

Common Caregiver Public Policy Initiatives:

Support for caregivers, support for health system

A “caregiver” is anyone who provides unpaid care and support at home, in the community or in a care facility to a family member or adult friend who is living with a disability, chronically ill, elderly or palliative. Caregivers offer a range of support, from physical care to personal care, emotional and social support, meal planning, transportation, and linking with health and community services.

A survey showed that 88% of surveyed Ontarians prefer to receive care at home, and 84% prefer their loved ones to receive care at home.¹ Caregivers support this preference by volunteering their service hours to spouses, parents and other extended family members and friends.

¹ Pollara, SSCA Procurement Review Quantitative Survey Results, March 2005, p28

In Canada, it is estimated that caregivers who care for seniors save the country's health care system from \$24 billion to \$31 billion annually.² In addition, many caregivers are employed, and the challenges of caregiving can lead to greater stress, absenteeism, and decreased effectiveness on the job. Family and friend caregivers, often women, sometimes must leave jobs, reduce the amount of time they work, or pass up career opportunities.³

Caregivers incur financial costs in different ways.⁴ First, they often have to pay for basic costs, such as rent and food, for family members unable to work. People with disabilities, regardless of condition, have lower and more sporadic participation in the labour force on average than other Canadians. The second financial pressure comes from employment-related insecurities. Many Caregivers reduce their work hours or leave their jobs altogether in order to carry out their caregiving responsibilities. By doing so, they jeopardize both their current income and

²Hollander, M.J, Lui, G., Chappell, N.L., Healthcare Quarterly. "Who Cares and How Much? The Imputed Economic Contribution to the Canadian Healthcare System of Middle-Aged and Older Unpaid Caregivers Providing Care to the Elderly" 12(2):42-49, retrieved from: <http://www.longwoods.com/product.php?productid=20660>

³ Caregiver Support Program, Vancouver Coastal Health, retrieved from <http://caregivers.vch.ca/>

⁴ Sherri Torjman, Caledon Institute of Social Policy, Caledon Commentary October 2009: Talking Turkey on Taxes

future retirement income. The third financial pressure comes from additional expenses related to age or disability. These include costs for transportation to medical appointments, unfunded personal care and therapy services, technical aids and equipment, and structural modifications to a vehicle or residence.

It is estimated that caregivers provide more than 80 percent of care needed by individuals with 'long-term conditions'.⁵ To sustain these valuable services, governments across Canada and around the world provide different types of support through their policies.

Eligibility for these programs can be based on caregiver income, number of hours of caring, and the level of acuity of the care recipient.

Public Policy Initiatives Supporting Caregivers

Public policies support for caregivers can come in different forms: financial support and tax credits to alleviate the costs associated with care-giving; education programs to provide information and counseling; respite care to allow caregivers a few hours of relief; compassionate care leave benefits available to working caregivers for short term needs. In the

⁵ Fast, J., Niehaus, L., Eales, J., & Keating, N., 2002, A profile of Canadian chronic care providers

following is a brief description of each of these forms of support, how they have been applied, and some of their benefits.

Caregiver Benefit

Caregivers incur direct costs - such as the cost of medical supplies – as well as indirect costs such as the loss of income resulting from having to take leave of absence from work or working part-time to care for the care-receiver.

Financial support to caregivers can take different forms. In the UK, weekly allowances are provided to care givers in the form of a Carer's Allowance (£50.55/week, conditions apply) in addition to a Carer Premium for low income individuals. Payments are also provided in Australia to caregivers in the form of a Carer Payment and a Carer Allowance (up to AUD\$525.10/ two weeks and AUD\$98.50/ two weeks, respectively). Similar payments exist in New Zealand to caregivers in the form of a Domestic Purposes Benefit - Care of Sick or Infirm, a weekly payment which helps people who are caring for someone at home who needs full time care (up to NZ\$374.51/week, pre-tax, for sole-parents). In France, the Personalized Allowance of Autonomy [Allocation Personnalisée d'Autonomie (APA)] and the Compensatory Allocation for

Third Person Benefits [L'Allocation Compensatrice Tierce Personne (ACTP)] provide compensation to caregivers depending on the severity of the care-receiver disability and income of the caregiver.

To qualify for these payments in these healthcare systems, a carer would usually have to give care above a certain number of hours or have annual income less than a certain amount. Most of these forms of support require a certain level of dependency or lesser-autonomy so the caregiver may qualify for such support.

In Canada, Nova Scotia Department of Health provides an allowance of \$400/month to caregivers with low income. An eligible caregiver must be 19 years of age, a resident of Nova Scotia and be providing 20 or more

Nova Scotia Caregiver Benefit

Eligibility Checklist:

The person receiving care must:

- Be 19 years of age or older
- Be a Nova Scotia resident
- Be in a care relationship with a caregiver
- Have a net annual income of \$18,785 or less, if single, or a total net household income \$35,570 or less
- Have a care assessment completed by a Continuing Care Coordinator indicating a very high level of impairment or disability requiring significant care over time

The Caregiver must:

- Be 19 years of age or older
- Be a Nova Scotia resident
- Be in a regular, ongoing care giving relationship with the person receiving care, providing 20 or more hours of assistance per week
- Not already be receiving payment to provide assistance to the person for whom she/he is providing care
- Be willing to sign an agreement which defines the terms and conditions for receiving the Caregiver Benefit

hours of assistance per week to a family member or friend who lives in the community and who also meets the program eligibility criteria.⁶

This type of benefit is one of the most effective and inclusive ways to provide direct support to caregivers, and reaches those on low incomes and caregivers who have reduced or eliminated work hours in order to provide care. In contrast, caregivers who are on low-incomes or are prevented from working may enjoy little or no support from tax credits, for example, as these individuals may be tax-exempt or pay little taxes.

It is worth noting that financial/monetary support is viewed as a financial expense to government as the fiscal and political environment may influence the willingness of a government to add another expense to its income statement.

Beneficiary: Caregivers, including stay at home and low-income and middle- and upper-income caregivers

⁶ Caregiver Allowance, Department of Health, Government of Nova Scotia
(http://www.gov.ns.ca/health/ccs/caregiver_benefit.asp)

Caregiver Tax Credits

Tax credits are another form of financial support, and reduce the amount of tax owed to the government by caregivers.

Tax credits are not a direct payment from the government to the caregiver, but rather a reduction in the tax burden for caregivers to compensate for the additional costs they face as a result of caring for their loved ones.

In the UK, tax credits take the form of a Council Tax Exemption and a Disability Reduction Scheme, which both reduce the amount of property taxes owed by caregivers, depending on the hours of care per week and level of dependency of the care-receiver. In Australia, the Invalid Relative/Parent Tax Offset is given to caregivers with a relative of less than 16 yr old who receives a disability support pension. In the United States, this type of assistance is available to working caregivers who can deduct up to US\$3,000 for care expenses from income per care-receiver (up to \$6,000) depending on the level of the caregiver's annual income. Medical expenses in the US that are above 7.5% of adjusted gross income can be also deducted from the caregiver's income. In addition, employees can put up to \$5,000 pre-tax dollars per year in a tax-free account to use for dependent or elder care.

Non-refundable tax credits are sometimes favoured by governments since they are not considered an expense but rather a reduction in income from taxation. Many caregivers are incurring costs as a result of the services they provide to the loved ones and tax credits are indeed a way to reduce such financial burden. However, typically, caregivers who spend significant amounts of time in the workforce and are on higher incomes benefit most from such credits.

Non-refundable tax credits typically do not benefit caregivers who are on low-incomes or provide care full-time because they either do not pay taxes or pay lower taxes.

One form of tax credits is *the refundable tax credits*. Under this policy, caregivers who are too poor to pay income tax would receive monetary support to help offset their caregiving costs upon filing a tax return. A Canadian example of such a refundable tax credit is the Manitoba Primary Caregiver Tax Credit. Manitobans who

Manitoba Primary Caregiver Tax Credit - Eligibility

- For this tax credit, people requiring care must be assessed at Level 2 or higher under the Manitoba Home Care Program guidelines. They are assessed based on the amount and type of care required for tasks like bathing, dressing, eating meals, mobility and receiving medical care. Level 1 requires minimal care in most cases and is not eligible. Level 4 requires maximum daily support for most tasks.
- To be eligible, the primary caregiver must be identified by the person receiving care (or their parent if the person receiving care is under 18) and must not be paid to provide care to this person. The tax credit will help cover caregiver expenses. This could include respite care, taking the client shopping, to medical appointments or on recreational outings.

act as the primary caregivers for family members or others may now be eligible for a \$1,020 tax credit. Manitoba's Primary Caregiver Tax Credit provides up to \$1,020 a year to people who act as primary caregivers for spouses, relatives, neighbours or friends who live at home in Manitoba. Caregivers may earn \$1,020 per client, for up to three people, for any given time.⁷

To enhance caregivers' engagement and experience, eligibility for refundable tax credits can be attached to participation in training. Such training can constitute completing an online module to allow for caregivers' home-based-training and avoid adding hardship resulting from conflict of schedules in the case of institute-based training.

Beneficiary:

Refundable tax credits: Caregivers, including stay-at-home and low-income and middle- and upper-income caregivers

Non-Refundable tax credits: Middle and upper-income caregivers

Caregiver Support and Training Programs

⁷ Primary Caregiver Tax Credit, Manitoba Tax Assistance Office, Province of Manitoba (<http://www.gov.mb.ca/finance/tao/caregiver.html>, accessed February 7, 2011)

Support for caregivers can be in the form of education, training, counseling and peer support.

An example on such support is the Saint Elizabeth Health Care Foundation's Caregiver Support Program in Victoria, BC. The charitable program, which is delivered by ElderSafe Support Services, provides essential care, training and support free of charge to overburdened family caregivers.⁸ The program currently is provided in Vancouver by Vancouver Coastal Health and in Ontario through the Ministry of Health and Long Term Care's Aging at Home Strategy and the Saint Elizabeth Health Care Foundation.⁹

Another example is the Victorian Order of Nurses (VON)'s Caregiver Support and Education programs. VON provides information, emotional support and education to family caregivers. Participants gain insight through the experiences of other caregivers and build a network of support. A series of videos is used to encourage reflection and discussion.¹⁰

Caregivers are at increased risk for some specific task-related injuries and illness including: injuries, musculoskeletal disorders (MSDs); violence and aggression (b/c of dementia for

⁸ <http://www.saintelizabeth.com/news/charitable-program-family-caregivers-expands-victoria>

⁹ <http://www.saintelizabeth.com/news/caregiver-support-services-get-much-needed-boost>

¹⁰ Victorian Order of Nurses, http://www.von.ca/en/programs/program_listing.aspx?cat=1, accessed February 2, 2011.

example) and infections. Because of the similarity between the work homecare workers and informal caregivers provide, the WSIB 2003 document on Health and Safety in the Home Care Environment is useful in addressing health and safety training for caregivers. Such training would cover:

- Personal Safety
- Home Hazard Assessment
- Disease Prevention
- Musculoskeletal Injury Prevention
- Motor Vehicle Safety
- Wellness Promotion
- Emergency Preparedness

Beneficiary Caregivers: All caregivers, especially new caregivers.

Respite and Paid Absences from Work

In Canada, compassionate care benefits are Employment Insurance (EI) benefits paid to people who have to be away from work temporarily to 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). A maximum of six weeks of compassionate care benefits may be paid to eligible people. Most provincial and territorial labour codes provide job protection for workers in this type of family situation. However, the definition of “family member” varies.¹¹ A study by Dr. Janice Keefe noted that Canada’s leave policy is lagging in a number of areas including definition of relative and proportion of income replaced. In Japan, Sweden and California, leaves and benefits are more accessible and, in some cases, benefits replace 80% to 100% of regular employment income compared with 55% in Canada.

When it comes to respite care, two Respite/Caregiver Support programs that are provided in Ontario by Community Care Access Centres are Short Stay and Adult Day Programs.

The Short Stay program offers clients who are living at home or leaving a hospital an opportunity for respite or supportive care within a long-term care home. The maximum length

¹¹ http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#Definition

of stay is 30 days at a time, up to three times a year (90 days). There is a flat fee of \$32.37 per day for all short stay clients.

Adult Day Programs provide a day away (or part of the day) for isolated and frail elderly persons, including those with Alzheimer disease and dementia, who live in the community. Some accept adults with physical disabilities. Recreational and social activities, meals, personal care and basic health care services are tailored to the special needs of this clientele. Day programs provide an opportunity for friendship, wellness and therapy and a break for caregivers.

There are also programs provided by non-profit organizations. Victorian Order of Nurses provides several programs for caregiver respite such as In-Home Adult Respite, In-Home Children's Respite and Overnight Respite Services (see Appendix A).¹⁰

In Feb 2003, Sherri Torjman carried out a survey of selected key informants who have a policy interest in respite for caregivers. Her report concluded that there is a need for policy development that involves rigorous analysis of the various dimensions of respite. Respite often is seen as subsidiary to home care, just like the needs of caregivers generally are considered

secondary to those of care receivers.¹² The study pointed to the need for a knowledge-centre on respite that can facilitate knowledge-transfers with respect to research on respite.

A report by Alzheimer Society of Canada found that investment in flexible respite options will decrease long-term care use, with \$50,000 saved each year that a person does not enter LTC who otherwise would have. Supporting informal caregivers will save at least \$5 billion over 10 years.¹³

Beneficiaries: Working Caregivers and long-term caregivers

¹² Sherri Torjman, Caledon Institute for Social Policy, Feb 2003: *What Are Policy-Makers Saying about Respite?*

¹³ Alzheimer Society of Canada, 2010, *10 by 20: Ontario Action Plan for Dementia*

Conclusion

In conclusion, there are a range of policy options that exist in jurisdictions across Canada and worldwide that Ontario could adopt, strengthen or expand in order to provide support to caregivers and ensure they are able to continue to provide valuable services to their loved ones.

Appendix A: Victorian Order of Nurses Respite Programs¹⁰

In-Home Adult Respite

Caregivers of family members with Alzheimer's or other chronic illnesses frequently do not have respite time for themselves to go for coffee with a friend, or get some needed rest. They shoulder the responsibility of care 24 hours a day, seven days a week. Trained personal support workers and/or volunteers are available to meet the needs of the client and free the caregiver from a feeling of total responsibility for a few hours or shifts of care. Respite may include homemaking services, recreation and stimulation activities.

In-Home Children's Respite

Respite is available to families of chronically ill children who are physically or intellectually handicapped. A VON nurse and the child's caregiver develop a plan of support for the family and the patient. For a minimum of 6 hours per week, trained health aides provide personal services to free up regular caregivers. The same health aide is assigned to the client each week to ensure continuity of care.

Overnight Respite Services

VON operates several centres where seniors, the intellectually challenged and people with chronic conditions can come to a home-like setting custom-built for care, to allow caregivers much-needed rest. There is nursing care and recreational and therapeutic activities. Clients are assisted by a multi-disciplinary team that monitors their progress.