

A Call to Action: Doing the Right Thing for Caregivers

In 1999, J.W. McConnell Family Foundation launched a three-year program in support of family caregivers across Canada. A family caregiver is defined as “an individual who provides ongoing care and assistance, without pay, for family members and friends in need of support due to chronic physical, cognitive, or mental health conditions” (Canadian Caregiver Coalition, 2002). According to Statistics Canada (1997), one in eight Canadians over the age of 15 is a caregiver.

The eight organizations funded during Phase I of the Foundation’s “Respite for Family Caregivers” program confirmed that a major challenge for the Canadian health care and social services systems continues to be how respite is understood and how support is provided to caregivers. Clearly many caregivers continue to carry out their role at the expense of their own physical, mental, financial, and/or social health. Genuine respite is “anything that contributes to a caregiver's emotional, spiritual, physical and/or social rejuvenation enabling them to have the reserves and resources they need to care for their family member or friend.” The literature shows that caregivers are minimal users of the health care system and that solutions to meet their needs, do not have to be costly (Hillman and Chappell, 2000).

The eight projects have come together in Ottawa in October 2003 to share what they have learned and to promote the advancement of a national public policy agenda for caregivers. They agree that to be effective, caregivers must be involved in setting the agenda. They also agree that while governments have a central role to play, all of us – communities, employers, the voluntary sector, researchers and others – have a collective responsibility to address the challenges faced by 2.85 million family caregivers across the country.

Guiding Principles

- Family caregivers must be recognized for the essential role they play in the country’s health and social systems.
- Caregiving is not only an individual responsibility, it is a social and collective responsibility.
- Supports need to emphasize the *voice* and *choice* of caregivers.
- Supports need to be multifaceted, flexible, coordinated, and involve partnerships with the person requiring care, the caregiver, the provider, and the system.
- Respite is not a service, but an outcome, resulting from time off from caregiving responsibilities (Canadian Association for Community Care, 1998).
- Caregivers will not experience respite unless the needs of the person they provide care for are met through meaningful and appropriate levels of support and services across the country.
- The needs of caregivers change over time; therefore, supports must be flexible and responsive.

Recommendations

1. Be a champion for caregivers and ensure caregivers have the supports and services within a system that is responsive to their needs and goals across the continuum of care.

Caregivers are the experts on their own situations yet, due to the nature of their responsibilities and their relationship to the person who requires care, need assistance to identify the strategies that will be of greatest help to them. We need to invest in community initiatives that build on the capacity of the community to support caregivers.

What action can you take?

- Endorse a ‘caregiver day’ in your community and a National Caregiver Week in Canada.
- Provide adequate financial resources to community groups to enable them to support caregivers effectively.
- Encourage organizations that work with caregivers to network and to provide coordinated and targeted responses.
- Support an assessment process for caregivers to identify their goals through an assessment following the assessment conducted for the person requiring care as part of a core basket of services available through home and community care.
- Invite other key stakeholders knowledgeable in caregiving, including caregivers, to meetings to provide relevant information and recommendations.
- Explore international legislation that supports caregivers, for example, the UK Carers Recognition and Services Act, 1995.

2. Embrace the philosophy of “respite as outcome.”

Respite is both a preventative support for caregivers as well as a lived experience. Caregivers need to be involved in all aspects of respite planning including defining what respite means to them. Access to opportunities to experience respite should be a condition of taking on the caregiving role.

What action can you take?

- Support flexible funding models to ensure a range of options for caregivers. Veteran’s Affairs Canada – Veteran’s Health Benefits and Independence Programs and Care for the Caregiver Program and the MS Society of Canada – Caregiver Special Assistance Program are two such examples.
- Explore international legislation that supports respite, i.e. the US Lifespan Respite Care Act, 2003.
- Support relevant research and the dissemination and application of the learning from this research, such as the CACC National Respite Care Project and the “Give Me a Break!” Project funded by Health Canada.

3. Ensure the economic security of caregivers.

While this was not a focus of the projects, the financial aspects of care were raised by caregivers in every project and have been cited in the work of the Canadian Caregiver Coalition and other stakeholders. The present and future economic security of caregivers who incur out of pocket expenses related to caregiving, who are not in the labour market, and those who are employed needs to be taken into consideration. It is estimated that two-thirds of caregivers are spending more than \$100 per month on caregiving (Health Canada, 2002). The economic value of caregivers' unpaid work to the Canadian economy is estimated to be over \$5 billion (Fast, Eales, and Keating, 2001). Employed caregivers incur lost income, benefits, and pension in the attempt to balance their responsibilities, Employers incur costs due to lost productivity, absenteeism, and work life related stress. Strategies need to be investigated and implemented to address all three groups of caregivers.

What action can you take?

- Support provisions in the tax system to reimburse caregivers for out of pocket expenses similar to the Medical Expenses and Attendant Care Expenses.
- Support a 'caregiving drop-out' clause in the Canada Pension Plan (CPP) for caregivers similar to the Child-Rearing Drop-Out provision.
- Allow for contributions to the CPP while one is caregiving and not in the labour market.
- Support the amendment of the Canada Labour Code to provide job protection and other family leave provisions for those who temporarily leave the workforce to provide for a family member.
- Enhance the compassionate care benefits made available to caregivers under the Employment Insurance Program effective January 1, 2004 by
 - expanding the eligibility definition of 'family,'
 - providing benefits to caregivers of individuals with chronic but not necessarily palliative conditions,
 - increasing the length of the benefit beyond 6 weeks to include other crisis times during their caregiving career, and
 - establishing an evaluation plan for the new benefit.
- Explore international legislation that supports caregivers financially, i.e. Australian Assistance For Carers Legislation Amendment Act, 1999.

McConnell Respite Projects – Phase I

- **Family Caregivers Network Society**, Victoria, B.C.
- **Family Caregivers' Association of Nova Scotia**, Halifax, Nova Scotia
- **VON Canada**, Ottawa, Ontario
- **Seniors Resource Centre of Newfoundland and Labrador**, St. John's, Newfoundland
- **Providence Centre**, Tamil Caregiver Project, Toronto, Ontario
- **Caregiver Respite and Support (CaReS) Project**, Hamilton, Ontario
- **Multiple Sclerosis Society of Canada**, Toronto, Ontario
- **LePhare/The Lighthouse**, Montréal, Québec

References

- Canadian Association for Community Care. (2002). *Give Me a Break! Helping Family Caregivers of Seniors Overcome Barriers to Respite*. CACC: Ottawa. www.cacc-acssc.com.
- Canadian Association for Community Care. (1998). *Final Report: National Respite Care Project*. CACC: Ottawa. www.cacc-acssc.com.
- Canadian Association for Community Living and Canadian Caregiver Coalition. (February 2003). *Policy Forum on Unpaid Caregiving*. Ottawa. www.cacl.ca.
- Canadian Caregiver Coalition. (2003). *Caring Together: Caregiver Recognition is Sound Social Policy*. Policy Paper Series Number 2. CCC-CCAN: Ottawa. www.ccc-ccan.ca.
- Canadian Caregiver Coalition. (2002). *Calling for a national caregiving policy: A prerequisite for providing home and community care*. Policy Paper Series Number 1. CCC-CCAN: Ottawa. www.ccc-ccan.ca.
- Commission on the Future of Health Care in Canada. (November 2002). *Building on Values: The Future of Health Care in Canada, Final Report (Romanow Report)*. Ottawa. www.healthcarecommission.ca.
- Conference Board of Canada. (1999). *Caring about Caregiving: The Eldercare Responsibilities of Canadian Workers and the Impact on Employers*. CBC: Ottawa. www.conferenceboard.ca.
- Cranswick, K. (1997). "Canada's Caregivers," *Canadian Social Trends*, <http://www.hc-sc.gc.ca/seniors-aines/pubs/unsorted/survey.htm>.
- Health Canada. (2002). *National Profile of Family Caregivers in Canada – 2002 Final Report*. Ottawa. www.hc-sc.gc.ca.
- Fast, J.E. and N.C. Keating. (2000). *Family Caregiving and Consequences for Carers: Toward a policy research agenda*. No.F/10. Canadian Policy Research Networks: Ottawa. www.cprm.org.
- Fast, J., J. Eales, and N. Keating. (2001). *Economic Impact of Health, Income Security, and Labour Policies on Informal Caregivers of Frail Seniors*. Status of Women: Ottawa. www.swc-cfc.gc.ca.
- Hillman, Lorna and Neena Chappell. (2000). *Stolen Moments: Getting a Break when you're a Caregiver*. Centre on Aging, University of Victoria: Victoria, BC.
- Hollander, Marcus and Michael Prince. (2002). *'The Third Way': A Framework for Organizing Health Related Services for Individuals with Ongoing Care Needs and Their Families*. Health Canada: Ottawa. www.hollanderanalytical.com.
- The Standing Senate Committee on Social Affairs, Science and Technology. (October 2002). *The Health of Canadians – The Federal Role, Volume six: recommendations for reform (Kirby Report)*: Ottawa. www.parl.gc.ca/common/Committee_SenHome.asp?Language=E&Parl=37&Ses=2&comm_id=47.

International Legislation

- UK Carers Recognition and Services Act*. (1995). www.hmsso.gov.uk/acts/acts1995/Ukpga_19950012_en_1.htm.
- US Lifespan Respite Care Act*. (2003). www.archrespite.org/NRC.htm.
- Australian Assistance For Carers Legislation Amendment Act*. (1999) <http://scaleplus.law.gov.au/cgi-bin/download.pl?/scale/data/comact/10/5926>.

For more information on these McConnell Foundation projects and the ongoing work of the Respite for Family Caregivers Project, contact the Secretariat:

Faye Porter, National Director
Family Caregivers Project, Phase II
VON Canada, 110 Argyle Avenue, Ottawa, Ontario K2P 1B4
Phone: (613) 233-5694 ■ Fax: (613) 230-4376 ■ caregiving@von.ca ■ www.von.ca