



Caregiver Support and Mental Health

The aging population and longer life expectancy rates coupled with a shift in the provision of health care services from institutional to community-based settings is translating into an increased requirement for individuals to care for family members in the home who have chronic health problems or disabilities.¹ Statistics Canada estimates that there are over 2.8 million Canadians providing care to people with long-term health problems.

Although short-term compassionate care benefits are available for eligible workers who are caring for a gravely ill or dying family member, the absence of extended caregiver relief programs and benefits has taken its toll on Canada's informal health care providers. Whether caring for a disabled child, an elderly parent or chronically ill spouse, the physical, emotional and financial burden can be enormous. Families represent the largest group of community caregivers for those with serious and persistent mental illness.

SCOPE OF THE ISSUE

- The economic value provided by family caregivers is enormous. It is estimated that help given to seniors alone saves the public system over \$5 billion per year which is equivalent to the work of over 276,500 full time employees.
- According to a Health Canada study conducted in 2002, caregivers are most likely to feel stressed in terms of their emotional health, with close to eight in ten reporting that caregiving has resulted in significant (29%) or some (48%) emotional difficulties for themselves.
- Approximately 30% of informal caregivers work outside the home. Over one million working Canadians take care of a person diagnosed with a mental illness. Of these, one-third report that it interferes with their paid job due to chronic health problems, depression and excess stress when the burden of work or caregiving increases.
- A 1999 Health Canada report estimates that employees juggling work and family demands cost Canadian employers at least \$2.7 billion a year in absenteeism, and the health care system approximately \$425.8 million for physicians' visits.
- Although the male caregiver population is growing, over 75% of informal caregivers are women, mostly wives and daughters. Many belong to the growing "sandwich generation", caring for young families at the same time as they care for elderly infirm parents. Due to the enormity and complexity of the task, caregivers of older people have higher than average rates of clinical depression.
- Family members caring for those with serious and persistent mental illness tend to find themselves becoming a nurse/counselor/advocate/crisis worker/home-care and income provider all rolled into one. In the not so distant future, ageing parents will no longer be able to carry on their active caregiving roles, leading to increased rates of relapse and need for acute crisis care.

FEDERAL ACTION

At present, a national home and community care program does not exist. The current Canadian home and community care system is a blend of public and private arrangements, provincial and territorial differences, and a mix of local organizations delivering the care.

In the September 2002 Speech from the Throne, the Government of Canada committed to modifying existing programs to ensure that Canadians can provide compassionate care or support for a gravely ill or dying child, parent or spouse without putting their jobs or incomes at risk. The 2003 budget followed through on this commitment with the government announcing that it will implement a new six-week block of *compassionate care benefits* through the EI program effective January 4, 2004. In order to provide flexibility in meeting the varying needs of individual families, eligible family members will be able to share the benefit.

The Romanow Commission on the Future of Health Care in Canada, in its final report (2002), acknowledged that the health care system simply could not function without the invaluable contribution of informal caregivers. Along with proposing amendments to the EI program to allow caregivers to qualify for time off work (as noted above), the report also recommended that the federal government implement the following income support strategies to support employed caregivers:

- Amend the Canada Labour Code to allow employee leave for family crisis situations, such as care of a dying family member, and work with the provinces to encourage similar changes to provincial labour codes;
- Expand the tax measures already available to people providing care to dying family members or to those who purchase such services on their behalf.

COMMUNITY RESPONSE

In 2000, the Canadian Caregiver Coalition (CCC), a bilingual alliance composed of individuals, groups, and organizations came together with a unified voice, to influence policy, and to promote awareness and action to address the needs of caregivers of all ages across Canada. In May 2001, an advocacy survey conducted by CCC identified a *national home and community care program* as the number one priority. A policy paper was subsequently developed calling for a *national caregiving policy*, as a prerequisite for providing home and community care.

In November 2002, the Coalition along with partner associations like Canada's Association for the Fifty Plus [CARP] and the Canadian Association for Community Care applauded the Romanow Commission for presenting a comprehensive vision of health care that enshrines home care as an essential service and supports caregivers as "partners in care".

While CCC believes that the introduction of compassionate care benefits under the Employment Insurance program is a definite step in the right direction, other fiscal measures must be considered to support those caregivers not attached to the labour force. Options should be explored both within the tax system (e.g. an expanded caregiver tax credit) and the pension system (e.g. an extended CPP "drop-out" provision to include informal caregivers) to reflect actual costs for out of pocket expenses incurred by caregivers.

In April 2003, CARP initiated an open letter urging federal, provincial and territorial health and first ministers to take immediate legislative and fiscal action to create a *national home and community care system* and keep the commitment to support informal caregivers, which was made by the federal government in the September 2002 Speech from the Throne. Although CARP represents the interests of Canadians fifty-five plus, the issues identified below equally reflect the concerns of younger and middle aged Canadians providing care to disabled or chronically ill family members.

CARP is pressing governments to:

- Establish principles for an equitable national standard of home and community care similar to those under the Canada Health Act.
- Determine that certain core health-care services are available to all Canadians in their homes and communities.
- Create a national pharmacare program that incorporates home and community care.
- Recognize and support family caregivers by providing access to practical and appropriate information and instruction, compensation (e.g. employment insurance), respite and other support services.
- Ensure that families are protected from attempts by government to off-load health-care services.
- Develop programs and incentives to overcome the current shortage of professional and paraprofessional home and community care workers while at the same time ensuring that service quality, stability and reliability are sustained.
- Earmark new federal funding for effective national standards for home and community care.

CMHA National's document, *Home Care & People with Psychiatric Disabilities: Needs & Issues: A National Evaluation*, recommends that any individual providing care and support for people with serious mental illness should have:

- Information on supports in the community;
- Linkages made to community supports;
- Long term planning needs of the family member and the consumer addressed; and
- Respite available to avoid and respond to crisis situations.

References available upon request.

¹ According to Health Canada's Report (2002), *National profile of family caregivers in Canada*, recipients of family care are most likely to be spouses or parents. One in six are children, many of whom have some form of mental disability.