with complex needs.



43% of seniors in Ontario have two or more chronic health conditions.

The problem:

Why is improving care and support for unpaid caregivers challenging?

>> Improving care and support for unpaid caregivers is challenging because their needs vary widely and shifting demographics will likely put an increased burden on their shoulders.

In this section, we highlight some factors that contribute to the problem and that require careful consideration.

An aging and diverse population has significant need for unpaid caregivers

In the next two decades, the number of Ontarians aged 65 years or older is expected to double, those over 85 to quadruple, and those 100 and over to triple.(19) This aging population has increasingly complex care needs. For example, it is estimated that 43% of Ontario seniors have two or more chronic health conditions, and the risk of developing chronic health conditions grows steadily with age.(20) As we describe later, providing care to people with complex chronic health conditions can be challenging, stressful and expensive.

Ontario is also a multicultural society with a large and vibrant immigrant population, mostly concentrated in large urban areas.(21) It is estimated that 6.5% of all immigrants (and 15.6% of immigrants who are 65 years and older) in Ontario are unable to carry on a conversation in English or French.(21) These immigrants are likely to face significant challenges when engaging in conversations with healthcare providers who are not proficient in their patients' first language.(22) These individuals are also likely to face significant barriers to navigate the system and access support.(23) Beyond language, culture (and religion) may shape the values and norms regarding various dimensions of caregiving. This can include the patient's and family's perspectives on health, suffering, death and dying, the use of Western medicine, the provision of information about the likely outcome of the illness, and the role of the patient and family in decision-making.

Unpaid caregivers aren't always available, are getting older, and can face demanding roles

Unpaid caregivers aren't always available

Family structures (and traditional support networks) are changing.(19) Older adults increasingly live alone with few extended family members. The number of families with two adults and children fell by 18% from 2001-2006, 51.5% of the adult population is not married, 42.7% of households have no children, and approximately 25% of families are led by a single parent.(9) These changes can have important consequences. For instance, they can limit the ability of unpaid caregivers to rely on, or seek help from, other family members when in need. Therefore, unpaid caregivers may increasingly require access to formal programs and services to fill the gap to obtain care and support.

Unpaid caregivers are getting older

The next challenge is that the unpaid caregivers who provide the majority of care to older adults are getting older as well.⁽¹⁹⁾ A report by Statistics Canada revealed that current caregivers are most often between the ages of 45 to 54 years (24%) and 55 to 64 years (20%). Seniors aged 65 and older represent 12% of all caregivers in the country, and they are the ones most likely to spend the longest hours providing care (generally to a spouse).⁽⁹⁾ With the aging population, it can be expected that we will increasingly see situations where both patients and their caregivers are older adults.

Older caregivers also have unique needs to be considered. For instance, a report published by the Canadian Association of Occupational Therapists indicates that older people are more vulnerable to the negative effects of being caregivers. Specifically, older caregivers are at additional risk for health problems, due to increased risks for:

- injuries or exacerbation of pre-existing health conditions;
- risky health behaviours (e.g., neglecting health promotion activities, or not attending regular medical check-ups);
- physiological changes due to chronic stress (e.g., increased risks of infection due to poor immune response, slower wound healing, or changes in heart health);
- mental health problems (e.g., depression and anxiety); and
- restrictions in daily life activities (e.g., neglecting care for self, leisure or social activities).⁽²⁴⁾

Caring for someone with certain health conditions can be particularly difficult

While caregiving can be a very fulfilling and rewarding experience for many, caregivers also find it challenging, stressful and expensive. In some cases, the burden of caregiving can have an impact on physical and emotional wellbeing. Caregivers experience more distress in their roles when they provide care to persons who:

- have limitations in their ability to care for themselves or conduct daily activities;
- have limitations in their ability to communicate;
- exhibit verbally or physically abusive behaviour;
- have depression; and
- require more hours of care.⁽²⁵⁻²⁷⁾

Caregivers of persons with multiple chronic health conditions experience particular challenges related to a lack of care coordination, poor communication and long wait times.⁽²⁸⁾ Also, caring for palliative care patients and individuals with Alzheimer's disease and its associated behavioural symptoms is particularly challenging. In such situations, caregivers often report high emotional

stress, severe fatigue, depression, and/or experience social isolation.(29-32) The chronic stress of caregiving can worsen their own health conditions, limits their ability to maintain a healthy lifestyle, and may result in increased risk of premature death.(29)

Existing programs and services often don't fully meet the values, needs and preferences of unpaid caregivers

Many programs and services are available for unpaid caregivers. Some examples include:

- practical, social and emotional support (e.g., peer or professional-led caregiver support groups);
- informational support such as advice, guidance, suggestions or useful information to help caregivers navigate a complex health system (e.g., Alzheimer's Society, family health teams);
- respite care services (i.e., providing temporary relief or breaks to caregivers) and counselling, including grief and bereavement services (e.g., adult day centres);
- technology supports such as websites for caregivers and caregiver blogs; and
- financial support (e.g., through the Compassionate Care Benefits program).

However, these programs and services often do not always fully meet the needs of caregivers. Results of 800 interviews with caregivers of older Ontarians conducted in 2012 found that there were a number of key areas in which caregivers and care recipients reported needing more support, such as:

- having a single point person to discuss care;
- assistance with navigating the health system;
- information on government, social and community services;
- finding trained and reliable home care services;
- home maintenance services;
- assistance with shopping and cooking;
- mental health/emotional support; and
- getting a break from caregiving (i.e., respite care).(2)

Home care services are also often inadequate (in both quantity and quality) for those who need care (resulting in increased caregiver burden), there are limited respite and support programs for caregivers, and there are inadequate options to address the isolation that can be part of caregiving.(33) Further, citizens have also noted that there are variations across the province in availability, costs and access to support programs and services for caregivers.(34)

Health-system arrangements complicate the situation

Limited financial aid is available to patients and caregivers in need

Caregiving is also challenging because of the economic costs that caregivers often face. Employed caregivers often experience work-related impacts such as reduced work hours or taking time off, taking a leave of absence, taking a less demanding job, or giving up work entirely. In addition to the loss of income and benefits as well as career limitations, many caregivers also incur significant out-of-pocket expenses as part of providing care.(2;29)

Those seeking financial assistance for caregiving and/or leave from work also find that only unpaid caregivers who meet very specific eligibility criteria can benefit from the federal Compassionate Care Benefits (35) and Ontario's unpaid Family Medical Leave.(36) A recent evaluation of the Compassionate Care Benefits program revealed the limited public awareness of the existence of the program, the complex application process and requirements, and the limited support offered (both in terms of financial assistance and length of coverage).(37)

Unpaid caregivers are often not engaged in decisions about how care and support is organized

The last set of challenges relates to the lack of opportunities and/or supports for engaging unpaid caregivers in planning and decisions about how care and support is organized.(16) A recent report observed that “most public policies have been developed without taking into account the needs that affect caregivers of older adults. Their contribution has been mostly overlooked, largely under-valued, and even undermined. Often these policies have unintentional negative effects on caregivers and their families, potentially increasing the burden on themselves, those they care for and the health care system.”(38) According to the Mental Health Commission of Canada, greater engagement of caregivers could lead to meaningful transformative changes to the health system, since caregivers are well-positioned to plan and evaluate the programs and services intended to support them.(39)

Box 3: A few recent initiatives

There have been some promising steps taken by several organizations and governments at all levels to improve care and support for unpaid caregivers in Ontario. However, efforts of this kind take time, resources and commitment from many players to bring about change. We describe some recent initiatives below.

- After consultations in 19 Ontario communities with more than 5,000 older adults and 2,500 health, social and community care providers, the report *Living Longer, Living Well* was released in January 2013 and provided 166 recommendations (including a set focused on better supporting caregivers) to inform the Ontario Seniors Strategy.(2)
- In April 2014, amendments to the Employment Standards Act to expand the province's "Family Medical Leave" to include three new leaves of absence were passed. This includes creating a new "Family Caregiver Leave," which will provide "up to eight weeks of unpaid, job-protected leave for employees to provide care to a family member with a serious medical condition."(4)
- In July 2014 the Federal government launched the Canadian Employers for Caregivers Plan, which will include an employer panel that will seek to "identify promising workplace practices that support caregivers."(6;7)
- The province of Ontario released a *Vision for Home and Community Care* that will be used to inform "a series of home and community care summits across Ontario to gather feedback from providers, patients and their families", (8) and has committed to investing \$750 million by 2015-16 to increase capacity to provide care after discharge from hospital.(10)
- 54 Health Links (of an anticipated total of 90) support the delivery of integrated care for those with complex needs.(12)
- A number of resources have been developed to help caregivers and those they support find and access the services they need, including a search engine from the Ontario Community Support Association containing caregiver services and supports,(14) a website from the Ontario government (www.respiteservices.com) that provides information and links to local respite services for people with disabilities and their families, and First Link® from the Alzheimer's Society, which "is designed to help newly diagnosed people with dementia get the help they need as soon as possible."(17)



We have selected three options (among many) for which we are seeking public input.

Options:

How can we address the problem?

>> To promote discussion about the pros and cons of potential solutions, we have selected three options for improving care and support for unpaid caregivers in Ontario.

Many options could be selected as a starting point for discussion. We have selected three (among many) for which we are seeking public input:

1. addressing the economic security of unpaid caregivers;
2. engaging and supporting unpaid caregivers; and
3. providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions (e.g., dementia).

The three options do not have to be considered separately. They could be pursued together or in sequence. New options could also emerge during the discussions.

In the following sections, we examine what is known about the pros and cons for each option, by summarizing the findings of systematic reviews of the research literature. A systematic review is a summary of all the studies addressing a clearly formulated question. The authors use systematic and explicit methods to identify, select and evaluate the quality of the studies, and to summarize the findings from the included studies.

Not all systematic reviews are of high quality. We present the findings from systematic reviews along with an appraisal of the quality of each review.

- High-quality reviews: conclusions drawn from these reviews can be applied with a high degree of confidence.
- Medium-quality reviews: conclusions drawn from these reviews can be applied with a medium degree of confidence.
- Low-quality reviews: conclusions drawn from these reviews can be applied with a low degree of confidence.

Option 1 – Addressing the economic security of unpaid caregivers

This option might include (but is not limited to):

- fostering a workplace culture in the province that supports flexible employment arrangements for caregivers who are working or would like to work;
- government-provided income supports for caregivers who face a financial burden in providing care (e.g., for those who meet specific needs tests); and
- making supportive housing available both to older adults and their caregivers to allow them to continue living at home or in the community.

We did not identify any systematic reviews related to flexible employment arrangements or providing income supports. However, these activities featured prominently in the 2014 Ontario Caregivers Summit that convened a group of caregivers, providers and government representatives to discuss how employers and governments can better support unpaid caregivers.⁽¹¹⁾ Specifically, two of the final recommendations from the summit included: 1) “enabling employed caregivers to continue to work and care” and 2) “providing income support for those that need it most”.⁽¹¹⁾

However, we did identify an older overview of systematic reviews that assessed the impact of housing and neighbourhood interventions on health and health inequalities (but was not focused specifically on caregivers).(40) This overview found:

- strong evidence that interventions that alter the neighbourhood conditions of disadvantaged people by moving them to a more affluent area leads to reduced depression and an increase in those reporting good/excellent health;
- strong evidence that improving housing conditions results in better health status; and
- some evidence to suggest that efforts to improve living conditions in areas with high poverty rates also improve health.(40)

Option 2 – Engaging and supporting unpaid caregivers

This option might include (but is not limited to):

- opportunities for caregivers to engage in decision-making about how care and support is organized to ensure services are aligned with the values, needs and preferences of patients and their caregivers;
- handbooks or toolkits that help caregivers identify the full range of resources available to them in their community; and
- education and supports to reduce caregiver burden and to help them cope and build resilience.

Engaging caregivers in decision-making about how care and support is organized

We found several high- and medium-quality systematic reviews about engaging consumers/citizens (including caregivers) in decisions about how care and support is delivered. One review found that there are several benefits to including patients and their caregivers in the planning, monitoring and development of health services, such as:

- improved self-esteem for patients;
- a more rewarding experience for healthcare staff;
- production of updated/improved patient-information resources;
- simplified appointment procedures;
- more efficient transportation between treatment sites;
- improved access for people with disabilities; and
- organizational attitudes that are supportive to patient involvement.(41)

Another review found that providing training to consumers (e.g., caregivers or the people they provide care to), as well as healthcare professionals, is an important part of meaningfully involving them in policy and planning.(42) While reviews have found that there is no ‘best’ approach for consumer engagement, they do indicate that it is because approaches need to be tailored to the local context of each community and policy issue.(43;44)

Handbooks and toolkits to identify available resources

We did not identify any systematic reviews specifically about the effects of handbooks or toolkits. However, many reviews have found that resources such as decision aids (i.e., materials that help individuals and/or their caregivers make decisions about their healthcare) are helpful because they:

- increase knowledge about healthcare options;(45-48)
- encourage consumer involvement;(48)
- support realistic perception of outcomes and risk;(46;48-51)
- reduce decision-related conflict;(48)
- increase patient-practitioner communication;(48) and
- support professionals to provide information and counselling about available choices.(45)

Education and supports to reduce caregiver burden and to help them cope and build resilience

We identified several recent reviews of high- and medium-quality that evaluated education/training, support programs and respite care (i.e., providing temporary relief or breaks to caregivers) for reducing caregiver burden. Key findings from these reviews were mixed and indicated that:

- providing training in problem solving and communication skills to caregivers for adults with cancer increased quality of life;(52)
- interventions that provided support, information, education and/or counselling did not reduce the stress or strain for caregivers of stroke survivors;(53)
- the most promising intervention for caregivers of stroke survivors is to provide education to them before the stroke survivor leaves hospital;(53)
- respite care for caregivers of frail elderly people has been found to result in small improvements in caregiver burden, mental health and physical health,(54;55) but overall the evidence is limited;(56)
- caregiver satisfaction with respite care is high;(54) and

- internet-based interventions that include information/education, self-management and communication skills training have been found to reduce caregiver stress and improve well-being.(57)

Option 3 – Providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions (e.g., dementia)

Given the added challenges faced by those providing care to people with complex conditions, this option is focused on providing enhanced training and support beyond what might be offered as part of option 2. This option might include (but is not limited to):

- programs that provide education and support that is tailored to caregivers of people with complex conditions; and
- system navigators or coordinators that help to identify and connect both the people with complex conditions and their caregivers with the care and supports they need.

Providing education and support

A recent high-quality review outlines three types of interventions for caregivers:

1. educational (e.g., those that provide information, education materials or feedback/advice about dementia and its complications);
2. supportive (e.g., providing assistance and/or emotional support to caregivers); and
3. multi-component (e.g., incorporating a mix of educational and supportive interventions in one package for caregivers).(58)

We outline below the key findings from the most relevant and recent systematic reviews of high or medium quality that we identified.

For educational interventions, we found that:

- teaching coping strategies to caregivers individually or in groups appears to improve their psychological health;(59) and
- providing communication skills related to dementia care improves caregiver communication skills, competencies and knowledge as well as the quality of life of people with dementia.(60)

For supportive interventions, we found that:

- supports to improve the mental and physical health of caregivers of people in terminal phases of an illness improved the caregiver's ability to cope with psychological distress;(61)
- support groups for caregivers of people with dementia have been found to significantly improve the mental health of caregivers, reduce caregiver depression, relieve caregiver burden, and improve caregivers' social engagement;(62)
- telephone counselling has been used successfully to reduce depression in caregivers of people with dementia;(63) and
- there is a lack of evidence to determine whether respite care for caregivers of people with dementia is beneficial.(64)

For multi-component interventions, we found that:

- offering a package of educational and support-based programs helps reduce the burden for caregivers of people with dementia;(65) and
- interventions that combine one or more of skills training, telephone support or direct help to people with dementia in finding the care they need, help to reduce caregiver burden and stress.(66)

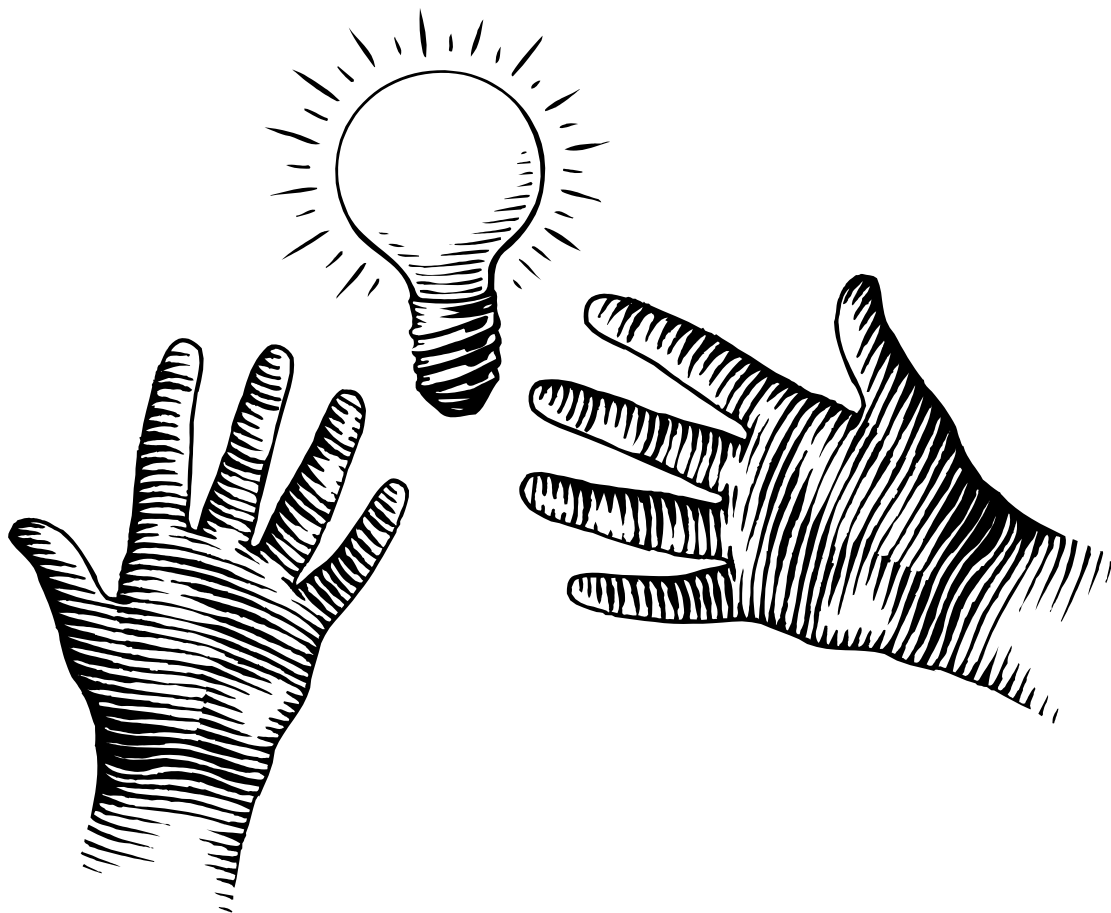
We should note that three older reviews found mixed evidence about the benefits of educational and support interventions. Specifically, these reviews found that:

- information/educational and support-based interventions for caregivers of people with dementia did not reduce caregiver burden or depression(67) and have inconsistent effects on improving quality of life;(68)
- behavioural or supportive therapy are less effective in a group setting than when delivered individually;(59) and
- support interventions for caregivers of people with dementia have in some instances resulted in increased caregiver burden because of difficulties with handing over care to someone else, concerns with nursing quality and not wanting to take time off.(67)

System navigators or coordinators to connect caregivers to the care and supports they need

Several recent reviews evaluated care coordination for people with complex conditions (but none specifically focused on helping caregivers) and found that:

- the use of system navigators for supporting chronically ill older adults is a relatively new intervention and there is a lack of evidence to determine if care coordinated by a system navigator is helpful to older adults transitioning between different care settings;(69)
- case management for people with dementia reduced the risk of being placed in long-term care,(70) improved their adherence to clinical recommendations, increased the quality of life for people with dementia and their caregivers, and had inconsistent impact on reducing the use of healthcare resources (e.g., on preventing hospitalization);(71) and
- case management for frail older adults “improves function and appropriate use of medication, increases use of community services and reduces nursing home admission.”(72)



Summarizing what we know about the three options

In the following table we summarize what we know about each of the three options.

Option 1 – Addressing the economic security of unpaid caregivers
Summary of what is known about this option
<ul style="list-style-type: none"> • No reviews assessed flexible employment arrangements or providing income supports, but there is: <ul style="list-style-type: none"> ○ strong evidence that interventions that alter neighbourhood conditions for disadvantaged people by moving them to a more affluent area leads to reduced depression and an increase in health status; ○ strong evidence that improving housing conditions results in better health status; and ○ some evidence that improving living conditions in areas with high poverty improve health.(40)
Option 2 – Engaging and supporting unpaid caregivers
Summary of what is known about this option
<ul style="list-style-type: none"> • Engaging caregivers in decision-making about how care and support is organized was found to have a range of benefits (e.g., improved self-esteem for patients, updated and improved patient-information resources and organizational attitudes that are supportive to patient involvement).(41) • Materials that help individuals and/or their caregivers make decisions about their healthcare are helpful in many ways (e.g., by increasing knowledge about healthcare options, encouraging consumer involvement, reducing decision-related conflict and enhancing communication).(45-48) • Evidence about education/training and support programs are mixed, but training has been found to increase quality of life for cancer caregivers,(52) and internet-based educational interventions have been found to reduce caregiver stress and improve well-being.(57) • Limited evidence about respite care for caregivers of the frail elderly indicates high caregiver satisfaction and small improvements in caregiver burden, mental health and physical health.(54-56)
Option 3 – Providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions (e.g., dementia)
Summary of what is known about this option
<ul style="list-style-type: none"> • Teaching coping strategies and communication skills helps to improve their long-term psychological health,(59) communication skills, knowledge and quality of life.(60) • Evidence about supportive interventions is mixed: <ul style="list-style-type: none"> ○ supportive interventions have been found to improve caregivers’ ability to cope, mental health and social engagement, and reduce psychological distress, depression and caregiver burden;(61-63) and ○ other reviews found a lack of evidence to determine if respite care is helpful for caregivers,(64) and that support interventions including in dementia homecare may increase caregiver burden.(67) • Incorporating a mix of educational and supportive interventions in one package for caregivers helps to reduce the burden and stress of caregivers of people with dementia.(65;66) • There is a lack of evidence to determine if care coordinated by a navigator is helpful to older adults who require care in different settings,(69) but case management for people with dementia and frail older adults increases appropriate use of care and quality of life, and reduces nursing home admission.(70-72)

Implementation considerations

It is important to consider what barriers we may face if we implement the proposed options. These barriers may affect different groups (e.g., 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 option.

The implementation of each of the three options could also be influenced by the ability to take advantage of potential facilitators or windows of opportunity. A window of opportunity could be 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.

A list of potential barriers and windows of opportunity for implementing the three options is provided below. This table is provided to spur reflection about some of the considerations that may influence choices about an optimal way forward. We have identified the barriers and windows of opportunity from a range of sources (not just the research literature) and we have not rank ordered them in any way.



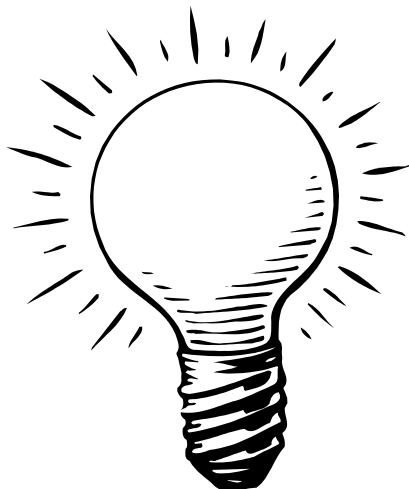
Option 1 – Addressing the economic security of unpaid caregivers	
Barriers	Facilitators
<ul style="list-style-type: none">• Decision-makers will need to build consensus across a range of stakeholders, including private sector employers, to implement a plan that allows for flexible employment arrangements for caregivers.• Decision-makers may be unwilling to make additional investments in income supports and supportive housing given pressure to constrain public-sector spending.	<ul style="list-style-type: none">• In July 2014 the Federal government launched the Canadian Employers for Caregivers Plan, which will include an employer panel that will seek to “identify promising workplace practices that support caregivers.”(6;7)

Option 2 – Engaging and supporting unpaid caregivers

Barriers	Facilitators
<ul style="list-style-type: none"> • Providers and organizations that develop and deliver services may find it difficult to adapt services to many languages and cultures. • Decision-makers seeking to involve caregivers as part of system- and community-level planning may face difficulty in identifying and engaging those who are currently unknown to the system. 	<ul style="list-style-type: none"> • The recent release of a Vision for Home and Community Care and the planned \$750-million investment by the province for home and community supports seem to signal a willingness to engage in long-term planning and allocate needed resources to the types of activities included in this option.(8;73) • Recent policy guidelines from the province focus on supporting the client care journey and working with clients as partners, which may also provide an opportunity to more consistently engage caregivers.(73)

Option 3 – Providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions (e.g., dementia)

Barriers	Facilitators
<ul style="list-style-type: none"> • In addition to the barrier listed for option 2, decision-makers face difficult decisions about what types of supports will be provided and whether all or part of the costs will be paid for by government. 	<ul style="list-style-type: none"> • Emerging and innovative approaches, such as Health Links, which aim to support coordinated care for people with complex needs may provide a ‘way in’ for training and supports for caregivers.

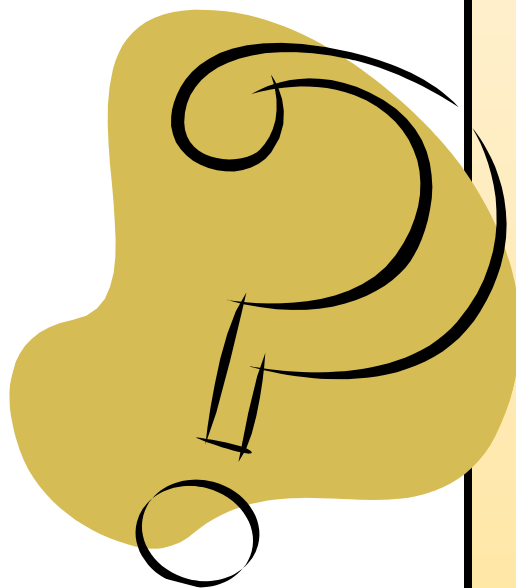


Questions for the citizen panel

>> We want to hear your views about the problem, three options for addressing it, and how we can move forward

This brief was prepared to stimulate the discussion during the citizen panel. The views, experiences and knowledge of citizens can make a significant contribution to finding viable solutions to the problem.

More specifically, the panel will provide an opportunity to explore the questions outlined in Box 4. 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.



Box 4: Questions

>> What are the biggest challenges faced by unpaid caregivers who are:

- facing financial difficulties as a result of balancing paid work and caregiving responsibilities?
- seeking information and support to help them provide care as well as greater engagement in decision-making processes about how care and support is delivered?
- providing care to someone with complex care needs (e.g., dementia and Alzheimer's)?

>> What types of care and support do you think would be needed to support each of these groups of unpaid caregivers?

>> What are potential barriers and facilitators to moving forward?

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the citizen brief. The funders 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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