

A Caregiver Tribute

To find a wonderful example of caregiving one need look no further than Regina's Bill Hastie. Bill, 83, has been his wife Barb's caregiver since 1994; they have been married for 58 years. She resides in Pioneer Village where Bill visits her daily. She was first diagnosed with progressive MS in 1997 and currently uses a wheelchair full time.



Bill Hestie participates in the MS Bike ride to support his wife Barb and others living with MS

Bill says that Barb has very little pain, but all her movements have deteriorated. A self described "active 83 year old" who lives close to Barb's home in Pioneer Village, Bill provides Barb continual assistance and care—and it is easy to see while watching the two that there is no shortage of love in their relationship.

In addition to being an active caregiver, Bill also participates each year in the MS Bike. He has been an avid cyclist since his youth and fondly recalls winning bike races around a local baseball diamond as a young adult. In 2011 he attended the Manitou Beach tour, and he raised on average \$1500 each of the 10 years he participated.

Bill is a member of the MS Society of Canada Regina Chapter Board, helps with the MS Society Carnation Campaign, and does many hours of volunteering at seniors and care homes. "Active" is certainly the right adjective to describe his dedication to the community.

As for the future? Bill isn't sure if he will be participating in the RONA MS Bike tour next year. But he does know that he'll be by Barb's side as she continues to fight MS Every day.

And every dollar he has fundraised since he began cycling ten years ago is one dollar closer to finding an MS cure. You could say that Bill is a fantastic caregiver twice over—both for Barb and for everyone in Canada with MS who benefits from the funds he raises.

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Share your story!

Do you have an inspiring story you would like to share with others?

Submit your contributions to the MS Society today for the chance to be profiled on our website or in our next newsletter. Contributions of all types are encouraged (written, photo, drawing, poetry, etc).

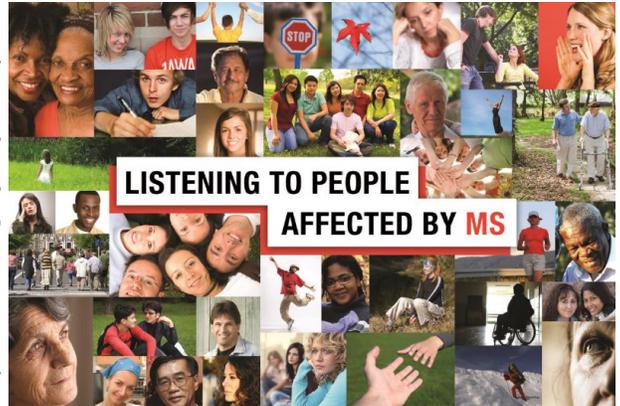
For more information about this newsletter, contact us at:

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Listening to People Affected by MS Initiative

Canada has the highest rate of MS in the world. 100,000 Canadians live with MS and hundreds of thousands more are affected by it as the family, friends and communities of those diagnosed. But what does it really mean to live with MS in Canada?

The Listening to People Affected by MS initiative had the single purpose of hearing from Canadians affected by MS about their quality of life priorities, needs and barriers so that the MS Society of Canada can better inform decisions that relate to our programs, services and advocacy. All of these elements were designed to help us explore aspects of quality of life and MS.



We heard from over 6000 Canadians affected by MS (including caregivers, people with MS as well as family and friends). Information was collected through two distinct online surveys, eight focus groups (including a caregiver focus group), one-to-one interviews as well as a review of the Canadian legislation and regulations.

We have recently completed the data collection of this initiative and are pleased to share the results with you. Below is a sample of the infographic produced from this initiative, highlighting the caregiver information.

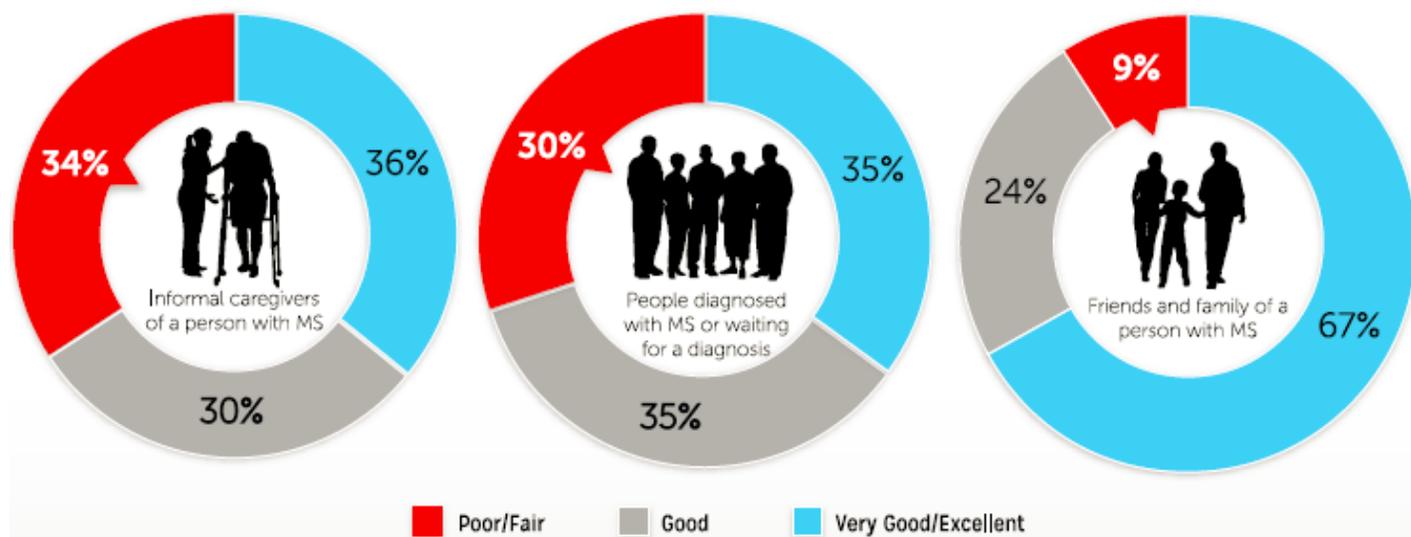
WHAT WE HEARD

WHAT QUALITY OF LIFE (QOL) MEANS TO PEOPLE AFFECTED BY MS:



SELF-REPORTED QOL IN THE PAST 12 MONTHS:

MS has a negative impact on quality of life. People with MS and their caregivers reported an *overall lower QOL* than their family and friends.



CARE FOR THE CAREGIVER



72% do not have the support they need as a caregiver



77% of caregivers who require respite care do not have access to it



79% do not have access to professional help to deal with the stress related to caregiving



26% say their children under 18 years have caregiving responsibilities

Unlike other developed countries, Canada does not have a federal action plan to support caregivers.

Support for family members was ranked the second most important QOL priority.

Manitoba is the only province that has put legislation in place to recognize and support caregivers.

WHAT WE ARE DOING



Reviewing our own processes, programs and strategic directions



Continuing to offer locally-based programs and services



Asking federal, provincial and territorial governments to take action in 4 crucial areas



Developing a nation-wide information and support service that will be available online and by telephone

Support secure jobs and income for people affected by MS

Call to action

The federal government needs to take leadership with provinces and territories to improve job retention and better coordinate income and disability benefits for people impacted by MS.

Recommendations

-  Change employment programs
-  Improve income supports for people with MS

Care for the caregiver

Call to action

The federal government should initiate the development of a **National Caregiver Action Plan** working with provinces, territories, caregivers, employers and organizations.

Recommendations

-  Refundable caregiver tax credits
-  Increase caregiver tax credits amounts

Coordinate quality lifelong care and support for people with MS

Call to action

Provincial and territorial governments must lead the development of MS strategies that better coordinate lifelong care and support for people affected by MS.

Recommendations

-  Equitable access to housing and care
-  Fund rehabilitation services
-  Ensure access to affordable treatments

Accelerate progressive MS research

Call to action

Develop therapies for people living with progressive MS within the next 8 years.

Recommendations

-  Increase investments in development of therapies for progressive MS
-  Increase investments in the commercialization of health research
-  Restore Canada's leadership as a place for human clinical trials

To view the full infographic and access all of the Listening to People Affected by MS reports, please visit: mslistening.ca

Nominate a Family Caregiver for the Canada Cares Family Caregiver Awards



Do you know a family or friend who deserves recognition for their caregiving activities? Canadian residents are being asked to nominate a caregiver for the Canada Cares Caregiver Awards. Canada Cares supports and salutes caregivers of all kinds across the country.

The Awards will be presented at both a regional and national level and will recognize five exceptional caregivers who may be a family member, friend or other significant person and select one of these regional winners to be the **Canada Cares National Caregiver of the Year**.

In addition, one outstanding caregiver will win \$10,000 to make a wish come true! Nominations will be accepted until September 15, 2014 at www.canadacares.org.

ADDITIONAL AWARDS



FOR COMMUNITIES



FOR EMPLOYERS

Canada Cares

CAREGIVER AWARDS

Help us find this year's National Caregivers

Tell us about outstanding family or professional caregivers in your life.

- Regional awards for Western, Northern, Central and Atlantic Canada.
- The \$10,000 **Canada Cares One Wish Award** will be granted to one exceptional application from anywhere in Canada.

Visit canadacares.org

Nominations close September 15th, 2014.

Canada Cares is a not-for-profit organization that celebrates and recognizes caregivers from coast to coast.

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MS Answers: Caregiver Q&A

Question:

I am 15 years old and live with my dad who has MS. I'm angry about all of the extra chores I have to do around my house. I know it's not his fault but I don't know what to do about my feelings.

Answer:

It's completely normal to feel angry or frustrated. You've already made the first step in making the situation better by reaching out. Many young caregivers go through a range of emotions including anger, frustration, worry, fear, anxiety, sadness and jealousy. While it's important to 'feel' these emotions, it is also important to manage them so that they don't get worse.

Making time to exercise, spend time with friends, hold a part time job, or take part in extra-curricular activities will provide you with time away from your caregiver responsibilities and will allow you to let go of some of those feelings in a healthy way. Talk to your dad and any other family members about how you are feeling and let them know that you would like some time to the things you enjoy doing.

Some families find it helpful to use a calendar and make a schedule of activities so that everyone is aware of their roles, responsibilities and non-caregiver activities.

If you feel as though you need more help, it's important that you speak to an adult that you trust and feel comfortable talking to. This could be a teacher, doctor, nurse, family friend or coach. Also, you can always reach out to someone at the MS Society.

Have a question? Send it in. Visit: www.msanswers.ca



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