Fact Sheet: The Role of Family and Informal Caregivers

“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers.”

Rosalynn Carter, former First Lady

- A caregiver is an individual who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions. The term is sometimes qualified with family caregiver, informal caregiver, or unpaid caregiver to differentiate from providers and other health care professionals who provide care.¹
- Based on a study in Ontario, palliative care clients were cared for primarily by their spouses or partners (57%) or their children or children-in-law (29%).²
- In 2007, 23% of Canadians said that they had cared for a family member or close friend with a serious health problem in the last 12 months. Adverse effects on this group of people included: using personal savings to survive (41%) and missing one or more month of work (22%).³ In 2006, of the 26% of Canadians who said that they had cared for a family member or close friend with a serious health problem in the previous 12 months, other adverse effects reported were: negative effect on mental health (41%) and negative effect on physical health (38%).⁴
- With the devolution of care to the community and the home, families are facing an increased burden to care for loved ones with little formal support.⁵
- Most caregivers found caring for loved ones manageable and rewarding. However, more than one in four (22%) showed signs of distress, including anger, depression, being overwhelmed and unable to continue providing care. Caregivers of 12% of Ontario palliative home-care clients exhibited more than one sign of distress.⁶
- Longer hours of informal care and the health status of palliative home-care clients led to significant caregiver distress. Those who provided 18–35 hours of care had high levels of distress. Interestingly, as care topped 36 hours, caregivers learned to manage better. The dying person’s health status—health decline, depressive symptoms and cognitive impairment—also added to caregiver distress. As the health of the loved ones deteriorated and/or depressive symptoms escalated, caregiver distress increased. A mild/moderate decline in cognition of palliative home-care clients was stressful for caregivers. Over time, they learned to cope better.⁷
- Since January 2004, Human Resources and Skills Development Canada has offered the Compassionate Care Benefit through the Employment Insurance program. The benefit provides 8 weeks leave (6 weeks paid) to eligible Canadians to care for a dying loved one.⁸
In June 2006, the Government implemented changes to the Compassionate Care Benefit through the Employment Insurance (EI) program to increase the number of people who can access the benefit. The expanded definition means that EI-eligible workers can claim the Benefit while they are absent from work to provide care to a sibling, grandparent, grandchild, in-law, aunt, uncle, niece, nephew, foster parent, ward, guardian, or a gravely ill person who considers the claimant to be like a family member. The Benefit remains available to those caring for parents, children and spouses. Common-law partners are also eligible to receive the Benefit. This refers to people who have been living in a conjugal relationship for at least a year, and includes same-sex couples.9

A 2009 evaluation of the Compassionate Care Benefit from the perspective of family or informal caregivers confirmed that there are a number of critical barriers to the successful uptake of the benefit, including:

1. the general lack of awareness regarding the Compassionate Care Benefit existence;
2. various issues with the application process;
3. the requirement of a two week unpaid waiting period;
4. the inadequate amount of time the leave provides; and
5. the inadequate financial compensation the Compassionate Care Benefit offers.10

As a leading-edge global company, GlaxoSmithKline includes in their employee benefit package the option of up to 13 weeks paid leave to employees who require time away from work to care for a dying family member.11

A 2002 study showed that 70% of family caregivers acknowledge that providing care to a loved one is stressful, and 70% of family caregivers indicate that they require time away from the responsibility of caring for a loved one.12

Whether or not the family or informal caregiver has a choice in taking on the role of caregiver is a significant factor in the degree of stress and disruption they experience.13

Formal support is important, but does not seem to reduce stress.14

Family and informal caregivers providing hospice palliative care at home are undertaking a wider range of tasks in an environment where they typically have less support from professional caregivers. Tasks assigned to family and informal caregivers may include: psychological, social and spiritual care; personal care; medical care, including administration of medications and injections; homemaking services; and advocacy and care-coordination.15

Current estimates for replacement costs for unpaid care-giving in Canada indicates a significant economic contribution by caregivers; estimates for care provided in 2009 range between 25 to 26 billion dollars.16

In a qualitative study inclusive of caregivers 75 years and older, it was concluded that the higher risk of health issues amongst this older cohort produced more complex care-giving issues. However, it was also found that the caregivers tended to downplay their care-giving situation in an effort to make it more manageable, and consequently were reluctant to access formal services for assistance.17

A meta-analysis of 23 studies comparing the health indicators of caregivers for people with dementia with non-caregivers matched for age and gender found that stress hormones in caregivers were 23% higher, and that their antibody responses were 15% lower than those of non-caregiver. These findings suggest the care-giving may influence the physical health of caregivers.18
• The increasing reliance on de-institutionalized care has had a great impact on Canada’s 1.5 to 2 million caregivers, a group that provides hands-on care, spiritual and emotional care, and care coordination worth $25-26 billion annually, while incurring $80 million dollars annually in out-of-pocket costs.¹⁹

• Family and informal caregivers of patients in the advanced stages of cancer experience a high level of psychological distress, which increases significantly as the patient loses autonomy. Health care policies and programs need to be revisited in order to take the reality of these patients and their families into account.²⁰

• The Senate’s Special Committee on Aging’s final report Canada’s Aging Population: Seizing the Opportunity released in April 2009 made the following strong recommendations in support of assistance for caregivers:
  o That the Employment Insurance Act be amended to:
    ▪ eliminate the two-week waiting period before receipt of the compassionate care benefit;
    ▪ increase the compassionate care benefit to 75 (seventy-five) percent of the earnings of workers;
    ▪ increase the length of the benefit from 6 to 13 weeks; and
    ▪ provide access to the benefit during times of medical crisis, and not only during the palliative stages of illness.
  o That the federal government works collaboratively with the provinces and territories, policymakers, stakeholders and family caregivers to establish a National Caregiving Strategy. The Strategy should form part of a larger federal integrated care initiative.

² The Change Foundation, 2011, Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions, www.changefoundation.ca/news.html#informalseniorcare.
⁵ Voice in Health Policy: The Role of Informal Caregivers in Hospice Palliative Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges, CHPCA, August 2004.
⁶ The Change Foundation, 2011, Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions, www.changefoundation.ca/news.html#informalseniorcare
⁷ The Change Foundation, 2011, Because this is the rainy day: a discussion paper on home care and informal caregiving for seniors with chronic health conditions, www.changefoundation.ca/news.html#informalseniorcare
⁸ Website: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
⁹ Website: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml
¹¹ Website: http://www.gsk.ca/
¹² Website: http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal-eng.php#a1
¹³ Website: http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal-eng.php#a1
¹⁴ Website: http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal-eng.php#a1
¹⁵ Voice in Health Policy: The Role of Informal Caregivers in Hospice Palliative Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges, CHPCA, August 2004, p. 9


20 Journal of Palliative Medicine – Caring for a Loved One with Advanced Cancer: Determinants of Psychological Distress in Family Caregivers