

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. Caregiving in Canada however provides many challenges and obstacles to caregivers, including isolation, lack of training, hopeless and ‘burn out’, and financial insecurity.

The provision of care often taxes caregivers emotionally, physically, mentally and financially. 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 few years ago, 800 interviews were conducted with caregivers and the following were commonly shared as the key areas in which caregivers and recipients needed more support:

- Have a single point person to discuss care;
- Assistance with navigating the health system;
- Finding training and reliable home care services;
- Home maintenance services;
- Assistance with shopping and cooking;
- Mental Health/Emotional Support;
- Getting a break from caregiving.ⁱ

A Growing Issue

About one-third of caregivers are 55 years of age or older.ⁱⁱ 34% of senior caregivers provide at least 10 hours of care per week.ⁱⁱⁱ

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

- Unpaid caregivers contribute in excess of \$5 billion each year worth of labour to the health care system^{iv} – some studies report this figure to be significantly higher;^v
- 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;^{vi}
- Chronic disease rates are increasing in Canada at a rate of 14% each year,^{vii} and
- By 2031, the number of Canadians projected to require care is expected to **double**.^{viii}

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.^{ix}

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.^x 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

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 D – p. 7)

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.^{xi} 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.^{xii}

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.^{xiii}

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.^{xiv} Studies and CARP

polling demonstrates that approximately 10% of older Canadians experience some form of abuse, much of which goes unreported.^{xv} For more information CARP's elder abuse priority, visit our policy located at: <http://www.carp.ca/2016/05/30/carp-action-elder-abuse/>

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.^{xvi} 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. The only one specifically applying to caregivers is the *Caregiver Tax Credit*, which provides a non-refundable credit up to a maximum of \$691.00 per year for care provided to dependent relatives, spouses, common-law partners and minor children.

Because this program 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”.^{xvii} 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).^{xviii} 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.^{xix} 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.
- Norway provides a “Care Wage”, a monthly taxable wage, to caregivers who are providing extraordinary care to those in need.^{xx} The amount paid is based on care needs but the average payment is kr. \$4,600 (approximately \$878 CAD) per month.

- Sweden provides caregivers with a taxable wage and social security protection that similar to that paid to employees in the formal caregiving sector.^{xxi}

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.^{xxii}

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 and Provincial Governments to implement a Caregiver Benefit Program akin to programs offered in Nova Scotia or Sweden, where low-income caregivers are provided with a suitable monthly payment;
3. CARP calls upon the Federal Government to amend 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.

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, and
5. CARP calls for formal, government-funded training for informal caregivers via the formal health care system.

OTHER

Creative Opening Cut for Jeremy for Campaign/Website

Imagine that when you wake tomorrow morning, your telephone rings and you answer and to your surprise are offered a second job on top of the already full-time hours you work. You begin to discuss the terms and are told that you will be on call 24/7, will receive minimal or no training, the work can be physically and emotionally exhausting, and you won't get paid. Would you accept this second position?

This is the reality faced by millions of unpaid caregivers across Canada

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.

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

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

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.

ⁱ SOURCE D – p. 9

ⁱⁱ 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. (“SOURCE AA”)

ⁱⁱⁱ SOURCE AA – p. 20

^{iv} 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]

-
- ^v 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]
- ^{vi} SOURCE C – p. 3
- ^{vii} SOURCE C – p. 3
- ^{viii} SOURCE D – p. 7
- ^{ix} SOURCE C – p. 10
- ^x SOURCE D – p. 8
- ^{xi} SOURCE C – p. 9
- ^{xii} SOURCE C – p. 10
- ^{xiii} SOURCE AA – p. 16
- ^{xiv} World Health Organization. *Elder Abuse*. Located online at [http://www.who.int/ageing/projects/elder_abuse/en/]
- ^{xv} Statistics Canada. *Family Violence in Canada: A Statistical Profile 2000*. No. 85-224.
- ^{xvixvi} SOURCE C – p. 8
- ^{xvii} Government of the United Kingdom. (2016). *Carer's Allowance*. Located online at [<https://www.gov.uk/carers-allowance/overview>]
- ^{xviii} Australian Government. (2016). *Carer Payment*. Located online at [<https://www.humanservices.gov.au/customer/services/centrelink/carers-payment>]
- ^{xix} Australian Government. (2016). *Carer Payment*. Located online at [<https://www.humanservices.gov.au/customer/services/centrelink/carers-allowance>]
- ^{xx} Keefe, Janice. (2004). *Policy Profile for Compensating Family Caregivers: Norway*. Maritime Centre for Aging Research and Policy Analysis. Located online at [<http://www.msvu.ca/site/media/msvu/2004%20Policy%20Profile%20for%20Compensating%20Family%20Caregivers%20-%20Norway.pdf>]
- ^{xxi} SOURCE C – p. 14
- ^{xxii} SOURCE C – p. 10