

Why Canada Needs to Better Care for Its Working Caregivers.



**Why Canada Needs to Better Care for Its
Working Caregivers.**

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National Institute on Ageing Foundational Report on Caregivers in Canada

Suggested Citation:

National Institute on Ageing. (2018). Why Canada Needs to Better Care for Its Working Caregivers. Toronto, ON: National Institute on Ageing White Paper.

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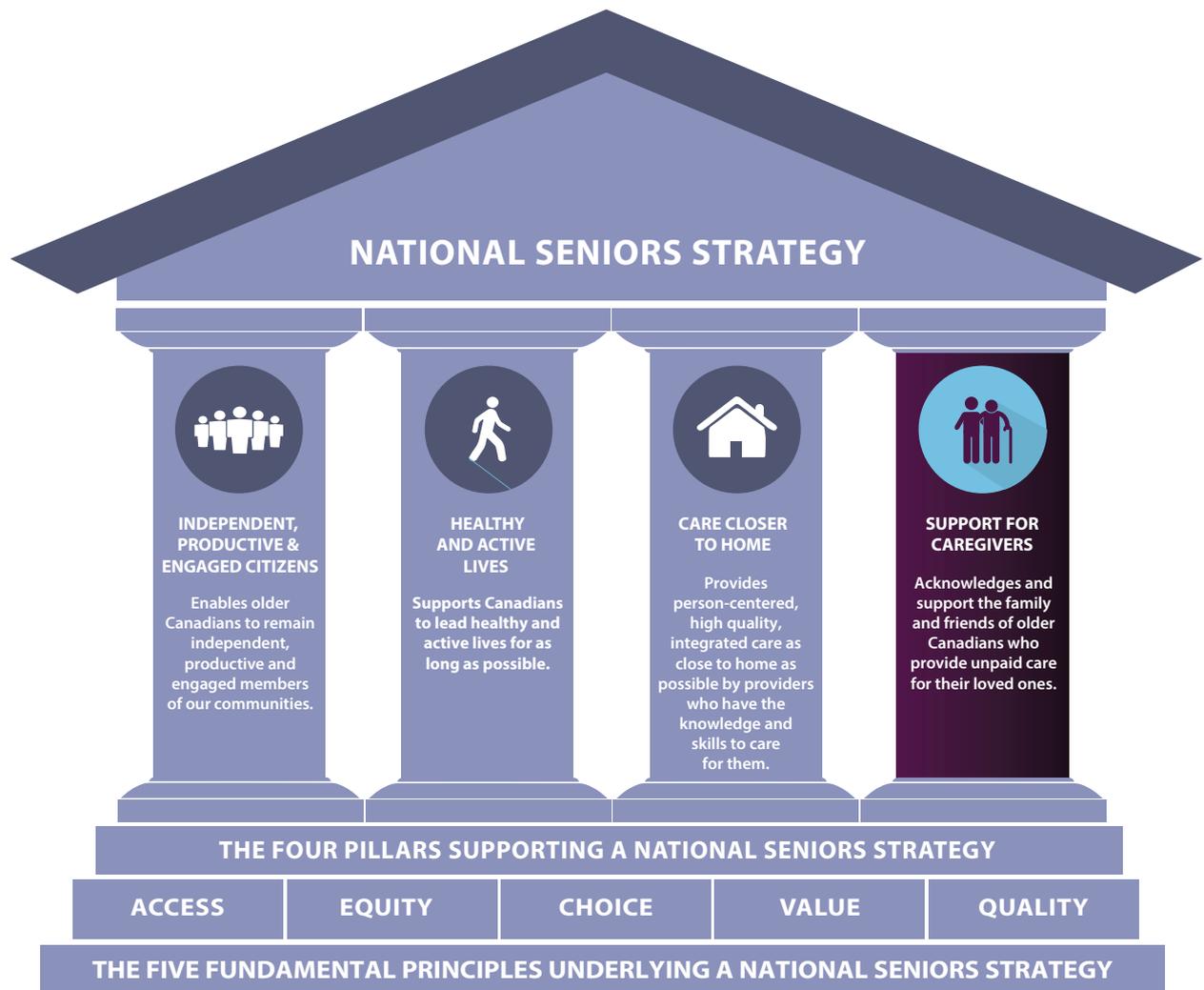
The National Institute on Ageing (NIA) is a new policy and research centre based at Ryerson University in Toronto. The NIA is dedicated to enhancing successful ageing across the life course. It is unique in its mandate to consider ageing issues from a broad range of important perspectives, including those of financial, physical, psychological, and social wellness.

The NIA is also focused on leading cross-disciplinary research to better understand the issues that can lead to the development of evidence-informed actionable insights that can meaningfully contribute towards shaping the innovative policies, practices and products that will be needed to address the multiple challenges and opportunities presented by Canada's coming of age. The NIA is committed to providing national leadership in promoting a collaborative approach that also seeks to continually establish municipal, provincial, federal and global partnerships with other academic centres, and ageing-related organizations.

The NIA further serves as the academic home for the National Seniors Strategy (NSS), an evolving evidence-based policy document co-authored by a group of leading researchers, policy experts and stakeholder organizations from across Canada and first published in October 2015. The NSS outlines four pillars that guide the NIA's work to advance knowledge and inform policies through evidence-based research around ageing in Canada that include Independent, Productive and Engaged Citizens; Healthy and Active Lives; Care Closer to Home; and Support for Caregivers.

This is the foundational report in the NIA's ongoing examination of caregivers in Canada. The NIA will be further exploring issues facing Canadian caregivers under the 'Support for Caregivers' pillar of work. This work will aim to highlight key challenges

facing caregivers and help policy and decision-makers to better understand, support and acknowledge the contribution of Canadians who provide unpaid care to people in their lives.



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Disclaimer: The NIA has developed this document to provide a summary of general information about working caregivers in Canada, as well as provide evidence-informed recommendations to support better acknowledgement and assistance for these Canadians. The NIA's work is guided by the current evidence. This document can be reproduced without permission for non-commercial purposes, provided that the NIA is acknowledged.

Executive Summary

Canadians want to age at home, with dignity, in familiar surroundings, and with their families. Caregivers make this desire a reality. But in as much as caregivers provide the heavy lifting at home, they also provide considerable social and economic value by offsetting costs and capacity in public health care systems. For many caregivers, these responsibilities are layered on top of their ongoing need to remain productively employed, raise a family, and to take care of their own needs.

Governments in Canada have come to recognize the desire Canadians have to age in place and the value that ageing in place provides to communities and to government-funded health care systems. But this recognition has only slowly started to translate into support for caregivers who shoulder much of the weight of the provision of home and community-based care in Canada.

The result is that a significant share of the cost and burden of ageing at home falls on the shoulders of caregivers. As the Canadian population continues to age, the financial, social, and personal health burden on caregivers will only increase.

Half of all Canadians over the age of 15 report having provided care to someone they know. More than half of these caregivers are also attempting to balance their paid employment with unpaid caregiving responsibilities. The value of this unpaid care is significant. Unpaid caregivers reduce pressure on our health care system by enabling care recipients to remain at home, rather than in expensive institutional settings.

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Across Canada, our current health, home and community care systems remain organizationally fragmented, making them difficult to access and navigate, which creates additional burdens on care recipients and caregivers alike, who often receive no training when taking on their increasingly complex roles.

For Canadian caregivers, social benefit programs that do exist remain confusing and inadequate – often leaving them financially penalized, despite their economic contributions. It is estimated that the economic value of unpaid caregiving in Canada exceeds \$25 billion annually.¹ This direct benefit and valuable resource is often unacknowledged by governments and health care systems.

Due to our rapidly ageing population, an increasing number of Canadians will desire and require care at home. A commensurate number of caregivers will be needed to provide the care. If we do not support unpaid and working caregivers, the personal and economic consequences will be significant. This report highlights key issues that need to be addressed to ensure those who receive unpaid care and those who provide this care are adequately supported.

While there has been some recent progress in recognizing and supporting caregivers, much more needs to be done. This white paper sets the context, outlines the current challenges faced by caregivers," and makes the following five evidence-informed recommendations to support policy and practice approaches governments and employers can implement to provide better support to current and future working caregivers:

- 1. Provincial, Territorial, and Federal Governments Should Formally Recognize Caregivers with a Common Definition that Acknowledges Their Role and Provides the Foundation for Formalized Support**
- 2. Building on Formal Recognition, Health Care Systems Should Provide Caregivers with the Supports they Need, Including:**
 - a. Assessment of caregivers' needs by health professionals to provide caregivers with individualized supports**

- b.** Access to training, support services, and respite from the formal health care system
 - c.** Additional funding for home care to alleviate the systemic burden on caregivers and to further integrate community-based and institution-based health care
- 3.** Governments Should Further Support Working Caregivers Financially in Recognition of the Economic Value They Provide and the Personal Cost of Providing Care
- 4.** Employers Should Recognize the Dual Challenges Employed Caregivers Have in Meeting their Responsibilities at Home and at Work, by:
 - a.** Providing the leadership necessary to create a workplace culture change that accepts and supports employees who provide unpaid care to loved ones
 - b.** Provide caregivers with flexible working arrangements
 - c.** Provide employee benefits specifically targeted to caregivers such as Employee Assistance Programs (EAPs)
- 5.** Develop National Standards that both Governments and Employers can use to Measure and Evaluate the Overall Success of Programs, Services, and Supports to meet the needs of Working Caregivers

Setting the Context

Who Are Canada's Caregivers?



Defining a "Caregiver"

We have adopted the Change Foundation's definition: caregivers are "the people – family, friends, neighbours – who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or end of life circumstances."² Additionally, we will refer to the person receiving care as a "care recipient".

In 2012, approximately 8.1 million Canadians had provided care to another person within the preceding year.³

In 2012, Statistics Canada estimated that approximately 8.1 million Canadians aged 15 and over had provided care to another person within the preceding year.³ In fact, half of all Canadians aged 15 and over – or about 13 million individuals – have provided care to a family member or friend, at some point in their lives.⁴ Almost 90% of Canadian caregivers - 7.3 million Canadians - reported providing care for one year or

longer.⁵ Fifty per cent of caregivers report four or more years of caregiving, most of which are for an older adult.⁶ About 50% of caregivers care for parents or parents-in-law, with close friends, colleagues, or neighbours representing the bulk of the rest of care recipients.⁷

By 2036, it is estimated that 1 in 4 Canadians will be over the age of 65,⁸ and the need for caregivers will likely rise proportionally. In turn, this is expected to have a notable effect on the Canadian economy, as approximately 6.1 million Canadians, or 35% of employed Canadians, are working and balancing caregiving responsibilities at the same time.⁹

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Women Are the Majority of Caregivers

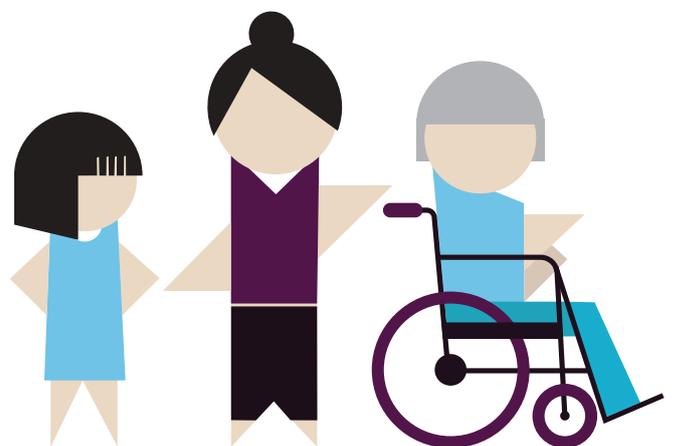
Canada has the distinction of having achieved the highest rate of female labour force participation among G7 countries (74.4% for those aged 15-64¹⁰). Male labour force participation rates remain significantly higher than females, with male participation for the same age group being 81.8%.¹¹

Despite high and increasing rates of labour participation amongst women in Canada, women still take on more than an equal share of caregiving duties. Women also tend to spend more weekly hours providing care and do so for a longer duration than men do. In 2012, an estimated 54% of Canadian caregivers were female. Women were more likely to spend 20 hours or more per week

providing care, while men on average spent less than one hour per week providing care.¹²

The amount of time and the duration of women's caregiving duties mean that women are more likely to feel the financial effects of caregiving, primarily through a loss of income and employment opportunities. Women take 30% more time off work than men do to provide care. Women are also more likely to reduce their work hours or work part time, retire earlier or leave the workforce temporarily to be caregivers.^{13,14}

In 2012, almost 30% of Canadian caregivers were “sandwich generation” women aged 35-44.¹⁵



This contributes to the increasing prevalence of what is being coined Canada’s “sandwich generation” - individuals caring for an older adult, and raising a child under the age of 18. These challenges are exacerbated when caregivers are also trying to balance their paid employment duties. In 2012, almost 30% of Canadian caregivers were “sandwich generation” women aged 35-44,¹⁵ which also happens to be the pivotal age range for building a strong career and working towards financial security.

How Changing Demographics Will Influence Caregiving

The number of Canadian caregivers is growing. This is due to changing demographic factors such as increasing life expectancy, declining fertility rates, the ageing of baby boomers, and an increased prevalence of older Canadians living with chronic conditions, functional impairments, and dementia.^{16,17}

Canadian caregivers provide vital support to people at home with complex health conditions. People over 65 are more likely to have one or more chronic health

condition.¹⁸ In 2009, a quarter of Canadian older adults reported having at least four chronic conditions, compared to only 6% of those aged 45-64.¹⁹ Therefore, caregiving is becoming more common and more complex as our population ages.

Alongside these trends, the current societal, political, and economic imperatives are encouraging a shift away from institutional care and towards “care at or closer to home.” This assumes that in addition to having enough accessible and affordable housing and community-based health care providers, families will be willing and able to continue shouldering a substantial portion of unpaid caregiver work.²⁰

What are the Issues Facing Canada's Working Caregivers?

1. Working Caregivers Remain Largely Invisible and their Role is Inadequately Recognized

Although caregivers often provide the bulk of support to care recipients, their work and care are largely unrecognized by employers, governments, and health care providers.^{21,22} As a consequence, caregivers often suffer financially, and, while maintaining employment, their full value to government-funded health-care systems is underappreciated, leading health care providers to fail to properly harness their significant contributions to patients.

Formally recognizing caregivers is the first step in supporting them and maximizing their contributions. Caregivers want and deserve to be recognized, both formally by governments and their employers, but also through the actions of health care professionals and the health care system.²³ Indeed, in describing what formal recognition means, caregivers have emphasized wanting to feel like they are equal members of the care team, and able to share and receive information from health care professionals (where consented to by the care recipient).²⁴

By not including caregivers in decision-making processes, health care professionals miss the expertise and vital knowledge that caregivers have about the care recipient.²⁵ Many caregivers are frustrated that they are not asked about how proposed or planned care options may affect them (personally or in their home, family and/or work life) – or whether the options would even be feasible.²⁶

Sometimes, caregivers are not able to fulfill their caring duties if their paid employment does not make accommodations for them. The Canadian Human Rights Act sets obligations for employers to adjust rules, policies, or practices that negatively impact individuals or groups of individuals based on prohibited grounds of discrimination.²⁷ Family status, which extends to a person's caregiving responsibilities, has been identified as one of the grounds for discrimination. For employers, the 'duty to accommodate' is required if the employee is unable to fully participate at their workplace because they are a caregiver.²⁸ However, the caregiver must show that other alternatives are not available and that there is a duty and 'obligation' for them to take on a caregiving role.²⁹

As a result, even current employment standards still put the burden on the employee to justify:

- Why providing care is obligatory and not a personal choice;
- What alternatives are available (i.e. friends, community supports);
- What efforts have been made to facilitate participation in paid employment and to provide the actual care;
- Why these efforts did not work;
- And, what will be required of the employer.^{29a}

What Can Organizations do to Better Accommodate Caregivers?

The Canadian Human Rights

Commission suggests three steps for organizations that want to better accommodate caregivers:

1. Talk with your employees about their caregiving obligations... gather information, acknowledge there is no one-size-fits-all solution, and provide reasons why the accommodation is denied if that is the outcome;
2. Be creative and flexible...an accommodation may not always be ideal and demands on the caregiver may change, so adjustments to an accommodation may be needed from time to time;
3. Follow-up and adjust... stay in communication with the caregiver, and work with them to make changes as needed.³⁰

2. The Current Lack of Support for Working Caregivers affects Canadian Economic Productivity

Why Governments and Employers Should be Concerned about Working Caregivers

With approximately 35% of working Canadians balancing their work and caregiving responsibilities at the same time,³¹ determining and providing appropriate support for working caregivers should be top-of-mind for both employers and governments. Given Canada's ageing population, this challenge will only become more pressing as more people will likely become caregivers while simultaneously trying to balance their work responsibilities. Furthermore, mounting evidence demonstrates that failure to balance caregiving and work-related responsibilities can increase absenteeism and decrease workplace productivity, leading to sub-optimal situations for caregivers and employers alike. Working caregivers report higher rates of:^{32,33}

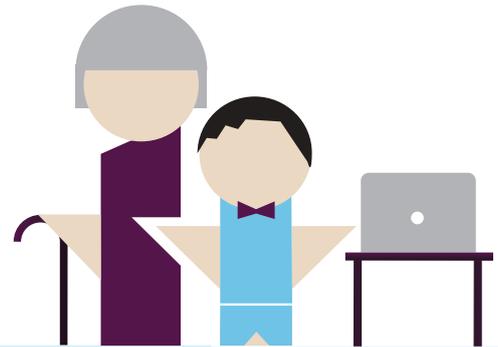
- Arriving late, leaving early, or taking time off for caregiving duties
- Feeling distracted or fatigued at work – due to dealing with phone calls, appointments, and emergencies related to caregiving
- Reducing hours

- Passing up promotions
- Being less likely to travel or unable to work overtime
- Choosing early retirement

The associated impact of caregiving on paid employment can be conceptualized into four main categories:

1. Labour force exit/preclusion,
2. Restricted work hours/absences,
3. Decreased productivity,
4. Career limitations.³⁴

Caregiving responsibilities have a meaningful impact on career and income. Given Canada's ageing population, increased longevity, and the fact that more people living longer with multiple chronic conditions, there's little reason to believe that caregiving duties won't increasingly affect employment and income. With a significant number of caregivers also being in their peak earning years, taking on these responsibilities can significantly influence their future earnings and career potential, including having to turn down promotions and travel or relocation required to sustain employment.³⁵



Caregiving Costs Canadian Employers More Than They Realize

Costs associated with caregiving have been estimated at approximately \$1.3 billion annually in lost productivity, absenteeism, and turnover for Canadian employers.³⁷

A 2017 report from the Canadian Imperial Bank of Commerce (CIBC) found that approximately 30% of caregivers for older parents took time off work, with the average time off taken estimated at 450 working hours per year (or approximately 8.5 hours per week) per caregiver – which is more than 20% of a typical work week. For people who earn hourly wages, this represents a significant loss of income.³⁸

Furthermore, if caregivers are forced to leave their jobs unexpectedly, employers also risk losing the knowledge, skills, and experience of these employees and must also spend more time and funds to hire and train new employees.³⁹ One study in the United States compiled findings of economic studies and found that the average cost of turnover is about 21% of an employee's annual salary.⁴⁰ For workers making less than \$75,000 annually, there is a typical cost of 20% of the salary of the employee for turnover.⁴¹ Those in very high paying jobs or at very senior levels can be as high as 213% of the salary.⁴²

This can result in dire financial consequences in the present and jeopardize an individual's overall retirement security. As caregivers are more likely than non-caregivers to be absent and distracted when at work, they are also more likely to have reduced performance and productivity, which can further impact overall job security.³⁶ This not only a time-limited problem for active caregivers, it also has the potential to cause ongoing financial challenges for caregivers.

Increased absenteeism adversely affects working caregivers. A reduction in working hours can lead to a loss of benefits, including extended health benefits, dental, pension, life insurance, or prescription medication coverage.⁴³ For employees paid by the hour, absenteeism equates to a loss of real income. One study looked at the impact of 'total role overload' (a measure of feeling overloaded at work and at home). It found that caregivers experiencing 'total role overload' were less satisfied with their work, less committed to their employer, more likely to contemplate leaving their employer, and more likely to report that their lack of work-life balance negatively affected their overall performance and productivity.⁴⁴ In another study, people who reported being "overloaded" felt less satisfaction in their employment and reported an increased likelihood of believing that work-life issues negatively impacted workplace productivity.⁴⁵

What are the Issues Facing Canada's Working Caregivers?

Working caregivers may also be more likely to be absent from work for their own health issues. Caregivers tend to use sick days and other leave options to perform care duties for others, leaving them fewer options and days off for their own physical and mental health needs.⁴⁶ This leads to a vicious cycle where caregivers forgo care to address their own needs in order to provide care for their care recipients, further jeopardizing their own health and well-being.

Caregivers save the Canadian health care system approximately \$25 billion annually.⁴⁹

Valuing the Economic Contribution of Caregivers

Caregivers provide significant value to the health care system, and to society overall. Caregivers are integral to enabling care recipients to remain at home safely and out of costly institutional care, thereby contributing to the sustainability of our publicly-funded health system.⁴⁷ Indeed, approximately 98% of care recipients who receive formal, paid home care also reported having a caregiver.⁴⁸

It has been estimated that caregivers save the Canadian health care system approximately \$25 billion annually.⁴⁹ However, these savings to the health care system may equate to extra costs that caregivers and their employers end up bearing. A 2017 report estimated that the combined direct and indirect costs (ie. taking time off work, lost income, leave) of providing unpaid caregiving in Canada is approximately \$33 billion annually.⁵⁰ Over the next decade these costs are estimated to further increase by 20% due to Canada's ageing population.⁵¹

3. The Health Care System is Difficult for Working Caregivers to Navigate Because of a Lack of Integration Between Different Service Providers and their Lack of Available Time to Arrange, Organize, and Provide Care.⁵²

One of the most significant sources of stress for caregivers is how fragmented our health and social services are, making it challenging and frustrating for them to determine what resources are available, how to access them, and how to link them together.^{53,54}

For example, when trying to coordinate care between two different health care professionals, caregivers often report communication gaps that lead to disruptions in care or that can leave the caregiver confused and unsure of next steps.⁵⁵

Caregivers find that community supports and the health care system need to be better integrated to share information. Caregivers also report a lack of integration between primary care, care support at home, and services in the community (i.e. services offered by the Alzheimer Society).⁵⁶ Many care recipients report receiving services from multiple sectors and organizations that do not seem to be connected to each other. This makes things difficult for caregivers to manage, as each provider has its own assessment, plan and delivery process. As a result, the burden of coordinating and integrating services falls to the caregiver.⁵⁷

Caregivers want to know how to access services, and more flexibility as to when and how services are provided. It has further been difficult for caregivers to access the services they need when they need them, and for services to be appropriate to the specific stage, condition or context of the care recipient.⁵⁸

In addition to the challenge of connecting services together, many caregivers report struggling to understand what supports are available and how to access them for their care recipients.⁵⁹ While there has been an active shift toward providing more care in home and community settings, the services that would enable this are not sufficient or accessible, and people are not aware that they exist. For example, in 2012, Statistics Canada estimated that 15% of Canadians receiving home care still had unmet needs.⁶⁰ Other studies have also demonstrated that many older adults do not access services they would likely benefit from because they do not know how to access them or do not think the services will be helpful or adequate.^{61,62}

The needs of care recipients also vary by condition and context. For example, there are acute issues that may arise quickly, short-term issues that may require care for a short time period, and chronic issues that will require evolving care as the issue progresses. Caregivers need access to services tailored to the particular needs of their care recipients. For those providing care to people with dementia or other forms of cognitive impairment, often more timely and flexible services are required than are offered.⁶³ This flexibility is crucial because of the progression of dementia.

Caregivers for people with dementia specifically noted that due to long waiting lists for services, they are unable to access services when needed because by the time they are provided with a service, it may not be appropriate as they may have moved to a different stage of the condition requiring increased support. They also say that services, even when accessible, are not offered when needed (for example on nights and weekends).⁶⁴ Caregivers have difficulty determining eligibility criteria to access services, amount and type of services that are accessible to them and the limits on what staff in the home are able to do.⁶⁵ Many caregivers report wanting more follow-ups and assessments to take place for care recipients with dementia in order to ensure the services provided are appropriate to the progression of the condition and the evolving needs of caregivers.⁶⁶ This is likely the case for other progressive illnesses and conditions as well.

In addition to home care, primary and acute care also have gaps in services. The Commonwealth Fund'sⁱ 2014 International Health Policy survey of patients and providers in 11 developed countries highlights a broad range of experiences with health care.⁶⁷ Out of 11 countries studied, Canada had the longest wait times to access primary and specialist care.⁶⁸ In 2017, Canada continued to experience long wait times with 59% of older adults being unable to get a same or next day appointment.⁶⁹

Out of 11 countries surveyed, Canada had the second highest number of older adults living (approximately 30%)⁷⁰ with three or more chronic conditions.⁷¹ Furthermore, Health Quality Ontario's 2015 annual report corroborated this finding as it concluded that providing timely access to home care services is essential for allowing people to remain in their homes and avoid preventable emergency department visits and hospitalizations.⁷²

ⁱ The Commonwealth Fund is a private foundation that supports independent research in order to promote high performing health care systems.

How are medical and non-medical services funded in Canada?

In Canada, there is no single national health service, but rather 13 provincial and territorial health care systems operating in accordance with the Canada Health Act. As such, the roles and responsibilities for health care services are shared between provincial and territorial governments and the federal government. The federal government directly funds the care for certain populations such as First Nations and Inuit peoples as well as Veterans. The federal government provides funding to the provinces and territories through pre-negotiated health accords.

Medical care provided in hospitals and by physicians is covered under individual provincial and territorial health plans in accordance with provincial laws and the federal Canada Health Act. The provision of home care, long-term care and prescription medication coverage are not guaranteed under the Canada Health Act. Every province and territory offers some form of publicly funded home care services to assist

those who have difficulty caring for themselves at home, which may include nursing, personal support, physiotherapy, occupational therapy, social work, nutritional counselling, speech-language therapy, dietitians, respite care, and provision of medical supplies.^{73,74}

However, the lack of a federal mandate that home care and long-term care be government funded means that there exists far greater fragmentation in how home care and long-term care services are resourced, organized and delivered. As a result, there are variations in care - availability, eligibility, quality and accountability for the provision of these services can vary significantly across provinces and territories, and even within these jurisdictions.⁷⁵

4. Financial, Emotional, and Physical Costs of Being a Working Caregiver in Canada

Financial Costs

Canadian caregivers face a confusing and inadequate system of supports. The costs of some services are publicly funded, fully or partially, whereas others are not. In most provinces, publicly funded (partially or fully) services are administered through regional health authorities. For home care, strict eligibility criteria must be met in order to receive publicly funded care.⁷⁶ Other services such as medications, community supports, and long-term care are partially subsidized by the health care system, with the additional costs being paid either out of pocket or covered (fully or partially) by private insurance plans.⁷⁷ For example, in Ontario, the government does not cover all costs of long-term care. Ontario publicly funds nursing and personal care, but then sets a co-payment amount residents must pay to cover their 'room and board'.⁷⁸ If you cannot afford this, there is an option to apply for a subsidy.⁷⁹

All these costs can quickly add up for caregivers. A 2017 CIBC report found that on average a caregiver will spend \$3,300 per year on out-of-pocket costs, which translates into just over \$6 billion to the overall economy.⁸⁰ Programs do exist that aim to alleviate these out-of-pocket costs such as home renovation credits and respite services; however, many of these credits

A 2017 CIBC report found that on average a caregiver will spend \$3,300 per year on out-of-pocket costs.⁸⁰

and services come with confusing eligibility criteria, (see box). CIBC also noted that many direct costs of caregiving disproportionately affect those with lower incomes. For example, Canadians who earn \$50,000 or less spent approximately 30% more than those earning over \$100,000 on caregiving-related expenses.⁸¹

Furthermore, almost 15% of working caregivers lost benefits and another 10% turned down or did not attempt to pursue a new job or promotion because of their caregiving responsibilities.⁸² It has been found that women at age 80 have fewer financial resources to support the provision of long-term care they will likely need.⁸³ Additionally, women who are 85 and over are much more likely than men to experience very serious declines in living standards.⁸⁴ It is hypothesized that this relates to the differences in male and female life expectancy, such that men at 85 are more likely to have a spouse who can provide care in the home and may be less likely to need to enter long-term care.⁸⁵

Caregiver Tax Benefits and Credits – Are they helpful, and reaching the caregivers who need the support?

Ironically, navigating programs that are meant to reduce stress and pressure on caregivers can contribute to caregiver stress. Many caregivers do not take advantage of the available benefits and tax credits because they are unaware that they are eligible, do not understand the application process, or do not know how to apply for them.⁸⁶

For example, to claim 'Home Accessibility Expenses' caregivers must be eligible to receive a disability tax credit (which is a non-refundable tax credit for persons with disabilities) or be 65 years of age or older.⁸⁷ Caregivers are eligible if they are the spouse or common-law partner of a qualifying individual, an individual who claimed the amount for an eligible dependent, caregiver amount, or amount for infirm dependants age 18 or older OR a person who can claim the disability amount for the qualifying individual.⁸⁸

If a caregiver is still eligible at this point, the home must also be eligible. This means the house must be a housing unit in Canada that is either owned by the

qualifying individual and is ordinarily inhabited in the year by the qualifying individual, or owned by the eligible individual and is ordinarily inhabited in the year by the eligible individual and qualifying individual, and the individual does not throughout the year own and inhabit another housing unit in Canada.⁸⁹ This excludes the large number of seniors and caregivers who live in rental accommodation and require modifications for accessibility and safe and independent living.

As of 2012, only 14% of caregivers of spouses and 5% of caregivers of parents received financial assistance from the government – with 42% of caregivers for spouses and 28% of caregivers for parents wanting to have more financial assistance.⁹⁰ Although there have been attempts to simplify the process of applying for assistance (i.e. announcing the creation of the new Canada Caregiver Credit in the 2017 federal budget) – there remains a need to simplify the process further in order to give more people the opportunity to benefit from government financial support.

Emotional and Physical Costs of Caregiving

While the financial costs of caregiving are well researched, the emotional impact remains one of the less recognized challenges that caregivers face. In a 2012 report by The Change Foundation, caregivers noted that caregiving takes an emotional toll and many found government and providers underappreciated this.⁹¹ Another report from 2012 found that many Canadian caregivers are negatively emotionally affected by their caregiving role with almost 30% reporting providing care was stressful.⁹²

A recent Health Quality Ontario report found that caregiving is linked to emotional stress - including feeling guilty about being tired, losing patience, having to make all the decisions, and feeling lonely and isolated.⁹³ This kind of stress and emotional toll can lead to reduced productivity and increased absenteeism among working caregivers.⁹⁴ Researchers looking at workplace policies on caregiving found that almost 40% of workplaces had employees who reported taking disability or stress leave, at least partially due to caregiving responsibilities.⁹⁵

The 2015 Federal Government's report from its 'Employer Panel for Caregivers' noted that employees also want help balancing work and caregiving because having to miss work adds further stress for them.⁹⁶

Emotional concerns are of particularly high importance. However, these are often compounded by physical health impacts as well. In 2012, 20% of Canadian caregivers reported that their physical or emotional health had suffered in the past 12 months.⁹⁷ In 2012, researchers found that one in five working caregivers reported high levels of caregiver strain, with 29% of these reporting physical strain.⁹⁸

5. Working Caregivers are not Usually Provided with any Formal Information or Training to Support their Caregiving Responsibilities.

Caregivers Need to be Supported with Information and Training to Take on Their Roles

Caregivers often report not being adequately prepared, or trained, to take on caregiving duties, even when they are performing tasks traditionally reserved for trained professionals. Many people become a caregiver suddenly, without preparation, and with little understanding of how to proceed and what to expect.⁹⁹ Caregivers want better education and training to be in place so that they are better able to care for their care recipient.¹⁰⁰

Caregivers say this should include skills training in personal or medical care.¹⁰¹ To engage and optimize the care provided by caregivers, we need to train them for the tasks that they can and want to do, but also make more care available as well so they are not penalized for wanting to care for the care recipient. Caregivers further report wanting health care professionals to consider their preparedness as caregivers as well as their level of confidence to take on tasks being asked of them.¹⁰²

Like care recipients, not all caregivers are the same. Some may be more naturally equipped to provide care than others. Education and training can help raise the standard of care provided and contribute to the confidence and general health and well-being of novice caregivers. Caregivers say that there are many tasks they would be willing to take on if they were adequately provided with training. Many have further voiced the desire to have a training course before the care recipient is discharged, in the same way that mothers are taught to breastfeed before going home, or people with diabetes are taught to inject insulin before discharge.¹⁰³

Some workplaces do provide access to counselling or assistance. Services other than counselling, however, including information and support services specific to the provision of adult/elder care are less commonly available.¹⁰⁴ On-site seminars and 'lunch and learns' are more available for parents than for those providing care for adults or eldercare - 19% for parents versus 13% for adult/eldercare.¹⁰⁵

Also, on-site child care services were available for 12% of the organizations studied (including public, private, and non-profit/voluntary organizations), while only 3% had on-site or near-site day programs for older adults.¹⁰⁶

Caregiver Support Needs to be Integrated into Training Requirements for Health Care Professionals

There are currently no mandatory clinical competencies or training requirements related to caregivers in the provision of care to older adults for almost all health professionals across the country.¹⁰⁷ Caregivers have asked for more training from health care professionals on supporting care recipients, as well as building greater awareness among health care professionals around the caregiver experience and their related needs.

Evidence-Informed Recommendations

Through examination of current evidence and the state of working caregiver policies across Canada and beyond, there is additional work that must be done to provide better support to the current and future working caregivers in Canada. The following five recommendations are evidence-informed policy and practice approaches for governments and employers to consider as they move to better support working caregivers across Canada.

1. Provincial, Territorial, and Federal Governments Should Formally Recognize Caregivers with a Common Definition that Acknowledges Their Role and Provides the Foundation for Formalized Support.

With approximately 8.1 million Canadian caregivers,¹⁰⁸ and many more likely to take on these roles in the coming years, establishing a national system that formally acknowledges the role of caregivers in our society through a common definition will be a critical first step towards better addressing their needs.

Internationally, there is a similar issue as there is not a common definition.¹⁰⁹ A common definition of caregivers will allow governments, our health and social care systems, and employers to more consistently acknowledge and address their needs in a more systematic way. Recognition can lead to deeper understanding, and thereby improve our approaches to supporting caregivers.

Currently, Canadian governments and employers are addressing issues in a piecemeal approach. Governments across Canada should therefore work together and with employers to address this issue as one of national significance and support movement towards a more coordinated approach. Formally recognizing caregivers with a common definition acknowledges their role and value in the provision of health and other services and supports. It also acknowledges their influence on Canada's current and future economic productivity. This will allow their needs to be better addressed while further enabling them to advocate for their rights at work, in the delivery of health and social services and in society as a whole.

Formally Recognizing Caregivers – Progress in Canada and Abroad

In 2011, Manitoba became the first province to enact formal legislation to recognize caregivers. ‘The Caregiver Recognition Act’ remains the only Act of its kind in Canada. It is meant to guide the government when they are developing, implementing, providing, or evaluating any type of caregiver support in the province. Manitoba defines a caregiver as “a person who provides informal and unpaid personal care, support or assistance to another person because that other person lives with challenges due to (a) a disability; (b) an illness; (c) an injury; or, (d) aging.”¹¹⁰ It presents a number of principles, including respect for their relationship with the person they care for, that their needs should be addressed beyond their caring role, their well-being should be supported, and that support should be timely, responsive, appropriate to need, and accessible.¹¹¹ The Seniors and Healthy Aging Secretariat (SHAS) is responsible for meeting the mandates set out in this legislation.¹¹² Some of these roles include supporting the Caregiver Advisory Committee, providing

leadership on the Age-Friendly Manitoba Initiative, and working across departments to incorporate the needs of older adults in policy, legislation, and program decisions.¹¹³ In 2015, the Manitoba Minister of Healthy Living and Seniors increased the Primary Caregiver Tax Credit by 10% bringing the refundable credit to a maximum of \$4,200 (\$1,400 for up to three care recipients).¹¹⁴

Additionally, in 2017 the Prime Minister of Canada released a video statement recognizing the diversity, role, and value of caregivers on National Carers Day (April 4th). As Canadians have been advocating for this action for many years, this was an important step in advancing the national agenda surrounding better support for caregivers.¹¹⁵ This also came after the federal government announced earlier in its 2017 federal budget the abolition of three previously problematic caregiver tax credits and replacing them with a new more generously funded and more easily accessible Canada Caregiver Credit (See more on page 24).

In the UK, caregiver recognition legislation was initially passed in 1995, and has since been replaced by the 'Care Act' in 2014, which requires local authorities to provide caregivers with information, advice, services, and assessments.¹¹⁶ It was meant to further strengthen recognition of caregivers in the health system – including providing caregivers with a legitimate right to receive services.¹¹⁷

In 2016, Scotland passed the 'Carers Act', which requires authorities to create a carer plan, create a carer strategy, and to involve caregivers when planning.¹¹⁸

In the United States, certain states have been working to improve recognition of caregivers through the passage of the 'Caregiver Advise, Record, Enable (CARE) Act' at the individual state government level.¹¹⁹ As of August 2017, 38 states have enacted this Act which requires that hospitals provide the opportunity for patients to designate a caregiver. This caregiver must be contacted when the care

recipient is going to be discharged or transferred out of the facility.¹²⁰ The health care professionals that are providing care must also consult with the caregiver to provide them with guidance on any tasks that they will be required to perform on the individual.¹²¹ Subsequent to this, in September 2017, Congress passed the 'Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017', or the 'RAISE Family Caregivers Act'.¹²² This complementary Act has been designed to address caregivers in: promoting person-and family-centered care in all health and long-term care services; assessments and planning involving family caregivers and care recipients; information, education, training support, referral and care coordination; respite options; financial security and workplace issues; and, delivering services based on performance, mission, and purpose of a program while reducing redundancies.¹²³

In developing a mechanism for formal recognition, it must be inclusive and encompass the breadth of the caregiver relationship. This may require adjusting eligibility criteria for caregiver supports (i.e. expanding the definition of “caregiver” to include family, friends, or neighbours who may not be relatives)¹²⁴, as the Manitoba Caregiver Recognition Act already allows for.

Formally recognizing caregivers with a common definition will encourage their inclusion as integral members of the care recipient’s care team. With the care recipient’s consent, it would encourage health care professionals to share information to provide better care and will encourage inclusion of caregivers in care planning. This will also ensure that caregivers are better able to understand the next steps and that the plans are suitable and achievable.¹²⁵

Once caregivers are formally defined and recognized, governments and employers can use these definitions to better support working caregivers. Employers can better identify caregivers in their workplace, and can create an open environment for caregivers to discuss their needs. If the caregiving role is properly recognized, health care professionals will better understand that caregivers need to be supported, that they are a vital source of information about the care recipient and that they may need services for their own well-being.¹²⁶

2. Building on Formal Recognition, Health Care Systems Should Provide Caregivers with the Supports they Need, Including:

- a. **Assessment of caregivers' needs by health professionals to provide caregivers with individualized supports**
- b. **Access to training, support services, and respite from the formal health care system**
- c. **Additional funding for home care to alleviate the systemic burden on caregivers and to further integrate community-based and institution-based health care**

Canadian Caregivers Require Appropriate, Individualized Assessment of Their Own Needs

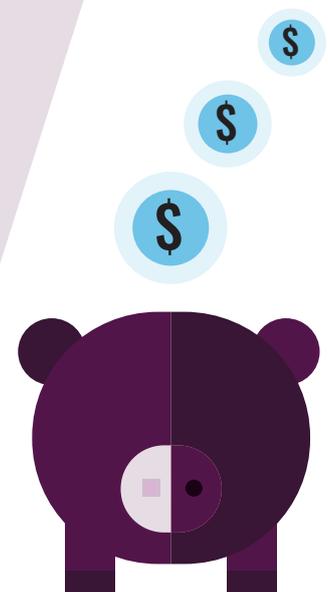
Caregivers should have their needs recognized and formally assessed separately from care recipients. This would enable them to better access services that reflect the needs of both caregivers and care recipients, and caregivers would be more empowered to decide which services and supports are best for them. Formally assessing the needs of caregivers is particularly important in ensuring that they are not penalized for taking on caregiving duties.

Caregiving Costs Canadian Employers More Than They Realize

In the UK, any caregiver who may require support is required to be offered an assessment – regardless of the amount or type of care provided to their care recipient.¹²⁷

The assessment extends beyond people living with the care recipient.¹²⁸ This assessment is done separately from the care recipient’s assessment. Even if the care recipient has not had an assessment, the caregiver is still eligible to be assessed.¹²⁹ Assessments are offered via local social services departments - and caregivers can contact them directly and request an assessment.¹³⁰

In Australia, after passing the Carer Recognition Act in 2010 to formally recognize carers (caregivers), the Australian Government has been working on the development of a federal service delivery model to better support carers, including needs identification.¹³¹ There are two ways of doing this – the first is an online self-assessment, and the second is through a phone or in-person meeting at a regional service hub.¹³² Carers in Australia were consulted during this process and indicated their interest in the development of an assessment questionnaire and process, specifically to learn more about how to better address their carer-specific needs and what supports they may be eligible to access and receive.¹³³



As societal preferences and government policies increasingly champion “ageing at home” and “care closer to home”, there have been calls for increased funding in home care. The Canadian government has responded by supporting an additional \$6 billion investment into home care over the next 10 years as part of its latest 2017 health accord with the provinces and territories.¹³⁴ Some of this funding is to be directed at providing better support for caregivers, as well as improving access to home, community, and palliative care services.¹³⁵ While this is a positive step, no specific details have arisen yet on how this investment would specifically support caregivers at the provincial and territorial levels and whether any of the provinces and territories would use their funding to specifically support caregiver assessments, as well as the development of services that address caregivers’ needs.

There is a need to create standardized assessments that assess caregivers’ needs separate from the care recipient. There is a need for a greater level of standardized assessments to take place providing a more comprehensive focus on caregiver needs.

Connecting Caregivers with Appropriate Programs, Supports, and Services

Canadian caregivers would also benefit from more reliable information about how to access support and services. To fill the current gaps in the public systems, private services have emerged which are aimed at providing easier access to information and supports for caregivers in Canada.

Private Navigation Services are Emerging to Fill Current Information and Navigation Gaps

A Paid Information and Support Service for Canadian Caregivers

Challenge: Providing caregivers with supports, information, and tools to better navigate and connect services for their care recipient.

Organization: Saint Elizabeth Health Care

Solution: Elizz is a paid service that connects caregivers to supports, information, health care system navigation tools, and provides fee-for-service virtual services. The service is accessed on a website that provides information about appropriate services for caregivers, and aims to support caregivers to manage their responsibilities and navigate health and social services. All services are paid for by the caregiver clients. Costs range from \$45/session for caregiver coaching, \$180/month for access to a nurse advisor, and \$85/session for virtual counselling. Caregivers can also set-up fee-for-service in-home care services for those they support.

Caregivers must be able to access services aimed to reduce stress and improve wellness. These include better availability of day programs, respite, and other services providing relief so caregivers can spend more time looking after themselves while knowing their care recipients are being well looked after. Furthermore, training, counselling services, and support groups, in addition to respite supports, have been shown to positively influence the health and well-being of caregivers – but, the availability and access to these services varies considerably across the country and by location.¹³⁶

Caregivers Require Adequate Respite Care Services

The need for in-home respite has been cited as one of the most important issues facing caregivers.¹³⁷ In-home respite services are difficult to access. They usually involve a fee, and are not connected with other services.¹³⁸ One report found caregivers of people with dementia had unmet respite needs, including in-home

respite, access to emergency respite care supports (i.e. for a crisis situation), flexible options and short-term day respite care, more supportive respite care services for those with cognitive impairment, and more meaningful and stimulating respite care services for the care recipient.¹³⁹

Currently, adult day programs are another option for caregivers seeking a safe place for their care recipients. These programs provide supervised activities, such as recreational or physical activities, for adults who require care or support, which in turn provides an opportunity for respite for caregivers. These programs also tend to provide meals, sometimes transportation, and a limited amount of personal care.¹⁴⁸ While various jurisdictions across Canada have promising publicly funded options that work (see box), these do not represent a common standard of care. As there also exists limited capacity¹⁴⁹ within the available publicly funded programs, alternative private options are being developed to fill in existing care gaps.

Respite Care Services in Canada are Patchy at Best

Although respite care services are not consistently administered or delivered across the country, there are areas of Canada that have taken steps to improve and innovate their respite services.

In 2010, the 'Alberta Caregiver Support and Enhanced Respite Demonstration Project' engaged with caregivers to help in the identification of flexible respite care that supports the health and wellness of caregivers by assessing their needs and stressors and then planning respite services accordingly.¹⁴⁰

The Health and Social Services Centre (CSSS) Cavendish in Quebec offers respite care that operates according to the caregiver's schedule.¹⁴¹ Quebec also offers a Respite Tax Credit, which is a refundable maximum tax credit of \$1,560 per year¹⁴², which can be used to cover costs from specialized respite care services.¹⁴³ In Nunavut, facility-based respite care is offered at their elder care centres.¹⁴⁴ The North West Territories offer in-home respite care with a home support worker and they have facility-based respite in long-term care facilities.¹⁴⁵

Below is a table adapted from Carers Canada summarizing respite service policies by province.¹⁴⁶ While it appears that every province and territory is providing respite care services, the reality is that in many cases, services can vary significantly at a regional level and can further vary in their availability as well, especially when some

provinces and territories use co-payment models to manage access to these services. There exists therefore and opportunity for potentially creating a national minimum standard of services and care that all Canadian caregivers and care recipients could expect to receive.

Respite Care Services in Canada are Patchy at Best				
PROVINCE/TERRITORY		RESPITE		
		IN-HOME	SHORT-TERM	DAY SERVICES
British Columbia	CO-PAYMENT:	✓	✓	✓
Saskatchewan	CO-PAYMENT:	✓ Based on income	✓	✓
New Brunswick	CO-PAYMENT:	✓ Based on net income		✓
Nova Scotia	CO-PAYMENT:	✓ Based on income	✓	✓
Alberta	CO-PAYMENT:			✓
Ontario	CO-PAYMENT:		✓	✓

Respite Care Services in Canada are Patchy at Best			
PROVINCE/TERRITORY		RESPITE	
		IN-HOME	DAY SERVICES
Manitoba	CO-PAYMENT:		✓
Quebec	CO-PAYMENT:	For housekeeping, meal delivery and home repair	✓
Prince Edward Island	CO-PAYMENT:		✓
Yukon	CO-PAYMENT:		✓
Northwest Territories	CO-PAYMENT:		
Newfoundland and Labrador	CO-PAYMENT:		
Newfoundland and Labrador	CO-PAYMENT:		

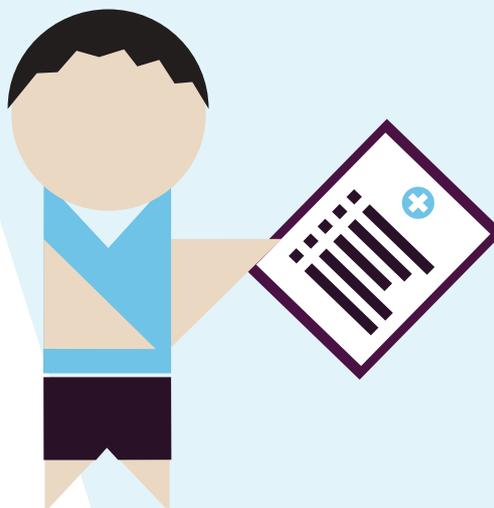
A Model for Providing Much-Needed Educational Supports for Working Caregivers

Challenge: Providing caregivers with the training, support and skills required to support their care recipients.

Organization: The Reitman Centre at Mount Sinai Hospital in Toronto

Solution: An intensive 8-week educational group training program offers a variety of programming being used province-wide to train caregivers with respect to their caregiving roles and tasks, with a focus on managing emotional challenges, problem-solving techniques, experiential learning using simulation and providing tailored dementia education.

It is made available online through an Employer Assistance Program (EAP). The cost of the program to be covered through an EAP benefits is \$5/month per employee.



A 'Gold Standard' Publicly-Funded Service in Southwestern Ontario for Individuals Living with Dementia

Challenge: Provide much needed respite care for caregivers.

Organization: McCormick Dementia Services in London, Ontario.

Solution: This publicly-funded day program (70% government-funded; 30% user-fees) provides many activities including art therapy, live entertainment, exercise, socialization, and much more for an individual co-payment of \$10 per day. They are also able to provide care functions such as bathing, foot care, and the administration of medications. Clients can attend in the morning or afternoon and evening. It also offers respite stays for up to five clients on weekends (Thursday, Friday, Saturday, and Sunday nights). Overnight respite can be accessed as either a four-night or a two-night stay.

A Private Adult Day Program in Ontario for Older Adults with Dementia

Challenge: Provide meaningful experiences for people living with dementia and respite care for their caregivers.

Organization: Memory & Company in Markham, Ontario

Solution: The program includes a state-of-the-art kitchen, putting greens, a spa, salon, and many other services. The main goal is to provide caregiver respite supports thereby prolonging the time that people living with dementia can remain at home. For a person with cognitive impairment, the aim is to slow their functional decline by giving them a place they want to go to, where they feel like an active part of the community, and where they feel stimulated. Clients pay for the days they want to attend the program. There are two types of memberships, fixed and flexible with options to pick and choose which days they attend throughout the year. On average 15-25 people attend per day. It costs on average \$100 for a full day and \$65 for a half day of care—with further differential pricing based on the level of care needed.

Additional Funding for Home Care Will Help to Support Canadian Caregivers

As there is a continued push to support older Canadians to age in place and closer to where they live, more investment will be needed in the adequate provision of home care and community support services to allow these individuals to remain living independently in their communities, rather than in costly institutional care settings like nursing homes.¹⁵⁰

Due to the growing need for more appropriate home care and community services across Canada, access to home care became a major federal election issue in 2015 and led the current federal government to subsequently double its election commitment – from a \$3 billion to a \$6 billion 10-year investment into strengthening the provision of home care - as part of the 2017 renegotiated federal/provincial and territorial health accords.

Although this new level of commitment has been acknowledged by many as a step in the right direction, many still recognize that it isn't enough. For example, in Ontario, approximately 30% of caregivers of care

recipients receiving publicly funded home care currently report experiencing anger, distress, or depression.¹⁵¹ While there currently exists a larger demand for home care than the resources and funding can keep up with, the demand for care will only increase as the majority of care recipients receiving home care are also becoming older and more likely to be affected by cognitive impairment, functional disability, and frail health.¹⁵³ Furthermore, when patients are discharged from hospital without the appropriate supports for them and their caregivers, there is a recognized greater risk of them being readmitted to hospital or becoming at higher risk for becoming prematurely institutionalized in a long-term care facility.¹⁵⁴ Therefore, there remains a significant and continued need for investment in home care and community supports to support both care recipients and caregivers in providing care in the community.

3. Governments Should Further Support Working Caregivers Financially in Recognition of the Economic Value They Provide and the Personal Cost of Providing Care.

Canadian caregivers often face significant financial burdens, which could be relieved by improving available financial supports such as workplace leave policies and tax credits. Canadian policies should also financially support caregivers to adapt the homes of their care recipients to improve their safety and accessibility, and to obtain

the required supplies and equipment to enable care to be provided in the community. These sorts of policies and initiatives would further enable them to keep care recipients in their homes longer, and out of more costly institutional care settings.



What Manitoba, Quebec and Nova Scotia are Doing to Financially Assist their Caregivers

Currently Manitoba, Quebec and Nova Scotia have implemented a variety of additional targeted financial supports for their caregivers. Nova Scotia has implemented a 'Caregiver Benefit Program' offering up to \$400/month for low-income caregivers.¹⁵⁵ ii Manitoba provides a refundable credit of up to \$1,400/year for those who are primary caregivers to care recipients.¹⁵⁶ Quebec also offers a refundable credit for caregivers that provides up to \$925 for those caring for spouses and \$1,154 for those caring for an eligible relative.¹⁵⁷

After the 2017 federal government's decision to simplify and consolidate its prior caregivers related tax credits, Ontario similarly followed and will also be combining their current tax credits into an Ontario Caregiver Credit. Despite the increased funding available through these

re-constituted credits, they will all remain non-refundable (meaning a tax credit can only be claimed based on the amount of income tax paid – therefore, a caregiver must have an income of some significance to claim their eligible amounts).

Caregiver advocacy organizations have applauded the federal government for changing the eligibility criteria for these credits by removing the requirements that the care recipient must live with the caregiver, and allowing for multiple caregivers involved in caring for an individual to be able to divide the credit based on their respective levels of involvement. However, they continue to advocate for these credits to become 'refundable' as well so that especially low and no-income caregivers will not be disproportionately penalized.

ⁱⁱ Eligibility criteria are: care recipient and caregiver must both be 19 years or over, a Nova Scotia Resident, in a care relationship with each other, the care receiver must have an income of \$22,125 or less and be assessed by a care coordinator, the caregiver must not be receiving payment to provide care and sign an agreement defining their terms and conditions. (<http://www.novascotia.ca/DHW/CCS/FactSheets/Caregiver-Benefit.pdf>)

Prince Edward Island has also launched the Seniors Safe @ Home Program, an innovative and targeted home renovation program to help low-income older adults remain at home. This program provides between \$1,000 and \$5,000 to assist with the cost of improving the accessibility of a home to enable lower-income older adults who would not otherwise be able to afford the costs of basic renovations to live more safely and independent at home.ⁱⁱⁱ

ⁱⁱⁱ The funding provided is based on the annual income of the care recipient (combined with spousal income) and the modifications must be necessary for accessibility, health, and safety. (<https://www.princeedwardisland.ca/en/information/family-and-human-services/seniors-safe-home-program>)

Options for Caregivers Taking Short-Term Leave from the Workplace to Provide Care

The Compassionate Care Benefit (offered through the federal government's Employment Insurance (EI) Program) provides financial support to caregivers who take a leave from their paid employment to care for a family member at the end of life for up to 26 weeks.^{158, iv} Each province and territory also has some type of leave program in place for caregivers that principally offers them job protection (i.e. critically ill childcare leave, family caregiver leave, family medical leave, and bereavement leave¹⁵⁹) but no additional financial support comparable to what is commonly provided during a maternity leave.¹⁶⁰ Furthermore, this benefit is limited to caregivers for people who are at the end of life and excludes those providing care for other common but time-limited situations (i.e. providing support to help a frail relative recover at home after a major surgery).

The 2017 federal budget addressed some of these concerns – including unifying three existing tax credits (Infirm Dependant Credit, Caregiver Credit, and Family

Caregiver Tax Credit) into a single 'Canada Caregiver Credit'.¹⁶¹ [see box for details]. The eligibility criteria for this new credit were also expanded to recognize different types of caregivers and included care recipients who do not reside with the caregiver. Although these changes are an improvement, it should be made a refundable tax credit (even if the caregiver does not qualify to pay taxes) in order to ensure that all caregivers can benefit equitably.

Another financial concern that needs to be addressed is that taking time off for caregiving should not negatively affect a caregiver's future government-sponsored pension. For example, in Norway, any working-age caregiver who provides more than 22 hours of care per week for at least six months in a year is given an automatic pension credit.¹⁶² Luxembourg guarantees pension contributions via dependency insurance while employees in Austria are granted compulsory pension insurance contribution periods and are covered by health insurance while on caregiving leave.¹⁶³

^{iv} Some of the eligibility criteria: proving that the care recipient is at significant risk of death within 26 weeks, that your earnings have dropped by 40% or more, and that you have 600 insured hours of work from the past year. (<https://www.canada.ca/en/services/benefits/ei/ei-compassionate.html>)

The reasons behind these pension preservation schemes are to ensure that upon retirement citizens will not retire in poverty which will only create additional difficulties to enable their ability to age in place and the government's ultimate responsibility to address their unmet needs later and likely at a greater cost. In Canada the Canada Pension Plan (CPP) currently ,

allows contributors to maintain benefit calculating pension benefits, for reasons levels by excluding 15% of the month or year of lowest earnings when including but not limited to caregiving.¹⁶⁴ Canada, however, should take this further and ensure that pension contributions for working caregivers are never penalized.

Understanding the Canada Caregiver Credit (CCC)

The CCC is a non-refundable tax credit, meaning you are only eligible if you have a taxable income.

It is also applicable to caregivers who do not reside with the care recipient. It provides up to \$6,883 (unless the dependent's net income is above \$16,163 when the amount becomes reduced) in assistance related to the care of dependent relatives – parents, brothers, sisters, adult children, and other specific relatives, as well as dependent non-relative care recipients. It also provides up to \$2,150 (unless the dependent's net income is above \$16,163 when the amount becomes reduced) in total for care of a dependent spouse/common-law partner or minor child.¹⁶⁶ When the dependent's net income is over \$16,163, the credit is reduced and indexed to inflation for years after 2017.¹⁶⁷ Therefore, if you are caring for your relative or friend who lives near you and they makes less than \$16,163, you can claim \$6,883. If you are providing care to your wife as long as your income is under \$16,163, you can claim \$2,150.

4. Employers Should Recognize the Dual Challenges Employed Caregivers Have in Meeting their Responsibilities at Home and at Work, by:

- a. Providing the leadership necessary to create a workplace culture change that accepts and supports employees who provide unpaid care to loved ones.**
- b. Providing caregivers with flexible working arrangements**
- c. Providing employee benefits specifically targeted to caregivers such as Employee Assistance Programs (EAPs).**

The 2015 federally-sponsored (Report from the Employer Panel for Caregivers) noted that many workplaces in Canada need to re-examine their workplace culture and available supports in regards to caregiving – that is, the “unwritten rules and norms” about how things are done in the workplace and how working caregivers are actually supported to balance their duties.

With regards to re-examining workplace culture, this includes evaluating what is implicitly valued. For example, some organizations may create an environment where workers feel they are expected to be available for work 24/7¹⁶⁸ and it’s not acceptable to even have their caregiving duties acknowledged or considered in the assignment of their work-related duties. Canadian workplaces, therefore, need to adjust their values and then establish practices that recognize the needs and responsibilities of working caregivers in order to create lasting changes in their organizational and workplace cultures.¹⁶⁹

In France, a new employment law gives employees the ‘right to disconnect’ from all technology, including being able to log-off from email on evenings and weekends¹⁷⁰ that follows a similar common practice in Germany.¹⁷¹ Such policies aim to level the playing field for individuals who are otherwise unable and to work long hours.

However, this alone will not be enough to create change. Employers must display supportive leadership at all levels. For example, there should be written policies or procedures in Human Resource documents, with support from executive levels of leadership, to guide managers and staff in supporting working caregivers.

In a report from Carers Canada, some employers are working on addressing their culture by holding quarterly meetings with employees to explain the benefits that are available to them as working caregivers and encourage them to take time they need to support the person they are caring for.¹⁷² Employers should assess their broader organizations

for their “caregiver friendliness”, and proactively reach out to caregivers in their organizations, and then create plans to assess and better address their needs. Caregivers need to feel they are supported and able to come forward should they require extra support.

Highlight from Abroad – Working Caregiver

Policies in Other Countries

The UK, New Zealand, and Australia have all implemented national strategies to better support caregivers, which include information services, financial supports, community supports, legislation to allow caregivers to request flexibility in the workplace, and working with employers to show the financial and organizational benefits of better supporting caregivers in the workplace.¹⁷³ Employers in the UK have also formed ‘Employers for Carers UK’, which is an employer membership forum that promotes how employers benefit from better supporting caregivers.¹⁷⁴

The idea of 'age-friendly' workplaces is becoming more accepted among employers. This momentum could be built upon to incorporate 'caregiver-friendly' workplaces as well, which encourage supporting caregivers in their organizations. Leaders and senior management should lead the change to implement 'age-friendly' and 'caregiver-friendly' policies and practices in their organizations.¹⁷⁵

In 2010, Canada's Top 100 Employers program expanded to include a section on the 'Top Employers for Canadians Over 40'.¹⁷⁶ Some of the criteria for this award include whether there are programs designed to assist older Canadians, workers age 40 and over are recruited, if HR policies address the needs of older workers, benefits for employees after they retire, and if phased-in retirement is offered.¹⁷⁷ Canada could lead the way by extending this concept to an award for 'Top Employers for Canadian Caregivers'. This could include criteria such as whether they offer a caregiving benefit in their EAP, top up compassionate care benefits, flexibility in the workplace, and whether pension contributions are protected during time off to provide care.

While there is often resistance to having governments lead a cultural change in the workplace, the federal government in

Canada should strongly consider its ability as a national entity to encourage and spearhead policies to support cultural change in Canadian workplaces. There are a variety of ways that the federal government could support such change – from the standpoint of introducing legislation that strengthens current labour codes, to sponsoring national initiatives that support the cultural shift required. Given the reasoning that strongly exists to preserve Canada's competitiveness and economic productivity by better supporting its working caregivers, a federal mandate in accelerating a change in Canadian workplace culture is needed.

Canadian Employers Should be Encouraged to Work with Caregivers to Provide them with Flexible Work Options and Leave Policies Beyond What Governments Currently Mandate

Recognizing that support for working caregivers is also an economic productivity issue, the 2015 federal 'Report from the Employer Panel for Caregivers' further highlighted a variety of current approaches used by a number of different workplaces across Canada. Some of these include providing emergency caregiver leave, flexible work locations and hours, and more flexible caregiver leave policies than currently required by government labour codes.¹⁷⁸ (see Appendix A).¹⁷⁹

Although these options may not be appropriate or feasible for all types of jobs or organizations, such as small businesses and self-employed individuals, all employers need to recognize who in their staff is a caregiver and how policies or workplace culture may adversely affect them.

A large employer in central Canada reported addressing this issue by allowing employees to work remotely, expanding sick leave to include caregiving activities, and by allowing its employees to work different daily hours to better manage their caregiving responsibilities.¹⁸⁰ Similarly, a small non-profit organization reported providing an employee with time, support, and leave as needed to balance work and caregiving responsibilities when his wife needed extra care after an accident.¹⁸¹ They also created an environment that encouraged people to work from home and with flexible hours.¹⁸²

Another employer reported using software that allows employees to view and change their schedules at home.¹⁸³ The program plans the schedules based on the employee's schedule variables and availabilities.¹⁸⁴ There tends to be flexibility in the hours that are available because of different shifts (i.e. morning, afternoon, evening, and weekend shifts).¹⁸⁵

Employers Should Provide Employee Assistance Programs (EAPs) and Benefits Specifically Targeted to Working Caregivers

As caregiving can have a significant impact on economic productivity, both employers and governments have a mutual interest in addressing the challenges facing working caregivers. Government can engage employers to highlight the business benefits for supporting working caregivers, including better retention of employees, reduced staffing and re-training costs.¹⁸⁶

Some forward-thinking employers are adding or expanding caregiving benefits in their Employee Assistance Programs (EAPs) beyond what may have been provided with

‘childcare’ in mind. Some of these caregiving benefits are designed to directly address care navigation and emergency care coverage issues. Others specifically target supporting the education and training needs of caregivers.

EAPs are an innovative option to better support working caregivers, however, not all employers will be able to offer these types of programs. Small businesses may also have challenges creating flexibility in workplaces. Employee Assistance Plans (EAPs) are more commonly available in large organizations, while those in more senior positions are more likely to have, or be able to negotiate, more flexible working arrangements and financial resources.¹⁸⁹

Innovative Employee

Benefits

A major Canadian pharmaceutical company became one of the first organizations to introduce an extended Compassionate Care Benefit (CCB) for its employees.¹⁸⁷ Their CCB provides eligible individuals with up to 13 weeks of full-salary paid over a 2-year period. The company’s vice president of human resources has reported that these policies have reduced employee stress and improved productivity upon return to work and that almost 9% of their Canadian workforce is now using this benefit.¹⁸⁸

An Innovative Employee Health Care Navigation Benefit Focused on Providing Support for Working Caregivers

Challenge: To support working caregivers in coordinating care services for care recipients, to reduce stress and improve productivity for working caregivers.

Organization: Bayshore HealthCare, a national home care provider.

Solution: Caregivers connect with Bayshore's Senior Advisory Program, where a Nurse Navigator helps determine the caller's specific needs. If the callers also have private insurance, the Nurse Navigators help to determine their eligibility for services through their insurance plan. They can also assist with connecting the caller to government home care services. The Nurse Navigator also connects the caregiver to community resources; they will help identify, and where relevant, will download and complete applications for government grants or funding. They will also identify both public and private accommodation and support options."

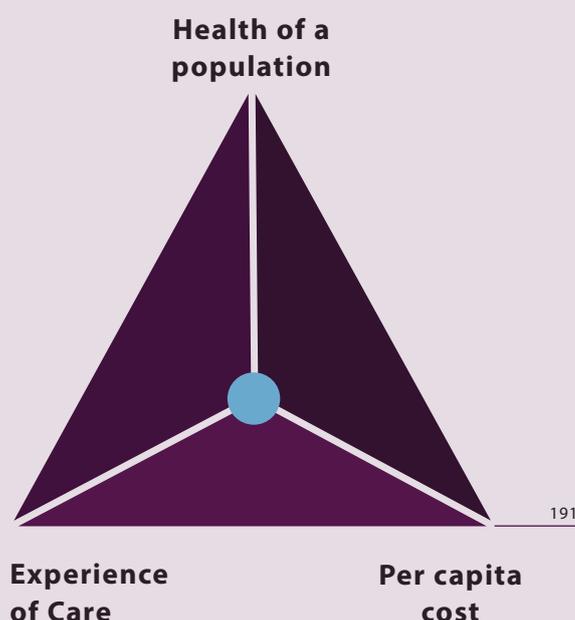
'The Triple Aim' and Caregiving

The 'Triple Aim' measurement framework was "developed by the Institute for Healthcare Improvement and describes an approach to optimizing health system performance".¹⁹⁰ It seeks to measure three dimensions: outcomes, experiences, and costs. This approach has been used recently to develop patient-reported outcome measures (PROMs), patient-reported experience measures (PREMs), and patient-reported outcome costs (PROCs).

Caregiver-reported Outcomes Measures - CREMs, CROMs, and CROCs

There has been a push to adapt these measures to be more inclusive of caregivers by looking at the development of caregiver-reported outcome measures (CROMs), caregiver-reported experience measures (CREMs), and caregiver-reported opportunity costs (CROCs). Better Access and Care for People with Complex Needs (BeACCoN) is an Ontario-based research network focused on developing partnerships between research, policy and practice, with the aim of generating evidence and innovations to advance

policy changes and improvements in patient health, health care, and the efficiency of service delivery.¹⁹² BeACCoN has been working on adapting this framework to generate a generic and standardized way to measure caregiver experiences, outcomes, and costs to be used for comparative policy development and analyses.¹⁹³ These measures will be highly important to identify patterns and priorities for action and policy development. They will also create an impartial and unbiased way to determine which innovative models and services, resources, or policies work and which do not.



5. Develop National Standards that both Governments and Employers can use to Measure and Evaluate the Overall Success of Programs, Services, and Supports to meet the needs of Working Caregivers

The importance of measuring outcomes to evaluate success and health system performance is well recognized.

Highlighting an area for measurement also promotes attention from system leaders, who have a vested interest in improving a system's performance. Given that so many Canadians are caregivers, and their well-being and needs have significant societal and financial implications, caregivers should be included in any measurement and evaluation framework related to monitoring health system performance and even Canada's economic productivity. There is promising movement in this direction already.

The majority of current measurement work in Canada and internationally has focused on measuring existing levels of reported caregiver distress and strain. The interRAI – Home Care Assessment Instrument,¹⁹⁴ is used in most parts of Canada to assess and plan care for Canadians who receive government-funded home care, and

routinely measures and allows for reporting levels of caregiver distress. Health Quality Ontario¹⁹⁵ has used its reported findings to inform the Ontario Government around the needs of caregivers, which has prompted a number of coordinated responses to better address the needs of caregivers in the province.

There are some limitations to this data, however, in that it only captures the view of caregivers of care recipients who are receiving publicly-funded home care services. Despite these limitations, caregiver distress levels have been shown to be increasing dramatically and are often affected by the evolving and increasing needs of care recipients.¹⁹⁶ Between 2009/2010 and 2013/2014 in Ontario, it was found that the rate of distress among caregivers of government-funded home care recipients had more than doubled.¹⁹⁷ Further, from 2012/2013 to 2016/2017, the number of caregivers of people receiving government-funded home care who reported experiencing distress increased by almost 15%.¹⁹⁸

The distress indicator is a start, however, caregiver measurement should cover a more holistic set of indicators. For example, caregivers have said that other aspects of caregiving they would like to see measured

include positive outcomes, isolation, stress, their personal health, their ability to maintain meaningful relationships, and costs associated with caregiving (i.e. out-of-pocket and opportunity costs).¹⁹⁹ Once developed, these agreed upon standards and their measures should be applied consistently and can then be used to measure the impact of any intervention on the well-being of caregivers and on system performance measures as a whole. Additionally, as was noted by the Alliance for a National Seniors Strategy, these standards can be used to inform the future and ongoing training of care professionals who will be working with care recipients, as well as their caregivers.²⁰⁰

Our federal government can also support the development of national standards and tools that employers can use to assess the needs of working caregivers.²⁰¹ This would enable employers to have a better understanding of how to best support working caregivers in their organizations²⁰² and how to best adapt their policies and practices to meet this goal. Employers can further use established national standards to evaluate the effectiveness of their workplace interventions and then use these findings to adjust their programs or services as needed.

Indeed, solely implementing a program or intervention is never adequate on its own – only through implementing measurement and monitoring procedures can we determine whether these supports are actually improving the situation for working caregivers

Conclusion

It is time for governments and employers to make the necessary changes to better support working caregivers now and in the future. With our rapidly shifting demographics, there will be increasing numbers of Canadians who need care and the support of unpaid caregivers. By supporting working Canadian caregivers, we can improve their health and well-being, as well as those of their care recipients, and in doing so, we can also help to safeguard and improve Canada's economic productivity.

Appendix A

Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Paid and Unpaid Leave Practices
Emergency Caregiving leave	<p>Employees can request up to five days paid leave to care for a family member or friend</p> <p>Employees can request up to five days paid leave for emergencies which could be health related but not for chronic health issues</p>
Combination of Leave	<p>Employees can request to use a combination of leave (personal/family, vacation or sick leave) to help care for a family member or friend</p>
Personal/Family Leave	<p>Policies vary within organizations (federally vs non-federally regulated employers). Non-federally regulated employment standards vary by jurisdictional legislation</p> <p>Non-federally regulated employees receive a range of 0-12 days per year. Some employers combine personal/family leave with sick leave</p> <p>Employees have three floating days (additional paid leave)</p>
Sick Leave	<p>Policies vary within organizations (federally vs non-federally regulated employers). Non-federally regulated employment standards vary by jurisdictional legislation</p> <p>Non-federally regulated employees are provided with a range of sick leave from one day to 26 weeks</p> <p>Employees may request to use sick leave for family illnesses.</p> <p>Self-insured medical leave where employees accumulate sick leave credits that they can use when they are ill or injured or in some cases to care for a gravely ill family member or critically ill child</p> <p>Unlimited sick leave</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Paid and Unpaid Leave Practices
Vacation Time	<p>Policies vary within organizations (federally vs non-federally regulated employers). Non-federally regulated employment standards vary by jurisdictional legislation</p> <p>Employees may purchase additional vacation time (up to a maximum amount of weeks)</p> <p>Ability for employees to take leave in hours rather than full days (e.g. two weeks' vacation made available in hours over an eight month period)</p>
Bank of Leave	<p>Employees who have exhausted his or her available paid leave can establish a leave bank under which a contributing employee can donate leave to the bank and recipient employees draw leave to cover time out of the office due to a personal or family medical emergency</p>
Bereavement	<p>Policies vary within organizations (federally vs non-federally regulated employers). Non-federally regulated employment standards vary by jurisdictional legislation</p> <p>Employees may receive a minimum of three to seven days of leave following the death of a family member. Some employers provide a combination of paid and unpaid leave</p>
Compassionate Care Benefits	<p>Non-federally regulated employment standards vary by jurisdictional legislation. Employees could have a range of 8-12 weeks of unpaid leave when a family member is gravely ill</p> <p>Employers may provide a top-up benefit for employees bringing their salary back to their full salary levels for part or all of the leave</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Paid and Unpaid Leave Practices
Leave to Arrange Care	Employees may take up to three days paid leave to make arrangements for care
Leave with Income-Averaging	Employee may request to take leave without pay for a period of a minimum of five weeks and a maximum of three months Employee's salary is reduced over a 12 month period
Leave without Pay	Employees may take up to 12 months of leave without pay. This type of leave can be used for both short and long-term leave Arrangements between employers and staff are discretionary
Family Caregiver Leave	Family caregiver leave provides employees up to 12 weeks of unpaid, job-protected leave to provide care or support to a family member with a serious medical condition. This type of leave is legislated in Saskatchewan, Quebec, and Ontario.

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Flexible Workplace Arrangements
Annualized Hours	<p>Allows employees to choose (within boundaries) their days and hours of work for a set period of time</p> <p>The period of time could be weekly (e.g. work 12 hours for three days and two hours for two days); or monthly (e.g. 60 hours one week and 20 hours the next week)</p> <p>This may be ideal for employers with peak hours or seasonal peaks</p>
Compressed Work Weeks/Banking of Hours	<p>Employee works for longer periods per day in exchange for a day off</p> <p>Employees may start earlier or finish later than the normal work day</p> <p>Common arrangements for 40 hours per week could include working an extra hour per day in exchange for one day off every two weeks</p>
Flexible Work Locations	<p>Employees can be transferred to alternate locations across the country and in some cases internationally (depending on the organization)</p> <p>Allows employees to choose their work location or choose to work off-site (e.g. from home)</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Flexible Workplace Arrangements
Flex-time Schedule/ Flexible hours/Breaks	<p>Employees work a full day but they set a range of start and finish times with their manager. Total hours of work per week are not affected</p> <p>Allows manager to establish core hours where all employees will be at work (e.g. 9:30 am – 3:30 pm)</p> <p>Employers provide flexible breaks where employees can undertake care responsibilities during their lunch hour. Provide preferred parking spaces for caregivers who are caring for a parent or child who are in critical condition and who may need to leave work urgently</p> <p>Employees do not need to take formal leave but can make up the time off required another day (e.g. if an employee needs to leave for an hour during the day, they can stay 30 minutes extra over the next two days)</p> <p>Employers can offer their employees different options for their work assignments (e.g. a truck driver who works long distances could temporarily move to shorter routes to allow him or her to be closer to home)</p>
Job Sharing	<p>Allows two or more people to share one or more positions or duties</p> <p>Job sharing must work effectively for the team and expectations around pay, benefits and holidays must be well-communicated</p> <p>This is an option for employers who do not have many part-time positions available</p> <p>Have colleagues assigned as “back-ups” to files when an employee has caregiving responsibilities and who might need to be absent for a longer period of time</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Flexible Workplace Arrangements
No Set Schedule	Allows employees to work the hours they choose, no questions asked, as long as work deadlines are met
Part-time/ Reduced Hours	<p>Employees can choose to work less than 37.5 or 40 hours per week</p> <p>Arrangements can be on a permanent or temporary basis Hours can be negotiated between employer and employee to ensure coverage at peak workload hours</p>
Phased Retirement	<p>Employees may reduce their working hours or workload over a period of time leading to full retirement</p> <p>Pension legislation allows for partial pension benefits to commence with formal phased retirement</p> <p>Phased approach could be used to train the replacement employee or adjust the redistribution of work among remaining employees</p>
Shift-Work	<p>Employees can work a type of shift-work schedule where a person's work day is split into two or more parts (e.g. employee can start at 4:00 am, provide care responsibilities during the day and do a second shift at night). Employees who work split shifts need to manage their schedule so they don't get burned out (especially if they are providing care during the day)</p> <p>In some cases where spouses work at the same company, they can stagger their shifts for one spouse to provide care while the other is working</p> <p>Employees can change their work shifts (e.g. can switch from a night shift to a day shift or exchange a Monday shift to Tuesday)</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Technology
Telework/ Telecommuting	<p>Allows employees to do some of the regular work from home instead of going into the office</p> <p>Employer and employees need to establish details such as hours of work, communications between teleworker, co-workers and clients</p> <p>Dependent on employee's roles and responsibilities</p>
Tools/Devices (Hardware)	<p>Depending on employees' roles and responsibilities, employers provide access to technology to enable them to work outside the office include hardware such as a laptop (with remote access), smart phone, tablet, teleconference/ videoconference capabilities</p> <p>In special circumstances, allow employees to have their cell phone close by while they are working in case of emergency (e.g. for employees who do not have direct access to a work phone)</p> <p>Loaner equipment available for employee use (e.g. smart phone, laptop, tablet, etc.)</p> <p>Establish policies around technology such as "technology free-time" or "smart phone free-zone" to allow employees to focus on work/home priorities (e.g. no answering emails from 6:00 pm to 6:00 am)</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Technology
Tools/Devices (Software)	<p>Web application that enables collaborative work (e.g. sharing of documents, access to intranet portals, document and file management, social networks, extranets, websites, enterprise search and business intelligence)</p> <p>Instant messaging software to allow employees to connect with colleagues regardless of their work location</p> <p>Ability to work from home through an internet platform that allows employees access to their work emails without being connected to the network (e.g. from home through a virtual private network). Provide access to a secure channel to access work emails from employee's mobile device (smart phone or tablet)</p> <p>Employees on shift-work can take advantage of scheduling software that allows employees to log-in to an online account to view and amend their schedule from home. This scheduling software also takes into consideration other variables such as vacations, leaves, etc. Provide employees with online access to HR policies, services, collective agreements, etc.</p> <p>Blogs/chat programs to stay connected</p> <p>Applications with EAP information</p> <p>Email notifications, online calendar to indicate regular hours and planned absences of employees</p>

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Report from the Employer Panel for Caregivers - Inventory of employer-led flexible workplace practices that support employee caregivers²⁰³

	Other Programs and Services
Employee and Family Assistance Program	Offerings vary by provider but can include referral services for community care options as well as counselling for the employee and/or their immediate family
Emergency Elder Care	Some employers offer emergency elder care (similar to emergency child care) at minimal cost to the employee (employers cover the cost up to a maximum amount per year) Back-up care is provided as an alternative when regular care is not available
Onsite Seminars/Lunch and Learns	Varies by employer, but can include internal or external speakers discussing various aspects of caregiving such as community services available or the health of the care provider
Online Networks/Applications	Online tools that help caregivers access information on programs and services available and connect them to existing networks Health application (and general phone line) that directs users to medical and community supports as well as providing user health assessments and general information Also provides information to employers via plan administrators such as a snapshot on the health of their workforce
Suite of Benefits/Cafeteria-style Plans	Web-based benefits platforms that connect employees to a menu of services and allow them to manage their own selections that are tailored to their needs and unique situation; similar to the ability of a customer to choose among available items in a cafeteria

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Funding for this white paper was generously provided by Bayshore HealthCare. All of the research, writing, and recommendations herein have been independently produced by the NIA on the basis of sound evidence.



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