

Informal Caregiving



“Informal” carers play a crucial role in maintaining the health, well being, functional independence and quality of life of people living in the community who are otherwise at risk of losing their independence. This *Backgrounder* focuses on informal supports primarily to older people. Here we use the terms “informal” and “unpaid” “carer” and “caregiver” interchangeably, while recognizing the debates and lack of consensus around terminology.

Who are Informal Caregivers?

Informal caregivers are individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental conditions (Canadian Caregiver Coalition, 2001). They can be primary or secondary caregivers or part of an informal network of multiple informal carers such as siblings who share caring responsibilities for a parent.

- The majority of those who provide informal care to older Canadians are **spouses** and **adult children** although roughly one-third of caregivers are friends, extended family and neighbours.
- Informal carers are mostly aged 45 and older representing **2.7 million Canadians**.
- Carers often have **multiple responsibilities** and provide assistance despite ongoing work and family demands.
- **1 in 4 Canadian informal caregivers** who provide support to older people are **themselves 65 years or older** (Cranswick & Dosman, 2008).

Why are Informal Caregivers Important?

Benefits for Care Receivers

Informal carers provide a range of emotional and instrumental supports that enable older people to stay where they most want to be –at home.

Informal carers can assist with:

- Instrumental activities of daily living (IADLs) (e.g., transportation, meal preparation, shopping, housekeeping, home maintenance, and medication management);
- Activities of daily living (ADLs) (e.g., bathing, toileting, eating, locomotion and personal hygiene);
- Formal service coordination and management (e.g., navigating formal health system, linking individuals to services and coordinating multiple services from diverse and multiple providers for older persons with complex needs).

Informal caregivers may provide short-term assistance such as following surgery, or long-term support for those with diminishing mental and/or physical abilities or other long term health conditions.

Importantly also, informal carers provide social supports through visits and outings. Such activities keep older people engaged, socially stimulated and mentally active.

Benefits for the System

A Statistics Canada report estimates that 2.7 million Canadians, aged 45 and older provide care to seniors (Cranswick & Dosman, 2008).

They provide approximately 80% of the care needs for people with chronic health issues (Fast et al, 2002) and contribute an estimated economic value of between \$25-\$26 billion (Hollander et al., 2009) and \$83.7 billion (Zukewich, 2003), depending on what factors are included in the calculations.

In Ontario, as in other provinces, hospitals face increasing pressures, due to hospital bed reductions and shortened lengths of hospital stays, to discharge as quickly as possible people who are in hospitals, but do not require hospital care (ALC patients). At the same time, in Ontario, Community Care Access Centers (CCACs) are dedicating greater proportions of available resources to meet the needs of those recently discharged from hospitals requiring post-acute care and proportionally fewer resources to meet the continuing care needs of older persons with chronic illnesses or ongoing support needs (Decima Research Inc., 2002).

Against the context of these system level demands, home is one of the most cost-effective places to provide care for seniors with chronic health conditions. Indeed, the Toronto Balance of Care project (Williams et al., 2009) concluded that 37% of those on the Toronto Central Long Term Care list waiting for costly long term care beds could potentially be supported safely and cost-effectively if they were to receive care in their own homes. If they received care in supportive housing, system costs savings would be even greater as even more people (between 46% and 53%) could be diverted from waiting for LTC beds.

In our Balancing Care with Supportive Housing study (Lum et al., 2010), supportive housing managers estimated that clients with low to medium level of IADL care needs would cost between approximately \$22 and \$40 per day while clients who had medium to high IADL needs but low ADL needs could approach \$70 per day. This cost compares favorably with residential LTC beds in Ontario which cost on average, about \$130 per day, shared between the provincial government, which pays about \$80 per day, and individuals, who pay about \$50, subject to ability to pay.

Such cost-effective care however often assumes considerable unpaid contributions from caregivers (Keefe, Legare & Carriere, 2005). In our supportive housing studies (Lum et al., 2005; Lum et al. 2010), we found that those who lived in supportive housing and received supportive services as a benefit of living in those units also received considerable informal care from relatives, friends and neighbours. Families did not disappear. Instead, they augmented the supportive housing services by:

- helping with transportation, shopping, chores, banking;
- enriching the social and emotional experiences of older people through these activities as well as outings and visits;
- providing an additional layer of monitoring so that necessary interventions could be made at an early stage potentially averting more costly medical crises and hospital visits.
- making sure that appropriate care was in place.

It is important to note that informal caregiving does not end when older people move to care facilities. While most carers support older people who live at home in the community, more than 1 in 5 caregivers provide care to older people living in care facilities (Cranswick & Dosman, 2008).

Trends in Informal Caregiving

Growing numbers of older people will place greater demands on informal caregiving. The 65+ population made up 13.7% of the total population of Canada in 2006 (Zukewich, 2007). The number of older people in Canada is anticipated to increase. Projections show that by 2065, the proportion of Canadians 65 years and older will more than double to over 1 in 4; the proportion of older people 80 years and over will triple to about 1 in 10 compared to 1 in 30 in 2005. While new generations of older people may be relatively active and healthy in comparison to past generations of older people, they are nonetheless more prone to multiple and chronic ailments as compared to younger populations.

On the supply side, delayed marriages, declining fertility rates and evolving family structures (from extended intergenerational family units or traditional nuclear families to single parent households or people living alone) mean that there are fewer family members to provide informal care (Keefe, Legare & Carriere, 2005). Furthermore, as children move away from home, geographical distances between children and parents may increase the difficulties and stress in providing informal care.

In short, future informal caregiver availability will not match the projected increases in the population and needs of older people.

What do we know?

Informal caregivers may incur personal/social, physical, emotional, psychological and economic costs (Keefe, Legare & Carriere, 2005).

Personal/social costs

- Time taken to perform caregiving responsibilities is time away from a person's own family responsibilities, social activities and personal relationships, all of which may add to a caregiver's emotional stress, sense of isolation, and feelings of being overwhelmed.

Physical health costs

- Approximately, 70% of Canadian caregivers acknowledge that providing care for aging family members is stressful (Decima Research Inc., 2002).
- Stress is strongly considered as a basis for ill health and chronic health conditions (Lazarus & Folkman, 1984; Roddenberry & Renk, 2010).
- The level of stress is proportional to the number of caregiving tasks performed, the level and intensity of the responsibilities, and the apparent lack of choice and alternatives in taking on caregiving responsibilities (Pinquart & Sorensen, 2005; Yee & Schulz, 2000).
- Caregivers are more likely than non-caregivers to experience compromised immune function which will affect their short

and long-term health outcomes (Kiecolt-Glaser et al., 1987).

Psychological costs

- Caregivers are more likely to experience psychological symptoms as compared to non-carers (<http://www.ryerson.ca/crncc/knowledge/event-s/pdf-healthyconnections2011/SADAVOY%20Healthy%20connections%20%20ryerson%20June%209%2011%2097.pdf>)
- Depression rates are higher among caregivers of dementia, with 14-47% experiencing depressive symptoms and 10% meeting the Diagnostic Statistical Manual of Mental Disorders' assessment for clinical depression (Dura et al., 1991).
- Caregiving responsibilities correlates with an increased vulnerability to anxiety, guilt, grief, rage, substance overuse (e.g., alcohol), and an increased likelihood of relapsing into pre-existing mental conditions (George & Gwyther, 1986; Whitlatch et al., 1991; Schulz et al., 1995).

Economic costs

- Caregivers may miss either full or part days of work due to unpaid caregiving duties or may not accept promotions which would require increased time commitments at the paid workplace. Some may opt for part-time positions to balance work with care responsibilities. Caregiving thus potentially affects paid work experience, future income and pension benefits (Canadian Association for Community Living and Canadian Caregiver Coalition, 2003).
- Overloaded caregiving duties and simple burnout may also decrease efficiency at work. Such economic impacts are especially devastating for women of the sandwich generation who generally earn less than their male counterparts, and look after children and aging parents.
- Informal caregivers may pay out-of-pocket to travel to care receivers and/or to purchase goods and/or services for care receivers. More than one third of caregivers report extra expenses due to their caregiving responsibilities (Cranswick, 2003). It is

estimated that two-thirds of caregivers spend more than \$100 per month on caregiving (Decima Research Inc., 2002).

Canadian caregivers support society and our formal health system and do so at significant personal costs. How can public policy support caregivers? Posed differently, the costs of not supporting informal caregivers will mean greater use of EMS services, hospital emergency rooms, inpatient hospital beds, and/or residential LTC beds as default options.

What needs to be done?

Here we draw from a growing body of studies and useful examples to suggest policy initiatives and directions which support individuals, their carers and the formal health system.

Recognize and give voice to carers

Define the roles of informal carers as part of the healthcare system

The definition should be inclusive, that is, gender neutral, incorporating a network wider than immediate family members to include friends, neighbours and people connected by their commitment to one another who may or may not live close by.

Ease system navigation

Caregivers must navigate the health and social care system so they can help care recipients get the appropriate level of care by the appropriate providers as smoothly as possible. Given the complexity and siloed nature of our health and social services systems, easy access to system navigators can help carers find the appropriate supports.

Assess the needs of both the care receiver and the informal caregiver as a unit

Findings from the Ontario Balance of Care Projects (Williams et al., 2009) suggest that there is a need to address the individual and their caregiver(s) as a unit of care when planning home and community care packages. Currently there is a lack of an assessment tool that appropriately addresses the needs of both the care receiver

and the informal caregiver(s). The integration of quality assurance and accountability guidelines must work to insure that appropriate amounts of services are in place to support the sustainability of the whole unit of care (Keefe, 2010).

Include carers as part of the multidisciplinary care planning team

The Sunnybrook Health Sciences Centre successfully used a model of Inter-professional Model of Practice for Aging and Complex Treatments (IMPACT) which includes caregivers as part of the assessment and care planning team. Not only is the resulting care plan effective in addressing the patient's medical issues, the process gives voice to concerns of the caregiver. www.crnc.ca/knowledge/events/pdf-healthyconnections2011/NICKELL%20Caregiver%20Workshop%20FINAL.pdf

Provide ready access to information, education, skills-training, counselling, and resource packages, and publicize where carers can access additional credible information.

For example, the Care-ring Voice Network provides free and confidential information and support to family caregivers through interactive tele-learning sessions. Caregivers connect via telephone or on-line, either from home, the office or on the go, and can participate in interactive workshops or seminars on caregiver relevant issues. www.careringvoice.com (English)
www.reseautreaidants.com (French)

Yee Hong Caregiver Education and Resource Services is a centre that provides culturally-specific workshops, support and skills-training in multiple languages, in three locations, for those caring for older people in the community. www.yeehong.com

The Canadian Virtual Hospice is Canada's largest repository of information on palliative and end-of-life care, loss and grief. It addresses every aspect of caregiving, in community and clinical settings, and covers topics from spiritual challenges to the day-to-day practicalities. All content is compiled and reviewed by a respected team of palliative care professionals. www.virtualhospice.ca.

The Alzheimer Society of Canada provides online advice for person-centred caring for people with dementia. Information includes understanding the course of the disease, the importance of caring for self, finding respite and long-distance care provision (Alzheimer Society of Canada, 2010).

www.alzheimer.ca/english/index.php

Enable carers to balance personal and social life with care responsibilities

Respite services provide a break for caregivers, and include a range of services such as adult day care, in-home respite care, overnight or longer-term respite stays in facilities or a mixture of services (Keefe & Manning, 2005). Reports emphasize the importance of flexibility in providing respite and the need to avoid complicated admissions criteria (Special Senate Committee on Aging, 2009).

While Canadians may have access to respite programs, the availability and accessibility of these services vary widely depending on province and locales within provinces (e.g., rural v. urban). While most jurisdictions have adult day programs, the costs and hours of operation also vary. In many places across Canada, caregivers have limited support to help them to identify and meet their needs.

In Australia, the *National Respite for Carers Program* gives carers a break from caring by coordinating access to respite services at the local level and by arranging 24 hour emergency respite care. A national web site contains contact information for local services as well as a 1-800 phone number for information including a National Carer Counselling Program (Australia Department of Health and Ageing, 2011).

<http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-carers-nrcp.htm>

The United Kingdom's *Carers Equal Opportunities Act* passed in 2004 aims to look after the well-being and livelihood of carers by providing them with employment opportunities, extended benefits, and additional assistance so they can continue to provide unpaid care. The Act

- informs carers about their right to a carer assessment;
- considers in the assessment process, the carer's work or wish to work, study or have some leisure activities;
- makes provisions to assist carers by enlisting the help of health, housing and education authorities in providing support for carers (United Kingdom Department of Health, 2009).

www.legislation.gov.uk/ukpga/2004/15/content/s

As well, the United Kingdom's *Work and Families Act* gives informal caregivers caring for older adults the right to a flexible work schedule as well as planned breaks to informal caregivers from their caregiving responsibilities (HM Government, 2008). See www.essex.gov.uk/Health-Social-Care/carers/Adult%20Carers/Documents/Work_and_families_act_2006.pdf

- Germany's Social Long-Term Care Insurance provides benefits to individuals with low incomes by paying for time taken off work to perform caregiving duties, as well as respite for the duration that an informal caregiver is absent from caring. The assessment for this benefit does not depend on tax or income, but rather on duration of care (Arntz et al., 2007). For more information, see: www.bmg.bund.de/ministerium/english-version/long-term-care.html

Provide financial support to caregivers

Problem with current Employment Insurance (EI) Compassionate Care Benefits protect employee's job position and through EI, pays for up to 6 weeks of leave to provide end-of-life care to a family member, extended family member or close friend or neighbor (Service Canada, 2011). www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#Who

However, these benefits are not sufficient to meet the needs of people providing care to their family members or friends and cannot be seen as a comprehensive set of supports (Keefe, &

Rajnovich, 2007). The program does not protect jobs for carers who take temporary leaves for medical crises as opposed to palliative stages of illness. EI as the basis for compensation does not financially support those who have not accumulated sufficient hours in paid employment over the last 52 weeks, stayed out of the labour market to provide unpaid care or have left full jobs for part time or contract work that give insufficient hours to qualify for EI. Finally, lower income workers (of whom the majority of minimum wage earners are women) would not be able to live on the current EI ceiling of 55% of their income.

Future policies addressing financial services and support for caregivers in Canada must legitimize the choices made by carers and care receivers to ensure neither will experience any short or long-term consequences or financial setbacks based on their choices (Keefe, & Rajnovich, 2007).

Problem with current tax credits

Canada offers indirect compensation through tax credits and benefits. The federal government offers several tax credit options depending on individual circumstances. Provinces and territories offer a variety of tax credits programs. Here too, the eligibility and total amounts vary depending on such factors as age, relationship with care receiver, time spent caring, and income. For provincial variations, see Appendix. For federal programs, see the *Medical and Disability Information Guide* from the Canada Revenue Agency.

<http://www.cra-arc.gc.ca/E/pub/tg/rc4064/rc4064-10e.pdf>

Overall, the consensus is that the benefits available to caregivers do not come close to compensating the costs carers incur through caregiving.

Problem with pension schemes

If a person takes early retirement so as to provide informal care, the Canada Pension Plan's dropout provision protects informal caregivers' pensions by exempting up to 15 percent of a person's years of low or no income (i.e., years spent in caregiving) from their pension calculation (Department of Finance Canada, 2009).

Pension schemes however do not help those who have stayed out of the labour market to provide unpaid care or have left jobs that do not have pension plans (part-time employees, contract employees, or full time non-permanent employees).

Alternative international examples

The Australian government provides caregiving allowances and compensation such as Mobility Allowance, Carer Payment and Carer Allowance as informed through the Home and Community Care (HACC) Program (Australia Department of Human Services, 2011). For more information, visit:

www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Government%20help-1

New Zealand's Domestic Purposes Benefit supports full-time informal caregivers in the form of weekly payments (New Zealand Work and Income, 2010). For more information, visit:

www.workandincome.govt.nz/individuals/a-z-benefits/domestic-purposes-benefit-care-of-sick-or-infirm.html

Summary

1. Recognize that caregiving is vital not only to care recipients but also to the formal health system and the broader economy.
2. Ease system navigation.
3. Assess the needs of both the care receiver and the informal caregiver as a unit
4. Include carers as part of the multidisciplinary care planning team
5. Provide easy access to education, skills training, wellness programs and opportunities for work-life-caring balance.
6. Provide compensation through policy tools beyond EI and tax benefits to support carers who do not work for pay and provide care for chronic issues (e.g., stipends, travel reimbursements, respite).
7. Broaden the definition in the Compassionate Caregiver Benefits to include medical crises and not only palliative care.
8. Enable work-life balance for employed caregivers by flexible scheduling and the option of working at home without penalty.

How Can I Learn More?

Alzheimer Society provides up-to-date information regarding Alzheimer's and dementia, treatment, research, and how to care for these conditions.

For more information, please visit:

www.alzheimer.ca/english/index.php

Baycrest provides information and resources for informal caregivers caring for a loved one.

www.baycrest.org/Health_Information/Healthy_aging/default.asp

Canadian Caregiver Association provides support and advocate for the rights of caregivers.

www.cca-acaf.ca

Canadian Caregiver Coalition and the Ontario Caregiver Coalition provides resources and offers information, educational tools, support programs and up to-date-research on current issues.

www.ccc-ccan.ca

Ministry of Health and Long Term Care. (2009). *Caring-about-caregivers: Caregiving for the future of Ontario – Long-range scenario planning supporting caregiving into 2033.*

www.theconference.ca/pdf/abrown_Caring_About_Caregivers_Final_Report.pdf

Respite for Family Caregivers: An Environmental Scan of Publicly-funded Programs in Canada:

www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php

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Wesway is an organization that provides creative respite for caregivers.

www.wesway.com

Homewatch Caregivers aims to support persons in the community:

www.homewatchcaregivers.com

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