



Caregiver Policy Executive Summary

Caregivers provide value to loved ones in their time of need and to society generally in unpaid labour that some estimated to value in excess of \$25 billion dollars. While providing care to a loved one is a rewarding experience, it also has its challenges and taxes caregivers emotionally, physically, mentally and financially. 50-75% of those caring for a loved one with dementia will experience symptoms of depression. 41% will have to use their own personal savings to survive while providing care. Unfortunately, the programs and supports currently in place for caregivers are not adequate. CARP's Caregiver Policy concludes with the following recommendations:

1. CARP calls upon the Federal Government to alter existing non-refundable tax credit programs available to caregivers to ensure that amounts are refundable credits and delivered as cash payments to homes as opposed to amounts deducted from tax owing.
2. CARP calls upon the Federal Government to expand the Employment Insurance Compassionate Care Benefit to provide a total of 52 weeks of benefits for caregivers who are providing care to an individual with a "significant illness". CARP calls for the abolishment of the requirement that the individual who is being cared for be likely to die within any period of time.
3. CARP calls upon the Provincial Governments to implement a Caregiver Benefit Program akin to program offered in Nova Scotia, where low-income caregivers are provided with a suitable monthly payment.
4. CARP calls upon the Federal and Provincial Governments to amend their human rights legislation to include 'care' as a protected ground of discrimination in the area of employment to ensure that a large segment of caregivers are not currently excluded from protections already offered.
5. CARP calls upon the Provincial Governments to increase funding for respite for caregivers and permit that funding to be self-directed so that the caregiver can best assess the method of respite required.



CARP POLICY – Caregiver Priority

Over 8 million Canadians aged fifteen and older provide unpaid care to family members and friends with health needs, disabilities and chronic conditions.

Providing care to loved ones often brings happiness and value to the caregiver and the individual receiving the care. Many Canadians are grateful they can provide care for their loved ones during times of need. Caregivers face many challenges including feeling isolated and hopeless. Many report insufficient training, financial insecurity, and ‘burn out’.

The provision of care often taxes caregivers emotionally, physically, mentally and financially. 41% of caregivers report detriment to their mental health and 38% report a negative impact on physical health.ⁱ 41% have used their own personal savings to survive while providing care. 50-75% of those providing care to a loved one with dementia are affected by the symptoms of depression.ⁱⁱ The impact on the caregiver is related to the number of hours of care they provide each week. For example, lighter caregiving duties average three hours per week, while heavy caregiving duties averages twenty hours or more per week.

A Growing Issue

About one-third of caregivers are 55 years of age or older.ⁱⁱⁱ 32% of caregivers aged 65 to 74 provide at least 10 hours of care per week.^{iv} This number increases significantly to 39% for caregivers aged 75 and older.

The issue society and government is facing is highlighted when considering the following facts:

- Unpaid caregivers provide over 80% of care to Canadians with long-term health conditions;
- Family demographics are changing and Canadians are increasingly finding themselves without family members to care for them informally or without family members to provide support and relief to the family member who is providing the bulk of informal care;¹

¹ The number of households with two adults and children fell by 18% from 2001 to 2006 and 42.7% of households do not have children at all. (Source: McMaster University Health Forum. (November 2014). *Improving Care and Support for Unpaid Caregivers in Ontario*. McMaster Health Forum Citizen Brief. Located Online at [<https://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/citizen-briefs/support-for-unpaid-caregivers-in-ontario-cb.pdf?sfvrsn=2>])

- Unpaid caregivers contribute in excess of \$25 billion each year worth of labour to the health care system^v – some studies report this figure to be significantly higher;^{vi}
- As the baby boomer population ages there is a large and growing group of Canadians, referred to as the “sandwich generation”, who find themselves caring for elderly parents and rearing children at the same time;
- By 2030, about one quarter of the Canadian Population will be over the age of 65;^{vii}
- Chronic disease rates are increasing in Canada at a rate of 14% each year,^{viii} and
- By 2031, the number of Canadians projected to require care is expected to **double**.^{ix}

From a governmental policy perspective this is a big problem – or at least it should be. As the number of caregivers lessens due to demographics and ‘burn out’, and the level of care required doubles, the significant contribution in excess of \$25 billion dollars that caregivers provide in unpaid care could rise substantially, and should informal caregivers be unable to meet this demand, this figure may need to be borne by the formal healthcare system, a system already in crisis. Consider for a moment the costs if unpaid care was shifted into paid care in the formal sector:

A personal care worker through an agency or private can cost \$20 - \$30 per hour. Registered nurses cost \$40 - \$69 per hour. A full-time, live-in caregiver may charge \$1,900 to \$3,500 per month plus room and board.^x

While costs for unpaid care are avoided by the formal healthcare sector, unpaid caregiving is not “free”. Informal caregivers often face the following challenges, which can be very costly to them. The problem is more pronounced for older caregivers providing, often substantial care, to a spouse. Seniors aged 65 and older represent 12% of all caregivers and they are more likely to spend longer hours providing care, typically to a spouse.^{xi} With the aging population, this number is likely to increase substantially. Older caregivers have increased risks relative to the general caregiver population.



1. **Loss of Financial Well-Being**

Out-of-Pocket Expenses for Care

Aside from not being paid for providing care, 70% of informal caregivers report providing out-of-pocket financial assistance for the individual in their care.^{xii} Many of these expenses are not reimbursed through government programs. Canadian caregivers spent an average \$12.6 million per year on care-related out of pocket expenditures in 2006.^{xiii}

Employment Issues

About 70% of caregivers are also employed in the regular labour market. 10% of caregivers report having to leave the labour market due to the care they are providing, 15% work reduced hours and 44% have missed time from work to provide care. Even when caregivers do not miss time from work, there are costs incurred by employers through decreased work performance.

Lack of Support

In 2012, only one in five caregivers reported receiving financial help. The most common source of assistance was financial help from family members (12%), whereas only 7% of caregivers reported financial assistance through a government program and 5% reported assistance through a tax credit.^{xiv}

2. **Decline in Mental, Emotional and Physical Health and Wellbeing**

Mental stress and emotional distress are the most common challenges faced by caregivers. Caregivers have reported commonly feeling worried, anxious, tired, overwhelmed, resentful and lonely. Studies demonstrate that caregivers with these experiences are at a higher risk for injury or aggravating pre-existing health conditions.

3. **Lack of Formal Support or Training**

Most Canadians become caregivers suddenly due to an expected illness of a loved one. There is often little preparation and when caregivers do seek out formal support and guidance, they often find that support to be quite limited.



Unpaid care and the stresses that can be associated with it can lead to elder abuse. Elder abuse is a single or repeated act, or lack of appropriate action, occurring within a relationship where there is an expectation of trust, which cause harm or distress to an older person.^{xv} Studies and CARP polling demonstrates that approximately 10% of older Canadians experience some form of abuse, much of which goes unreported.^{xvi} For more information CARP's elder abuse priority, click [here](#).

Respite

Respite is too-often thought of as a single-service, when instead respite should be viewed as an outcome. That outcome is to provide relief and rejuvenation to those providing unpaid care. Respite support may include a break from care, support in the caregiving home, education, training etc. What respite means to one caregiver may be different from respite for another caregiver.

One method to ensure respite is appropriate for the individual caregiver is to permit self-directed funding. Self-directed funding enables caregivers to select the support they need and purchase those supports/resources through a designated amount that is based on a needs assessment for the household.^{xvii} Funds could be used to purchase dental benefits, massage, medication, physiotherapy, mobility equipment, health-related transportation, homemaker services, time off caregiving, etc.

Government Support is Lacking and Requires Overhaul

While governments purport to recognize the value of informal caregiving, their policies often fail to reflect this value. Provincial programs vary widely, with some provinces taking the lead on progressive policy to support caregivers, like the Caregiver Benefit program in Nova Scotia, to very limited programs in many other provinces.

The Federal Government offers two programs for caregivers, both of which are lacking and will be discussed below. The first is a system of tax credits and the second is the Employment Insurance Compassionate Care Benefit.

Tax Credits

The Federal Government offers a number of tax credits, which are limited in scope and amount of funds. There are two programs applying to caregivers:



1. Family Caregiver Tax Credit → This program provides a non-refundable tax credit of \$2,093.00 for caregivers of a dependant with impairment in physical or mental functions. This program applies to individuals providing care for a spouse or common-law partner.
2. Caregiver Tax Credit → This program provides a non-refundable tax credit up to a maximum of \$691.00 per year to individuals providing in-home support to a dependant relative. This credit is not available to a spouse or common-law partner. The dependent must be the caregiver or his or her spouse's or common-law partner's child, grandchild, brother, sister, niece, nephew, aunt, uncle, parent or grandparent.

Because these programs offers a non-refundable tax credit, as opposed to a refundable one, 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.

Employment Insurance: Compassionate Care Benefit

The Employment Insurance Compassionate Care Benefit provides 26 weeks of employment insurance payments for people who absent themselves from their workplace to provide care and support to a family member who is gravely ill and who has a significant risk of death within 26 weeks.

The Federal Government recently expanded the period of coverage from 6 weeks to 26 weeks, but it is not long enough. Another issue is the very narrow definition of who qualifies. These benefits would not be available to a caregiver who just became a caregiver due to a serious medical diagnosis of a loved one if that loved one is not expected to die within 26 weeks. It would not permit support for a caregiver who must provide emergency care for a short period of time while a loved one undergoes dialysis or chemotherapy for example. The program is, unnecessarily, limited to care provided to the terminally ill.

Direct Compensation for Caregivers

There are examples of efficient programs that provide direct compensation to family caregivers internationally. For example:

- The United Kingdom provides a "Carer's Allowance".^{xviii} This allowance is 62.10 pounds per week and available to caregivers who provide at least 35 hours of care each week,



reside predominantly in the United Kingdom and earn below a minimum amount per week.

- Australia provides a “Carer Payment” to Australians engaged in full-time care to someone with a severe disability, medical condition or who is “frail aged” and has provided care for a significant period (typically a minimum of six months).^{xix} This payment is means-tested and provides \$794.80 AUD bi-weekly to single caregivers. Australia also provides a “Carer Allowance” of \$123.50 AUD bi-weekly to caregivers performing up to 20 hours per week.^{xx} This allowance is not means-tested. Caregivers receiving both the payment and allowance who are in the most financial need may be entitled to an additional payment of \$1,200.00 AUD per year.

Direct compensation is largely non-existent in Canada, with the exception of the Province of Nova Scotia. Nova Scotia has implemented the “Caregiver Benefit” program which provides \$400.00 per month to caregivers of low income who provide care to adults with a high level of disability or impairment. This is an excellent provincial program (although the amount of the benefit is insufficient) that is long-overdue at the federal level.

Provincial governments must implement programs to assist all caregivers, but particularly unpaid caregivers with the greatest financial need. In 2007, nearly 1/3 of caregivers aged 45 and older who had care-related expenses had annual household incomes of less than \$30,000 per year.^{xxi}

Limited Protection under Human Rights Legislation

The vast majority of human rights legislation existing provincially and federally includes protection against discrimination for employees on the basis of marital status and family status. Marital status protects Canadians who are caring for a spouse from discrimination in the workplace. Unfortunately, the ground of family status has been drafted and interpreted narrowly and only provides protection for caregivers caring for an individual in a parent-child relationship. A large segment of care is excluded – caring for an aunt, a dear friend, a brother or sister for example.

As demographics change and it is apparent that caregiving is often provided outside of the traditional parent-child relationship, it is time for the definition of family status to change to incorporate all relationships of genuine care for another.



CARP RECOMMENDATIONS

1. CARP calls upon the Federal Government to alter existing non-refundable tax credit programs available to caregivers to ensure that amounts are refundable credits and delivered as cash payments to homes as opposed to amounts deducted from tax owing.
2. CARP calls upon the Federal Government to expand the Employment Insurance Compassionate Care Benefit to provide a total of 52 weeks of benefits for caregivers who are providing care to an individual with a “significant illness”. CARP calls for the abolishment of the requirement that the individual who is being care for being likely to die within any period of time.
3. CARP calls upon the Federal and Provincial Governments to amend their human rights legislation to include ‘care’ as a protected ground of discrimination in the area of employment to ensure that a large segment of caregivers are not currently excluded from protections already offered.
4. CARP calls upon the Provincial Governments to implement a Caregiver Benefit Program akin to the program offered in Nova Scotia, where low-income caregivers are provided with a suitable monthly payment.
5. CARP calls upon the Provincial Governments to increase funding for respite for caregivers and permit that funding to be self-directed so that the caregiver can best determine the method of respite they require.



APPENDIX "A" ²

Alberta

British Columbia

Manitoba

Primary Caregiver Tax Credit

A refundable credit of up to \$1,400 per year for people who act as primary caregivers for spouses, relatives, neighbours or friends who live at home in Manitoba. To qualify, the individual requiring care must be assessed at Level 2 or higher under the Manitoba Care Program guidelines. This credit is refundable and not income tested, meaning that it can be claimed even if the caregiver does not have taxable income. It is available to those who live in Manitoba and do not receive pay for the care they provide.

New Brunswick

Newfoundland

Nova Scotia

Caregiver Benefit

A provincial program intended for caregivers of low income adults who have a high level of disability or impairment as determined by a Home Care Assessment. Qualified caregivers received \$400.00 per month. To be eligible, the person receiving care must have a net annual income of \$22,125 (if single) or \$37,209 (if married/common law), be assessed to have a very high level of impairment requiring significant care over time, and the caregiver must be 19 years of age or older, be providing 20 or more hours of assistance per week and not already receiving payment for the assistance being provided.

² <http://www.seniors.gc.ca/eng/sb/caregivers/index.shtml>



Supportive Care Program

Provides individuals with cognitive impairments with \$500 per month for Home Support Services (personal care, respite, meal preparation, household chores, etc). To qualify, Nova Scotians must be 65 years of age or older, be a resident of the province, have significant memory loss and memory problems that affect daily living, have a substitute decision-maker and be deemed by continuing care as needed a minimum of 25 hours of care per month.

Northwest Territories

Nunavut

Ontario

Prince Edward Island

Quebec

Tax Credit for Caregivers of a Spouse

A refundable tax credit of up to \$925.00, paid to a person who provides continuous care and assistance to an eligible relative who has lived with that person and who was not remunerated (includes caregiving for a spouse, caregivers housing an eligible relative and caregivers cohabiting with an eligible relative). The individual being cared for must be aged 70 and over, have a severe and prolonged impairment, have cohabited with the caregiver in a residence for a period of at least 365 consecutive days.

Saskatchewan

Yukon

Other Federal Tax Credits Not Directly Applicable to Caregivers

The *Home Accessibility Tax Credit* provides a tax credit of up to \$1,500.00 for eligible home renovation expenditures. The *Federal Medical Expense Tax Credit* provides a tax credit for a designated list of health-related services and goods in excess of a minimum amount. The *Infirm*

Dependant Tax Credit provides a tax credit of up to \$1,005.00 for providing care to adults aged 18 and older.

ENDNOTES

- ⁱ (2006). *Health Care in Canada Survey 2006*. National Survey of Health Care Providers, Managers and the Public. Located online at [http://www.who.int/patientsafety/news/2006_hcic.pdf]
- ⁱⁱ Luchesi, Bruna et al. (2015). *Evaluation of Depressive Symptoms in Older Caregivers*. *Arch Clin Psychiatry*. 2015;42(2):45-51. Located online at [<http://www.scielo.br/pdf/rpc/v42n2/0101-6083-rpc-42-2-0045.pdf>]
- ⁱⁱⁱ Sinha, Maire. (2013). *Statistics Canada: Portrait of Caregivers, 2012*. Located online at [<http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf>] at p. 19.
- ^{iv} Sinha, Maire. (September 2013). *Portrait of Caregivers, 2012*. Statistics Canada Analytical Paper – Spotlight on Canadians: Results from the General Social Survey. Located online at [<http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf>]
- ^v MS Society of Canada. (2008). *The Cost of Caring: Implications for Family Caregivers*. Located online at [https://mssociety.ca/en/pdf/socact_caregiver-pospaper-feb08-EN.pdf]
- ^{vi} Canadian Public Health Association. (Winter 2015/2016). *Caregiver Burden take a Toll on Mental Health*. Located online at [www.cpha.ca/en/about/digest/39-4/11.aspx]
- ^{vii} Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]
- ^{viii} Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]
- ^{ix} McMaster University Health Forum. (November 2014). *Improving Care and Support for Unpaid Caregivers in Ontario*. McMaster Health Forum Citizen Brief. Located Online at [<https://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/citizen-briefs/support-for-unpaid-caregivers-in-ontario-cb.pdf?sfvrsn=2>]
- ^x Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]
- ^{xi} McMaster University Health Forum. (November 2014). *Improving Care and Support for Unpaid Caregivers in Ontario*. McMaster Health Forum Citizen Brief. Located Online at [<https://www.mcmasterhealthforum.org/docs/default-source/Product-Documents/citizen-briefs/support-for-unpaid-caregivers-in-ontario-cb.pdf?sfvrsn=2>]
- ^{xii} Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]
- ^{xiii} Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]
- ^{xiv} Sinha, Maire. (September 2013). *Portrait of Caregivers, 2012*. Statistics Canada Analytical Paper – Spotlight on Canadians: Results from the General Social Survey. Located online at [<http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.pdf>]
- ^{xv} World Health Organization. *Elder Abuse*. Located online at [http://www.who.int/ageing/projects/elder_abuse/en/]
- ^{xvi} Statistics Canada. *Family Violence in Canada: A Statistical Profile 2000*. No. 85-224.
- ^{xvii} Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]
- ^{xviii} Government of the United Kingdom. (2016). *Carer’s Allowance*. Located online at [<https://www.gov.uk/carers-allowance/overview>]
- ^{xix} Australian Government. (2016). *Carer Payment*. Located online at [<https://www.humanservices.gov.au/customer/services/centrelink/carers-payment>]
- ^{xx} Australian Government. (2016). *Carer Payment*. Located online at [<https://www.humanservices.gov.au/customer/services/centrelink/carers-allowance>]
- ^{xxi} Torjman, Sherri. (May 2015). *Policies in Support of Caregivers*. Renewing Canada’s Social Architecture. Located Online at [<http://www.caledoninst.org/Publications/PDF/1071ENG.pdf>]