



The Caring Balance Family Caregiver Pilot Projects & Caregiver Strategy for the MS Society of Canada

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Presentation Outline

- Project background information
- Key findings & challenges
- Aspects of support that make a difference
- Overview of national Caregiver Strategy
- Consultation on Caregiver Strategy
- Conclusion



Caregiver Project Background (2000-2005)

- Central component of the two phases was *Caregiver Wellness Funding Pilot Project* involving more than 800 caregivers
 - From Atlantic, Manitoba & Saskatchewan divisions in Phase 1
 - From Atlantic, Ontario, Manitoba, Saskatchewan, Alberta and BC divisions participated in Phase 2



Caregiver Wellness Funding Pilot Project Purpose

- To provide caregivers of people with MS with opportunities to experience emotional, psychological, spiritual, physical and/or social relief or renewal through access to services or strategies intended to help them maintain their own health and achieve greater balance in their lives while caring for the person with MS.



Caregiver Wellness Funding Pilot Project Approach

- Direct funding (max. \$300) to caregivers for services and activities related to their individualized self care and wellness strategies
- \$ not intended as financial assistance or income support
- \$ was tool to deliver an individualized service because each caregiver is unique and may identify different ways to achieve a break, relief or renewal



Main Uses of Funding

- Break away, vacation – 25.3%
- Household help – 17.1%
- Gym Membership – 12.5%
- Spa/salon – 10.1%
- Sporting events/sports equipment – 9.7%



Wide Range & High Level of Positive Outcomes

- 83% of caregivers responded the support gave them ‘quite a bit’ or ‘considerable’ **peace of mind**
- 93% of caregivers responded the support gave them ‘quite a bit’ or ‘considerable’ **relaxation**
- 86% responded the support gave them ‘quite a bit’ or ‘considerable’ ability to **reduce stress**
- 53% responded the support gave them ‘quite a bit’ or ‘considerable’ **opportunity to get exercise**
- 75% stated the support helped to have their **caregiving needs recognized**
- 89% felt that the support enabled them to have **time to themselves.**



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Other Outcomes Identified & Achieved

- Opportunity to socialize with family/friends
- Opportunity for recreation
- Ability to pay for services
- Opportunity to be more productive at paid employment
- Opportunity to provide recreation for family



Key findings

- Support provided to caregivers usually resulted in positive outcomes and enhanced quality of life not only for the caregiver but often also for the person with MS and other family or support network members



Key findings (cont'd)

- Almost all caregiver respondents (95%) assigned a high level of importance to having the ability to choose the type of service or activity that they felt would meet their self-identified, caregiving related needs



Key findings (cont'd)

- Caregivers achieved a wide range and high level of positive outcomes related to their health and quality of life with a limited amount of funding for health promotion and wellness services and activities



Key findings (cont'd)

- Caregivers indicated that access to this type of support on an ongoing basis is needed to replicate and sustain these positive outcomes
- More than 1/2 of caregiver respondents reported that caregiving has a negative effect on their own health



Key findings (cont'd)

- The support provided to caregivers through the project did not address the significant financial security concerns identified by many caregivers and people with MS resulting from their direct and indirect caregiving- and disability-related costs



Caregiver Funding Challenges

- Responding to self-identified needs and supporting unique & creative approaches to address these needs can require complex & time-intensive administration and client follow-up
- Realistically acknowledging, responding to and creating awareness of caregivers' needs without negatively representing people with MS and their needs as a burden



Challenges (cont'd)

- Securing adequate funding for delivery of this type of program in a manner that aligns with the MS Society's commitment to balanced spending between research & services and balance between client services spending for all primary client groups.
- Evaluation feedback indicates that at least some caregivers need access to a higher amount of this type of funding on an ongoing basis in order to repeat and maintain the positive outcomes.



Caregiver Supports that Make a Difference

- The findings of the *Family Caregiver Pilot Project* (2000-2003) and *The Caring Balance Pilot Project* (2003-2005) clearly identified aspects of support that caregivers indicated resulted in positive outcomes that enhance their quality of life.
- These have implications not just for funding but for all types of caregiver supports & services.



Aspects of support that contribute to positive outcomes

- Recognition and appreciation of the role of caregivers
 - including greater awareness of and sensitivity to caregivers and their issues etc.
 - Incorporating a caregiver focus in communications messages and client services planning
- Recognition and acknowledgement of caregiver needs
- Recognition of the voice and choice of caregivers in MS Society decisions that have an impact on them (including the type of support they want)



The importance of recognition

- *“It gave me a sense that my role of being a caregiver is not taken for granted... it was recognized that I also need a break, to do something I enjoy and not feel guilty for doing so... It was much needed, more than I realized...”*



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The importance of recognition

“It was nice to be recognized as a caregiver”

“Realization that someone cares about caregivers”

“It gave me the chance to prove to my family that long-term caregiving is important enough to be recognized”



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The importance of choice

"The best feature is determining your own needs and not fitting in to how others define it".

"The fact that it allowed the caregiver flexibility to choose what is perceived to be helpful for themselves is a very strong point".



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Aspects of support that make a difference (cont'd)

- Flexible programs and services that respond to caregivers' self-identified needs related to assisting them in both their own self care and in their caregiving role.
- Flexible, responsive funding for caregivers' self-identified wellness and self care strategies



Future of Caregiver Wellness Funding Program

- The pilot project coordinated by the National Client Services department has concluded
- There are no plans for the National Client Services department to seek new funding to continue to offer a Caregiver Wellness funding program
- National Client Services department is using the pilot project findings to lead the development of a national Caregiver Strategy



Moving beyond the Caregiver Pilot Project

- Developing a MS Society of Canada Caregiver Strategy in order to sustain & anchor the findings & provide ongoing support to caregivers
- Caregiver Strategy will be presented to approved by National Board in November 2005 after broad consultation and caregiver endorsement



Highlights of Draft Caregiver Strategy

- The draft strategy includes:
 - Fundamental beliefs and recommended actions arising from key project findings
 - Involvement & collaboration from Client Services, Government Relations, Communications/public education, & Major Gift Planned Giving fund raising at all levels of the MS Society



Highlights of Draft Strategy (cont'd)

- Recommended actions include:
 - Activities for all previously mentioned departments
 - Creation of a National Caregiver Advisory Committee with nationwide representation (both volunteer and staff) from all stakeholder departments & accountable to National Board through National Client Services department



Conclusion

- Positive outcomes can be achieved for both caregivers and people with MS by explicitly listening to, acknowledging and responding to caregivers' needs



Implication & Opportunity

- Supporting caregivers and people with MS should not mean an 'either or' but a 'both and' approach
 - Support to one benefits the other
 - Caregivers want both their needs and those of person with MS addressed & vice versa
 - Need for an approach that balances the needs & well-being of both