



## CARP POLICY – Caregivers

### Introduction

Over 8 million Canadians aged 15 and older provide unpaid (informal) care to family members and friends with health needs, disabilities and chronic conditions.<sup>1</sup> This policy paper focuses specifically on caregivers providing care to older adults, but it is important to acknowledge that caregivers and care recipients are both diverse groups which include people of all ages and from a wide range of backgrounds and health situations. Unpaid care is commonly provided to older adults to assist them with instrumental activities of daily living (e.g., household chores, transportation, cooking), activities of daily living (e.g., personal care, toileting, mobility), management of care, and provide social and emotional support.<sup>2</sup> In Canada, it is estimated that about 80% of care in the home is provided by informal caregivers.<sup>3</sup>

Providing care to loved ones often brings happiness and value to the caregiver and the care recipient. Many Canadians are grateful they can provide care for their loved ones during times of need. Caregiving, however, can also provide many challenges and obstacles to caregivers, including isolation, lack of training, hopelessness and “burn out”, and financial insecurity. The provision of care often taxes caregivers emotionally, socially, physically, mentally, and financially. Caregiving also has broader costs for employers and the Canadian economy.

There is an urgent need for policies in Canada that a) provide supports to informal caregivers who are caring for a loved one and b) strengthen the formal care services available for older adults. While governments purport to recognize the value of informal caregivers, their policies often fail to reflect this value. Provincial programs vary widely, with some provinces taking the lead on progressive policies to support caregivers, while others provide very limited support. Stronger support is required for caregivers from all levels of governments, the health and social care systems, and employers and the private sector. This policy paper and the recommendations contained within were developed through a review of the literature, feedback from expert reviewers, and feedback from CARP members.

### An Urgent Policy Issue

Why is caregiving an urgent policy issue? The following points highlight why caregiving is an issue which deserves urgent attention from governments:

- **An aging population:** For the first time there are now more older adults in Canada than children.<sup>4</sup> By the year 2030 it is estimated that older adults will comprise 23% of the Canadian population.<sup>5</sup> Increasing age is associated with increased risk of chronic diseases

and disability. It is estimated that the number of older Canadians needing care will double in the next 30 years and plateau around 2046.<sup>6</sup>

- **Caregivers provide the bulk of care to older Canadians:** As mentioned previously, it is estimated that 80% of care in the home is provided by informal caregivers.<sup>3</sup> Few frail older adults are able to remain in the community if they do not have a caregiver, even if they are receiving formal services – 98% of older adults receiving publicly funded home care have a caregiver.<sup>7</sup>
- **Declining supply of potential caregivers:** At the same time our population is aging, factors such as increased geographical mobility, decreasing family sizes and number of children, changing work patterns, and changing preferences for formal care, mean there will be fewer informal caregivers available to provide care.<sup>3</sup> This will place increased pressure on caregivers and the formal care system. Furthermore, approximately 28% caregivers are part of the sandwich generation, meaning they have responsibilities to care for both parents and children, and 60% of caregivers are juggling caregiving responsibilities with work.<sup>8</sup>
- **Current supports for caregivers are not enough:** While all provinces and territories have some supports available for caregivers (e.g., respite services, tax credits, etc.), more supports are needed. 42% of caregivers caring for a spouse and 28% caring for a parent report they need more help.<sup>1</sup>
- **The economic value of caregiving:** It is estimated that caregivers provide the care equivalent to 1.2 million full-time workers in Canada,<sup>9</sup> and the economic contributions of unpaid caregivers aged 45+ in Canada have been estimated to be \$25-26 billion (calculated based on hourly market rates for homemakers).<sup>10</sup>

From a governmental policy perspective this is a big problem – or at least it should be. While caregivers will continue to make significant contributions in unpaid care in the future, changing demographics and increased pressures on caregivers mean that simply expecting caregivers to do it all on their own is no longer a policy option. While costs for unpaid care are avoided by the formal healthcare sector, unpaid caregiving is not “free”. Caregiving may have negative effects on the physical and mental health, social life, work and employment prospects, and finances of caregivers:

- **Impacts on physical and mental health:** Caregiving can have negative impacts on the physical and mental health of caregivers, particularly for those providing significant hours of care. Among caregivers regularly caring for their parents, 60% have reported symptoms of

psychological distress. Furthermore, 18% of adults caring for their parents and 33% of spouses have consulted a professional about health problems related to caregiving.<sup>1</sup>

- **Impacts on social life:** The time required for caregiving means less time for other activities, which can negatively impact relationships with family and friends. About half of caregivers report caregiving has reduced the time they have to spend with their spouse, children, and friends.<sup>8</sup>
- **Impacts on employment and finances:** Caregivers may be affected financially through employment consequences (e.g., work absences, career limitations, etc.), out-of-pocket costs (e.g., paying for private services, supplies, etc.), and caregiving labour (e.g., time spent on caregiving). This can result in reduced income, lost benefits, and reduced pensions for caregivers.<sup>11</sup> Data from Statistics Canada shows: 43% of working caregivers report caregiving has impacted their attendance at work;<sup>8</sup> 10% of adults caring for a parent have been prevented from holding a job;<sup>1</sup> and 7% of caregivers caring for a parent and 20% caring for a spouse have experienced financial hardship due to their caregiving responsibilities.<sup>1</sup> Average out-of-pocket costs of caring for an aging parent have been estimated to be \$3,300 per year, with lower income people incurring the highest expenses.<sup>12</sup>

Caregiving also may have economic costs for employers and the economy and government more broadly. Employers may experience direct costs (e.g., absenteeism), indirect costs (e.g., reduced productivity), and discretionary costs (e.g., workplace supports for caregivers) due to caregiving.<sup>11</sup> Unpaid caregiving can impact government costs through unemployment/lower income tax revenues, increased social assistance payments, and as a substitute for paid caregiving. An economic analysis found that at the lowest levels of caregiving intensity there was a net gain to government (\$4.4 billion), but at the highest level a net loss (\$641 million) occurred, mostly due to reduced labour force participation.<sup>13</sup>

## **Policy Options**

As our population ages, it is clear that more must be done in order to support older adults and their caregivers. Comprehensive policies and supports to caregivers are needed in four key areas: 1. Caregiver recognition and rights, 2. Services for older adults and caregivers, 3. Work-care reconciliation, and 4. Financial support.<sup>14</sup>

### ***1. Caregiver recognition and rights***



Caregivers make significant contributions to Canadian society but receive little recognition and support for their important roles. Recognizing the role of caregivers means providing caregivers with the supports they need to maintain their own health and wellbeing, as well as acknowledging caregivers as valuable partners in providing care. Qualitative research with caregivers has identified that caregivers often do not feel recognized or respected by the health care system, are frustrated by poor communication from care providers, do not feel their needs as caregivers are properly identified and addressed, and want more opportunities to receive support, training and education.<sup>16</sup>

Manitoba is the only province that officially recognizes caregivers through legislation through their *Caregiver Recognition Act*. Some provinces also have implemented provincial caregiver days.<sup>15</sup> However, recognition which is not tied to concrete actions or outcomes has little practical value for caregivers. One way to increase recognition and support for caregivers would be through the development of national and/or provincial/territorial caregiver strategies, that clearly recognize the role of caregivers, identify strategic priorities, and outline concrete actions to be taken to support caregivers.

***Recommendation 1.*** *CARP calls upon Federal and Provincial/Territorial governments to develop caregiver strategies that clearly recognize the role of caregivers, identify strategic priorities, and outline concrete actions to be taken to support caregivers.*

## **2. Services for Older Adults and Caregivers**

It should not be assumed or expected that caregivers bear the full responsibility of caring for their loved ones. Formal care services are essential to assist older adults to age in place. Continuing care systems should provide a full continuum of comprehensive supports, including services such as home support, home care, adult day services, supportive housing, etc. It is important that these services be responsive and flexible, and able to adjust to the needs of the older adult and their caregiver (please see our forthcoming policy on Continuing Care for more details).

Formal care services often focus exclusively on the care recipient and fail to acknowledge that the caregiver may also have their own needs. Assessments should take into account the needs of caregivers, and caregivers should be able to access continuing care services for themselves even if their loved one has chosen not to access formal services. Caregiver services such as education and training programs, mental health supports, and caregiver support groups should be considered essential components of continuing care systems. Caregivers need to be aware of the services and resources that are available to them, and accommodations should be



available to facilitate access to these services (e.g., provide respite care to allow the caregiver to access programs).

Respite is too often thought of as a single service, when instead it should be viewed as an outcome. That outcome is to provide relief and rejuvenation to those providing unpaid care. Respite is commonly provided through home support services, respite beds in long-term care, and adult day services.<sup>17</sup> Despite the significant potential benefits of these services, they are often underutilized. For example, the Office of the Seniors Advocate of British Columbia found that for care recipients whose caregivers might benefit from respite, only 7% of care recipients had used an adult day service in the last 7 days and only 53% home support.<sup>18</sup> Access to respite is directly linked to the availability of services, and in many cases there are not adequate continuing care services available. Ultimately, what respite means to one caregiver may be different from another caregiver, and respite programs should be as flexible as possible to meet the needs of caregivers.

***Recommendation 2.*** *CARP calls upon the Federal and Provincial/Territorial Governments to increase funding for continuing care services. In particular, CARP calls for increased investment in services that facilitate aging in place and provide respite in the community, such as home care, home support, and adult day services.*

***Recommendation 3.*** *CARP calls upon the Provincial/Territorial Governments to ensure that all caregivers have access to support services such as education and training programs, mental health supports, and caregiver support groups. This includes not only ensuring support services are available, but also ensuring caregivers are aware of these services, and providing necessary accommodations (e.g., respite, transportation, etc.) to facilitate access to them.*

### **3. Work-Care Reconciliation**

As mentioned previously, 60% of caregivers are balancing both work and caregiving responsibilities.<sup>8</sup> Most employers in Canada are unaware of the high number of employees engaged in caregiving, do not have specific programs/policies for caregivers, need to better understand the business case for supporting caregivers, and need tools and knowledge to help them support caregivers.<sup>19</sup> There is a need for government and other organizations to work with employers to raise awareness of the needs of caregivers and provide support for developing policies and programs to support them.

Providing flexible work arrangements (e.g., changing schedule, job sharing, extended leave, telework, etc.) is one of the key recommendations that has been made to assist caregivers to remain in the labour market.<sup>19, 20</sup> The right to flexible working arrangements and



accommodations for caregivers has not been firmly established for Canadians. While human rights legislation in Canada protects employees from discrimination on the basis of “family status,” across Canada there are differing interpretations of the meaning of “family status”.<sup>15</sup> The federal government amended the Canada Labour Code in 2017 to explicitly include the right for federally regulated workers to request flexible working. However, the majority of Canadians (94%) work in sectors that are provincially regulated, where equivalent legislation is not in place. Some countries (e.g., UK, Australia, New Zealand) have passed legislation guaranteeing all employees the right to request flexible work arrangements and establishing a formal process for requests and appeals. It should be emphasized that this legislation does not compel an employer to accept the request, and requests may be denied based on reasonable business grounds.<sup>21</sup>

***Recommendation 4.*** CARP also calls upon the Provincial/Territorial Governments to ensure the right to flexible work arrangements is clearly established for caregivers.

#### **4. Financial Support**

Caregiving may impact caregivers financially through lost/reduced wages, out-of-pocket costs, and loss of pension benefits. Governments can offer financial supports to caregivers through: indirect financial support (e.g., pension credits, tax credits), direct financial supports (e.g., consumer-directed budgets, care allowances, payments to caregivers) and employment insurance policies (e.g., compassionate care benefit).<sup>3</sup>

##### *Indirect Financial Support*

The federal government offers the new Canada Caregiver Credit that combines three previous tax credits (i.e., the Caregiver Credit, Family Caregiver Credit, and Credit for Infirm Dependants Age 18 or Older)<sup>22</sup> and provincial governments may also offer tax credits. However, the tax credits are non-refundable (with the exceptions of provincial tax credits in Québec and Manitoba), meaning the amount to be paid is deducted from the caregiver’s tax that is owing. If the caregiver has been forced to exit the labour force and does not have tax owing, these credits are of little value.<sup>15, 23</sup> In 2012, only 5% of caregivers reported receiving a federal tax credit.<sup>8</sup>

Currently there are no pension credits specifically for caregivers. Because pension benefits for the Canada Pension Plan are calculated based on contributions made over your working life, caregivers who take significant amounts of time off from work to care for their loved one may find themselves penalized with lower pension benefits in the future. However, the Canada Pension Plan has a dropout provision for years outside the workforce spent engaged in





childcare, and it has been proposed a similar clause be introduced for caregiving (in addition to what is already available in the general dropout clause).<sup>23</sup>

#### *Direct Financial Supports*

Currently every province in Canada offers self-managed care programs, where the care recipient is provided with a budget that they can use to arrange their own home care services. Some of these programs provide the option to hire family or friends as caregivers. These programs often are underutilized though due to lack of awareness, difficulty accessing the programs, and challenges with self-managing care.<sup>15</sup>

Direct compensation to caregivers via an allowance/benefit is largely non-existent in Canada, with the exceptions of the Caregiver Benefit in Nova Scotia, Primary Informal Caregiver Benefit in New Brunswick, and the Caregiver Recognition Benefit for Veterans. Nova Scotia has implemented the Caregiver Benefit program that provides \$400 per month to caregivers who provide care to low-income adults (income must be \$22,125 or less if single or \$37,209 or less for a couple) with a high level of disability or impairment.<sup>24</sup> Research on the costs of the program suggests that providing the caregiver benefit and home care services to older adults costs approximately \$5,151 per month compared to \$6,002 for long-term care.<sup>25</sup> An unpublished study on the impacts of the benefit found care recipients whose caregiver had received the benefit were half as likely to be admitted to a long-term care facility compared to care recipients whose caregiver did not receive the benefit.<sup>26</sup> New Brunswick has just recently introduced their own caregiver benefit, the Primary Informal Caregiver Benefit, which provides \$106.25 per month to eligible primary caregivers.<sup>27</sup> At the federal level, the Caregiver Recognition Benefit provides \$1,000 per month to the informal caregiver of an ill or injured Veteran.<sup>28</sup> There are also examples of international programs that provide direct compensation to family caregivers in the United Kingdom, Australia, Norway, Sweden, etc.<sup>29, 30, 31, 32</sup>

#### *Employment Insurance Policies*

The Employment Insurance Compassionate Care Benefit provides 26 weeks of employment insurance payments for people who take time off work to provide care and support to a family member who is gravely ill and has a significant risk of death within 26 weeks. Due to the requirement of the care recipient being at significant risk of death, many caregivers do not qualify for this benefit. The benefit would not permit support for a caregiver of a person with a serious but non-life-threatening condition, a caregiver providing emergency care for a short period of time, or a caregiver providing long-term care for an ailing parent.<sup>15, 23</sup> In 2017, the Federal Government introduced an additional Employment Insurance Family Caregiver Benefit for Adults. This benefit provides up to 15 weeks of employment insurance payments for



caregivers who take time off work to care for a critically ill or injured adult family member, with no requirement that they be terminally ill.<sup>33</sup>

While the Compassionate Care and Family Caregiver Benefits are steps in the right direction, it should be noted that for many caregiving is an activity that will last years rather than weeks. These benefits are also only available for caregivers who have worked enough employment hours over the past year to qualify for employment insurance. Furthermore, not all provincial jurisdictions provide employees with equivalent periods of unpaid job protected leave for caregiving (e.g., British Columbia provides only 8 weeks of unpaid job protected leave to care for a terminally ill family member) and leave may only be available to care for a person at significant risk of death, meaning caregivers may not be able to utilize these benefits to their full extent.

***Recommendation 5.*** CARP calls upon the Federal Government to strengthen employment insurance benefits for working caregivers by a) Changing the requirement for the Compassionate Care Benefit that a family member must be facing significant risk of death by including people who are critically ill; b) Increasing the Family Caregiver Benefit from 15 to 27 weeks; and c) Working with the provinces/territories to ensure their employment standards are aligned with Federal employment insurance benefits and provide a minimum of 27 weeks of unpaid, job-protected caregiving leave with no requirement that the person being cared for be terminally ill.

***Recommendation 6.*** CARP calls upon the Federal and Provincial Governments to improve financial supports to caregivers by a) Altering existing non-refundable tax credit programs for caregivers to ensure that amounts are refundable credits and delivered as cash payments as opposed to amounts deducted from tax owing, and b) Implement a national caregiver benefit program akin to the Caregiver Benefit program found in Nova Scotia and examples from other international jurisdictions.



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