



Care Renewal *Second souffle*
Reaching out to caregivers *L'élan vital d'un répit*

The Care Renewal Experience:

Finding Innovative Ways to Support Caregivers In Communities

Care Renewal: Reaching Out to Caregivers

c/o VON Canada
110 Argyle Avenue
Ottawa, Ontario
K2P 1B4

Tel: 613-233-5694

Email: respite@carerenewal-secondsouffle.ca

www.carerenewal-secondsouffle.ca

and

The J.W. McConnell Family Foundation

1002 Sherbrooke Street West, Suite 1800

Montréal, Québec

H3A 3L6

Tel.: (514) 288-2133

Fax: (514) 288-1479

E-mail: inquiries@mcconnellfoundation.ca

www.mcconnellfoundation.ca

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Introduction

Caregiving is becoming an increasing concern for Canadians. Our population is living longer and having fewer children; families are more geographically dispersed, often blended and sometimes culturally mixed; more women are in the paid workforce and health care costs are rising.

Approximately 2.85 Canadians¹ have a caregiver role, and their work saves the health care system an estimated \$5 billion annually.² Without caregivers, more people would be institutionalized because they cannot take care of themselves.

A **caregiver** is an unpaid individual who provides care and assistance for family members and friends who need support because of physical, cognitive or mental health conditions. Care recipients can be children, youth, adults or seniors.

Caregiving can involve personal hygiene (dressing, bathing, eating, grooming), household work (cleaning, meal preparation, shopping), care coordination (transportation and appointments), general support (checking in, supervision, interaction), or nursing (administering medication, changing dressings).

Financial burden, social isolation, family conflict, lack of focus on own physical and emotional well-being are common challenges caregivers face.

Care Renewal: Reaching Out to Caregivers brought together eight projects over three years, reached almost 3000 caregivers, and gave participating groups a national perspective of caregiving. Its goal was to recognize the contribution and enhance the quality of life of caregivers, by supporting projects that explore innovative ways to achieve respite as an outcome. The program was funded by the J.W. McConnell Family Foundation and coordinated by the Victorian Order of Nurses (VON) Canada.

The projects involved are quite diverse, ranging from national to regional, from condition-specific to general assistance. Progressive networks of organizations, volunteers and caregivers were created, ensuring the program's reach extends far beyond the individual projects. The unifying theme is the recognized need to support caregivers by offering respite opportunities.

Respite

Respite refers to caregivers'

experiences of relief or renewal.

This relief or renewal can be

physical, emotional, psychological,

social, and/or spiritual. Respite

results from services, activities and

planning that are in place to support

caregivers in maintaining their own

health and creating more balance in

their lives. Respite allows caregivers

to improve their quality of life and

be more involved in their

community. It may also help family

or friends that the caregiver supports

to improve their quality of life and

integration within the community.

(Care Renewal, November 2004)

"Just being recognized helps."

– Caregiver participant, Pauktuutit project"





“There’s an assumption that if you love someone, you’ll care for them, when really you can love someone but be totally ill-equipped to care for them,” says Mark Stollow of the Care-Ring Voice project.

As the projects demonstrate, caregivers’ quality of life (and their ability to provide care) can improve through many kinds of activities, and even small changes can make a big difference.

Projects:

- Alberta Caregivers Association – Freedom and Friendship
- Canadian Association for Community Living – Building Effective Strategies for Family Caregivers
- Foundation for Vital Aging, and CSSS Cavendish – Care-Ring Voice
- Lighthouse, Families and Children – Home Respite
- Multiple Sclerosis Society of Canada – Caregiver Wellness Funding Pilot Project
- Pauktuutit Inuit Women of Canada – Inuit Family Caregivers Strategy
- Schizophrenia Society of Canada – National Respite Strategies for Caregivers of Individuals with Psychiatric Disorders
- Seniors Resource Centre of Newfoundland and Labrador – Caregivers Out of Isolation

Key Lessons

To actually achieve respite as an outcome, shared experiences through the projects show several points must be considered when developing and implementing caregiver programs.

Flexibility

Funding and planning must be flexible. The projects covered a variety of care situations, from seriously ill children, to seniors and people with psychiatric disorders. Obviously needs vary according to situation and culture. In the Alberta Caregivers Association’s project, one care recipient could not be convinced to spend time with trained volunteer so his caregiver could have a break; instead, the volunteer helped around the house and acted as companion to the caregiver, to provide social stimulation. Respite activities for Northern Inuit in the Pauktuutit project included hunting and berry-picking, which do not adhere to schedules and routines very well.

Exchange

Exchanging knowledge is central to successful innovations, to build on work being done. The Canadian Association for

Community Living’s project enabled the organization to initiate a national discussion, establish connections, collect information for advocacy. The Care-Ring Voice telephone conferencing group was supported through website, media work, conferences and presentations, which also fostered more knowledge transfer.

Support and guidance

Support and guidance can enhance effectiveness in introducing and sustaining innovations to support caregivers. The Schizophrenia Society’s survey showed 75 per cent of caregivers had difficulty coping with their role, another 10 per cent had great difficulty, and 65 per cent said they rarely or never had time off caregiving duties to pursue their own activities. Through the Care-Ring Voice project, people obtained information through the telephone conferencing group, and realized they were not alone. Most planned on applying new strategies they learned.

Inexpensive

Respite does not need to be expensive. Small things can make a big difference in quality of life. As the MS Society’s experience shows, an effective, relatively low cost program can make a considerable difference in lives of caregivers and care recipients. The Care-Ring Voice program used simple existing technology to host workshops through teleconferencing, so caregivers could access expertise and have a chance to share their experiences.

Responsive

Programs need to respond to the priorities and needs of both caregivers and care recipients. The Lighthouse project identified and addressed a need for both caregivers and care recipients, then mobilized volunteers to offer support in local community settings. The Schizophrenia Society assessed members’ needs through a large survey, to find what gaps exist and better direct future work.

Choices

Caregivers need choices in order to experience respite. Caregivers used MS Society funding on whatever they felt they needed for themselves. Participants reported they achieved relaxation, stress reduction and peace of mind through activities like taking a holiday, getting some household help, going to the gym. One participant, a father of two young sons whose wife has MS, wanted a break from cooking and used the money for a pizza night once a month over an entire year. All projects educated caregivers on available supports, services and strategies they could use.



Common Themes

Despite the wide variety of the projects involved, common themes emerged through their focus on the caregiver.

Choice

Choice became an obvious key lesson because it was such an important theme throughout the projects. Caregivers make the most of their options, and appreciate the chance to choose. As another example, the Caregivers Out of Isolation program provided tangible means of support throughout the province, with a seniors' resource centre, website, caregiver phone line, newsletter, lunch and learn activities, and a day-away activity.

Respite as outcome

Leaving home usually creates feelings of anxiety and guilt, but in the Alberta Caregivers Association project, caregivers learned to entrust duties to trained volunteers, and developed a sense of hope and increased energy after short, pre-planned breaks. Many felt for the first time they had permission to consider their own needs. For most projects, an expanded network of support also reduced the isolation caregivers felt.

Voice

To identify gaps and support options needed, Caregivers Out of Isolation used surveys, roundtable meetings, reports, newsletters, brochures, and shared information with all government levels. The Canadian Association for Community Living incorporated feedback from caregivers into a resource guide and workshop, making them feel validated and heard. Parents involved with the Lighthouse project collaborated on research, training and committees, which made them feel they could give back. As a result of its project, caregiver voice has become a large and important part of the way the MS Society works at all levels.

Recognition

As Pauktuutit's Lynda Brown says, "You can't convince people of respite as an outcome if they don't recognize themselves as caregivers first." Pauktuutit's first challenge was getting caregivers to identify themselves as such, to acknowledge their own needs. They used radio phone-in talk shows and ads in multiple dialects, posters, social gatherings, traditional story telling and websites to get people talking about caregivers. Like most, the Lighthouse project used media relations to increase public awareness of caregiver living conditions and promote recognition of the caregiver role.

Empowerment

Recognition often led to a sense of empowerment. Through the Alberta Caregivers Association project, caregivers started feeling it was acceptable to focus on their own needs. By volunteering and actively participating to improve the Caregivers Out of Isolation program, caregivers became more engaged. Caregivers involved with the Canadian Association for Community Living project felt they now understood they have a right to respite, and realized they were not alone.

Sustainability

Most organizations involved are hoping to continue their work by finding new funding sources, while all projects have had a lasting effect on their audience and networks, through public awareness, connecting people to available services and other caregivers, and continued resource distribution. Ideas and information have been planted in individuals, homes and communities.



"We say we don't want our family members to leave the region for care, that we want them home. We assume that someone in the family is going to care for them. If it is a lengthy illness we gradually go back to our own lives and forget that the person looking after our family member needs our help and support."

– Caregiver participant, Pauktuutit project



Conclusion

The lives of many caregivers and care recipients were touched and improved by each project involved in the Care Renewal: Reaching Out to Caregivers program. Respite as outcome was achieved in innovative and diverse ways across Canada. The program helped make people aware of the invisible issue of caregiving, and the ripple effects will continue even as the need grows. As Brown notes, the surface has just been scratched, and the work has just started.

For more information on the Care Renewal project from a policy perspective, please see the policy implications of 13 caregiver respite projects.



Resources

- Alberta Caregivers Association
T: 780-453-5088
W: www.albertacaregiversassociation.org
- Canadian Association for Community Living
T: 416-661-9611
W: www.cacl.ca
- CSSS Cavendish
T: 514-484-7878
W: www.santemontreal.qc.ca/CSSS/cavendish
- Foundation for Vital Aging
T: 514-488-4561
W: www.bienviellir-vitalaging.com
- J.W. McConnell Family Foundation
T: 514-288-2133
W: www.mcconnellfamilyfoundation.ca
- Lighthouse – Families and Children
W: www.phare-lighthouse.com
- Multiple Sclerosis Society of Canada
T: 416-922-6065
W: www.mssociety.ca
- Pauktuutit Inuit Women of Canada
T: 1 800 667-0749
W: www.pauktuutit.ca
- Schizophrenia Society of Canada
T: 1 888 772-4673
W: www.schizophrenia.ca
- Seniors Resource Centre of Newfoundland and Labrador
T: 1 800 563-5599
W: www.seniorsresource.ca
- VON Canada
T: 1 888 866-2273
W: www.von.com

Care Renewal Caregiver Promise:

*As a caregiver, you are the very heart of our caring society.
We are here to ensure that the work you do is valued
and recognized, and to support your personal need to realize
yourself as a unique individual, not just a caregiver.*

*You deserve to be heard. You need to be able to choose how you provide
your care. Most importantly, you deserve the opportunity for
respite so that you can develop your own personal life to its full potential.
We will achieve these goals in partnership with you.*

¹ Cranswick K. General Social Survey, Cycle 16: caring for an aging society. Ottawa: Statistics Canada, 2003. Available: www.statcan.ca/english/IPS/Data/89-582-XIE.htm (accessed May 17, 2007).

² VON Canada Caregiving Program: An Overview. Ottawa: Victorian Order of Nurses Canada, 2005. p. 8.

*“This wonderful gift raised my spirits,
reduced my stress level and
seeing me so thrilled brought joy
to my husband.”*

– Caregiver participant, MS Society project



Care Renewal Team

c/o VON Canada National Office
110 Argyle Avenue Ottawa, ON K2P 1B4

Telephone: (613) 233-8825 ext. 2252 Fax: (613) 230-4376

e-mail: respites@carerenewal-secondsouffle.ca



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