



Maytree Policy in Focus

ISSUE 11 | MAR 10

**Background and
Context...2**

Caregivers do not have
supports they need

Featured Research...4

Caregivers and
Dementia
by Sherri Torjman and
Anne Makhoul

**Conclusions and
Additional
Information...6**

Protect caregivers from financial ruin as population ages

An estimated four million Canadians act as unpaid or informal caregivers to seniors and persons with disabilities. Many caregivers exit the workforce or reduce their hours of work, risking their economic security. They also absorb additional costs related to their caregiving functions.

This Policy in Focus highlights three proposals:

1. *Expand Employment Insurance (EI) compassionate care leave* to allow special leave for the care of persons with chronic conditions. Current provisions limit support to those caring for terminally ill relatives.
2. *Extend Canada Pension Plan (CPP) provisions* to protect the retirement earnings of caregivers who must temporarily leave the workforce, as is currently done for workers with young children.
3. *Make current tax credits for caregivers refundable* to ensure that households too poor to pay income tax receive some money from the government to help offset their caregiving costs.

These proposals are essential because by 2031, one in four Canadians will be over age 65. (Seniors will comprise between 25 to 30 percent of the population by 2056.)

Featured Research
SUMMARY

**Caregivers
and
Dementia**

by Sherri
Torjman
and Anne
Makhoul.
Caledon
Institute of
Social Policy,
June 2008.

This report presents the results of a study carried out by the Caledon Institute and the Alzheimer Society of Ottawa and Renfrew County in collaboration with the Champlain Dementia Network.

It presents a number of recommendations related to the recognition of caregiver needs, improving the quantity and quality of services for individuals with Alzheimer's disease and their families, and reducing the costs and financial pressures associated with caregiving.

The study consisted of a survey questionnaire, telephone interviews, meetings and in-depth interviews with both caregivers and service agency staff.

Caregivers do not have supports they need

An estimated four million Canadians act as unpaid or informal caregivers. They provide care and assistance for family members and friends in need of support because of physical, cognitive or mental health conditions. These individuals may care for sick or aging parents, or for a relative or friend with some form of severe disability. The economic value of their work has been estimated at more than \$5 billion.

While unpaid caregiving is not a new phenomenon, the context for this work is changing. Women, who make up the majority of unpaid caregivers, are now more likely to be participating in the paid labour market. Many are raising children at the same time, and are living in a different region than other close family members who might otherwise be able to assist them with their duties.

What are the financial impacts on caregivers?

Caregivers face increased financial expenses such as fees for home care services, transportation costs for medical appointments, drug dispensing, technical aids and equipment, and home modification.

Many must reduce their hours of work or leave jobs altogether. Caregivers who exit the workforce without leave, insurance coverage or pension protection risk their long-term economic security. For example, those who leave the workforce entirely no longer make contributions to the CPP, jeopardizing their financial security in retirement.

Do governments provide income support for caregivers?

Caregivers can receive support through the federal government Employment Insurance (EI) compassionate care leave. Launched in 2004, it allows Canadians who meet the eligibility requirements for Employment Insurance special benefits to take six weeks of paid leave to care for a gravely ill child, parent or spouse who is at risk of dying within 26 weeks.

While important, the compassionate care leave measure is too narrow. It leaves out many thousands of caregivers who may need some paid leave for caregiving responsibilities for persons not gravely ill or dying.

In addition, the federal government provides some income tax relief through two specific measures. *The caregiver credit* gives tax relief to individuals providing care in their home for a low-income infirm adult relative, or a parent or grandparent age 65 and over with a low income. *The infirm dependant credit* gives tax relief to individuals providing support to a low-income adult infirm dependent relative, who may live in a separate residence.

Caregivers get income tax savings worth only 15 percent of the amount of these credits. The amount of both credits in 2010 is \$4,223, which reduces federal income taxes by a maximum \$633. Many caregivers will not receive even this modest amount because they have little or no taxable income.

What should governments do to ensure the financial security of caregivers?

In *Caregivers and Dementia*, Sherri Torjman and Anne Makhoul present three ideas to financially protect caregivers.

Expand EI compassionate care leave -The federal government should expand EI compassionate care leave provisions to allow special leave for the care of persons with chronic conditions. Current provisions limit support to those caring for terminally ill relatives.

Extend CPP provisions -The Canada Pension Plan (CPP) currently permits workers to exclude from the calculation of pensionable earnings the years when they stopped work or had lower earnings while they had a child under age 7. The federal government should extend CPP provisions to protect the retirement earnings of caregivers who temporarily leave the workforce. Provincial agreement on this proposed measure would be required through a designated amending formula. (Québec has a similar arrangement – the Québec Pension Plan – with its own unique set of special leave provisions for personal and family reasons.)

Make current tax credits for caregivers refundable - This means that households too poor to pay income tax would actually receive some money from the government to help offset their caregiving costs. Alternatively, Ottawa could turn the tax credits into a modest caregiver allowance that would assist all caregiving households. The UK and Australia, for example, pay a small cash benefit to the family caregiver of individuals requiring chronic at-home care.

CAREGIVERS AND DEMENTIA

BY SHERRI TORJMAN AND ANNE MAKHOUL.

CALEDON INSTITUTE OF SOCIAL POLICY, JUNE 2008

www.caledoninst.org

In addition to the recommendations to reduce the financial pressures associated with caregiving which have already been highlighted, this report presents a number of recommendations to improve the quantity and quality of services.

Existing services and supports for caregiving fall under provincial jurisdiction. They range from regulated services delivered by someone with professional training and certification (such as catheterization and physical therapy), to help with in-home routine household activities including light housekeeping, laundry, and meal preparation. There are also day and overnight programs, either within institutions or in the caregivers home, which can provide some time off for caregivers to attend a special event, visit relatives or friends, or take a short vacation. Together these services help caregivers tend to their own emotional, physiological and physical needs.

In August 2007, the Government of Ontario announced its Aging at Home Strategy, which seeks to enable independent living at home alone or with family members. More than \$700 million in funding over three years will be invested in home care, community support services, assistive devices, assisted living services and supportive housing, long-term care beds and end-of-life care. The proposals put forward in this study were intended to guide the development of the Aging at Home Strategy as it unfolds over the next few years.

On paper, the system looks like a rich and robust package. But caregivers report long wait times for many services, and complain that existing services are insufficient or inappropriate:

- In Ontario the *Long Term Care Act* limits in-home support to 15 hours a week. Despite being insufficient for caregivers who are responsible for loved-ones round-the-clock, many caregivers report receiving much less time. For example, one caregiver explained that she received only one hour of respite to go to a medical appointment, despite requiring at least 90 minutes in travel time.
- There are also rigid models of service delivery, such as day programs with fixed hours and overnight programs that are not available on weekends. Out-of-home options tend to be institutional, even when they are not long-term care facilities. One caregiver pointed out, for example, that a short-term respite facility did not have a telephone or a television in the room.
- In-home personal support workers are often guided by rigid job descriptions that prevent them from providing the range of required supports. For example, an in-home personal support worker may refuse to help with basic meal preparation if she was hired to help with laundry.
- Care receivers may be unwilling to participate in existing programs if they are able to function better than other participants. Caregivers note, for instance, a lack of day and overnight programs for those in the early stages of Alzheimer's.

This report recommends that Ontario extend the maximum number of hours available for in-home services and change the formula for assigning hours to include both caregiver and care receiver needs and disease progression. It also suggests more flexibility in the provision of services, and that caregivers be involved in the development, implementation and evaluation of the services provided to them.

Within the next 20 years, nearly one in four Canadians will be over age 65. As a result, caregivers will continue to play an important role in the Canadian health care system. Sherri Torjman and Anne Makhoul suggest that the federal government formally recognize this role through the creation of a National Caregiver Strategy. It could be modelled on strategies already in place in other countries.

The United Kingdom, for example, has passed three Acts of Parliament relating to caregivers, and has had a *National Strategy for Carers* in place since 1999. As a result of these efforts, income support is provided directly to caregivers, who are also eligible for social security, sick days and vacation.

Australia also introduced caregiver policies more than ten years ago. Financial support is provided through direct compensation, home care and respite. A motion calling on all levels of government, businesses and schools to consider adopting caregiver-friendly work and learning practices was unanimously supported in the Australian Parliament in October 2006.

In April 2008, New Zealand launched a national Carers' Strategy to achieve improved recognition and support for New Zealand's carers. In partnership with the Carers Alliance, the Strategy sets a strategic direction for developing policies and services for New Zealand's caregivers over a ten-year period, starting with a five-year action plan.

Selected Annotated Bibliography

***From Insecurity to Prosperity: Practical Ideas for a Stronger Canada.* Maytree, 2010.**

This document is intended for policy makers and practitioners who are interested in ideas that reduce poverty and promote inclusion. The ideas have been prepared by Maytree's policy partners on issues such as Employment Insurance, caregiver benefits, community engagement, diversity in the arts, immigration and refugee policy.

Sherri Torjman. *The Three Ghosts of Poverty.* Caledon Institute of Social Policy, October 2009.

This commentary explores three main sources of financial insecurity for caregivers: purchasing the basics for care receivers; paying for additional health- and disability-related supports not covered by medicare or private insurance; and taking unpaid leave in order to carry out caregiving responsibilities.

Sherri Torjman. *Talking Turkey on Taxes.* Caledon Institute of Social Policy, October 2009.

This commentary explores the modest income tax relief provided by Ottawa through the caregiver credit and infirm dependant credit. The paper discusses the limitations of these measures and proposes preferred options for caregiver support.

Michael J. Prince. *Canadians Need a Medium-Term Sickness/Disability Income Benefit.* Caledon Institute of Social Policy, January 2008.

This paper explains that the eligibility criteria of EI and CPP-D leaves many workers with recurrent and cyclical health conditions without benefits. He presents three ways that this gap in income protection for individuals and families could be addressed.

Ken Battle, Michael Mendelson and Sherri Torjman. *Towards a New Architecture for Canada's Adult Benefits.* Caledon Institute of Social Policy, June 2006.

This report describes how income security benefits for adults, notably welfare and Employment Insurance, fail to meet the needs of working-age Canadians. The authors propose a new architecture for Canada's adult benefits.



About Maytree Policy in Focus

Maytree Policy in Focus, a publication of Maytree, identifies and shares practical research to help inform policy- and decision-making.

For more information, visit www.maytree.com/policyinfocus.

Please send questions or comments to policyinfocus@maytree.com.

Maytree. For Leaders. For Change.

Maytree invests in leaders to build a Canada that can benefit from the skills, experience and energy of all its people. Our policy insights promote equity and prosperity. Our programs and grants create diversity in the workplace, in the boardroom and in public office, changing the face of leadership in our country.

