

CARP's New Vision for Caregiver Support



Caregivers Need Comprehensive Supports

Over 8 million informal caregivers in Canada provide care to family members or friends with chronic conditions, disabilities, and other health needs. Informal caregivers are unpaid caregivers that provide critical support and care that allow Canadians to recover from illness and age at home. The economic contribution of informal caregivers is conservatively estimated at \$25-26 billion annually, taking into consideration the number hours of care provided and market wagesⁱ. The savings to Canadian health care systems are even greater since many people who would otherwise need care provided by hospitals and other care facilities receive care at home instead. Despite the support provided to family or friends and the savings to the health care system, caregivers face a variety of challenges, ranging from lost work and income to physical and mental burdens.

Caregivers are unlikely to have flexible work hours or arrangements or even unpaid job protection. Most caregivers do not receive financial support, adequate training, and support required to provide care. Many have to face the difficult choice between providing care to a loved one and leaving the labour force altogether, especially those providing heavy care, which is defined as providing 20 or more hours of caregiving each weekⁱⁱ. CARP calls on governments to take a comprehensive approach to providing greater supports for caregivers, recognizing the value caregivers provide to family and friends and the formal health care system. CARP's recommendations include increasing income support, providing respite care, providing job protection for caregivers, and creating adequate support services and training.

Caregivers in Canada

Many Canadians are taking on the responsibilities of caregiving:

- 8 million informal caregivers in Canada, representing 25% of all Canadiansⁱⁱⁱ
- 2 million informal caregivers provide heavy care (20+ hours/week)^{iv}
- 6 million of these provide care to a senior (75% of all informal caregivers)^v
- 70% of all care to seniors in the community are provided by informal caregivers^{vi}
- Majority of the caregivers is female (54%) and aged 45-64 (44%) – this group is of particular concern because they tend to outlive their spouses and suffer higher rates of work drop-out and poverty later in life.^{vii}

Caregiving Challenges

Caregiving is taxing physically, emotionally, mentally, and financially. The intensity of caregiving varies depending on the number of hours of caregiving per week and type of care. Lighter caregiving averages 3 hours a week, supporting the care recipient's independence by assisting with daily activities such as running errands, providing transportation, cooking meals, and grocery shopping. Heavy/intensive caregiving average 20 hours or more a week and provide more functional support in addition to the

the care provided in less intensive care, such as assisting with clothing, bathing, toileting, medications/injections, and feeding.^{viii}

Informal caregivers do much of the heavy lifting otherwise done by professional long-term care (LTC) centres, the out-of-pocket expenses for which are out of reach for most seniors, regardless of provincial subsidies and co-pays.^{ix} Although the high cost of institutional care is avoided, informal caregiving is not cost free. Informal caregivers experience challenges and burdens that are also costly in the following ways:

1. Loss of financial/employment well-being -

Caregiving responsibilities also disrupt normal work routines, requiring caregivers to adjust their working hours, take time off, or even leave the workforce to provide care that leads to a loss in income. Caregiving can have a significant financial impact on caregivers. Caregivers incur out-of-pocket expenses such as transportation costs, purchasing care aids, and hiring professional help to assist with care.^x

An OECD report found that caregivers providing heavy care are not balancing care and employment successfully but rather, caregivers are either more likely to leave the labour force entirely than to reduce their labour force hours or they limit care hours in order to remain fully employed.^{xi}

2. Decline of mental, emotional and physical health –

Mental stress and emotional distress are the most common challenges for caregivers.^{xii} Caregivers have reported commonly feeling worried or anxious, tired, overwhelmed, resentful, and lonely.^{xiii} Such stresses and emotional distress can also lead to negative effects on caregivers' physical health. Studies have shown that caregivers experiencing chronic stress are at a higher risk for injury or for aggravating pre-existing health issues.^{xiv}

The levels of emotional and health distress also increase with the intensity of care, especially those providing heavy care^{xv} and for people with depression, behavioural problems, or cognitive deficits, such as dementia.^{xvi} High levels of emotional distress and stress is also related to the health and safety of the care recipient.^{xvii}

- 3. Lack of formal support and training –** Most people become a caregiver suddenly, due to an unexpected health crisis of a family member. Not only is there no preparation for becoming a caregiver, when caregivers do seek out formal support, there is usually little or none. Workplaces lack caregiver leave programs, job protection for caregiving, and flexible hours or work arrangements. Governments provide limited financial support for caregivers and minimal funding for home care and social support programs. Often, caregivers must take on the full burden and costs when providing care.

Current Federal Programs are Limited

Governments have recently recognized the value of caregivers, notably with the federal non-refundable Family Caregiver Tax Credit and Ontario's Family Caregiver Leave Bill, which would offer job protection to caregivers. Recognition is important, but current programs and spending do not adequately recognize the challenges and burdens of 8 million informal caregivers.

Currently, two federal programs offer benefits and tax credits but with significant limitations:

The Employment Insurance Compassionate Care Benefit provides benefits through EI benefits up to six weeks at a maximum of \$514 per week. This is based on a basic benefit rate of 55% of average insurable earnings, up to a yearly maximum insurable amount (\$48,600 in 2014).^{xviii} However, few caregivers are able to benefit from the program because eligibility is limited to caregivers who fit all of the following:

- Experienced more than 40% decrease in their regular weekly earnings from work
- Have worked at least 600 insured hours of work in the last 53 weeks or since the start of the last claim.
- Provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months).

However, this program is limited in application to people caring for terminally ill care recipients.

The Family Caregiver Tax Credit is the second federal program which is a non-refundable tax credit that provides a maximum of \$300/year for caregivers caring for infirm dependent relatives, spouses, common-law partners, and minor children. Being non-refundable, the tax credit applies only to caregivers with taxable income, by passing heavy care providers who may not have income due to job loss or labour force withdrawal.^{xix}

CARP Caregiver Recommendations

CARP is calling for a more comprehensive approach to support caregivers and meet their various needs. CARP calls for:

1. Financial support:

- Greater financial support should be provided to caregivers to relieve the financial burdens of caregiving. For example, the current federal caregiver tax credit should be increased and made refundable.
- Financial supports should be available for all caregivers who provide heavy care and not limited to certain type of care, such as the Compassionate Care benefit's "terminal illness" requirement.
- Long-term care (LTC) insurance can be an effective way to provide financial support for caregivers. Germany's universal public LTC insurance, for example, provides caregivers with cash and/or in-kind benefits when LTC is needed.^{xx}

2. Workplace protection for caregiving

- Workplace protection should be available for informal caregivers balancing caregiving and work responsibilities. For example, Ontario's Family Caregiver Leave Bill would provide 8 weeks of job-protected leave for employees providing care for a family member with a serious medical condition.^{xxi}
- 90% of Canadian workers are covered by provincial labour codes but federally regulated industries are not. Federally regulated industries should also have job protection coverage for caregiving responsibilities.

- Proactive caregiver leave and support policies

3. Respite care options for heavy care providers

- Heavy care providers should be given respite care options to mitigate the high risk of their own physical, mental, and emotional health deterioration. For example, countries, such as Germany and the UK, have long-term care insurance that will help meet costly caregiving needs. In Germany, family caregivers can get up to 4 weeks of vacation while using their insurance benefits, which can be received in cash and/or in-kind services for long-term care, providing some respite care for caregivers.^{xxii}

4. Funding for home care

- More funding is needed for home care. CARP members identified government funding for home care as a priority in enhancing the caregiver-patient relationship.^{xxiii}

5. Integrated training and support for caregivers with formal health care system

- Formal training and support should be provided for informal caregivers and can be done via the formal health care system. For example, when a care recipient first comes in contact with the health care system due to an acute event, the health care system has the opportunity to also work with the informal caregiver from the start with resources and support.

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