

## Listening to People Affected by MS

Winter 2013

A key part of the mission of the MS Society of Canada focuses on ‘enabling people affected by MS to improve their quality of life.’ The Listening to People Affected by MS initiative aims to get to the root of what quality of life (QOL) means to those who are affected by MS. This initiative includes an anonymous survey which is available to:

- People with Multiple Sclerosis or Clinically Isolated Syndrome
- People waiting for a diagnosis with respect to MS
- Caregivers of people with MS (close people in the life of someone with MS who provide unpaid intermittent or ongoing care)
- Close friends/family members/significant others of people with MS



The survey will ask you about what you need and value as a caregiver. It will also ask you about the difficulties you face and the resources that could help you.

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### The goals of the Listening to People Affected by MS initiative are:

- To understand the QOL needs of people whom the MS Society currently serves as well as those it does not serve
- To determine the extent to which QOL needs are being met in Canada, identify barriers preventing QOL needs from being met for people affected by MS, and identify gaps in services and policies related to QOL needs
- To develop recommendations on what the MS Society needs to do, either directly through programs and services or indirectly through advocacy, in order to enable Canadians affected by MS to have their QOL needs met

Your voice as a caregiver is extremely important to us. Please take the survey!

**Online:** Please visit [www.mslistening.ca](http://www.mslistening.ca)

**In paper format:** If you wish to receive a paper copy, please call 1-800-268-7582 or print a copy from [www.mslistening.ca](http://www.mslistening.ca).

Please note: if you require support to help fill out the survey, please contact 1-866-922-6065 x3211

For more information, please contact: [mslistening@mssociety.ca](mailto:mslistening@mssociety.ca)

### 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 National 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:

[andria.samis@mssociety.ca](mailto:andria.samis@mssociety.ca)

## Caregiver speaks to parliamentarians during MS Society Day on the Hill reception

Award-winning caregiver Richard Jurewicz's story about how he supports his wife Teresa brought home the realities of caregiving to parliamentarians during the MS Society of Canada reception on Parliament Hill in late September.

He pointed out caregiving at times is like tightrope walking -- it is a very fine balancing act between offering enough help but not too much. He said individuals receiving care are above all "our spouses, parents, significant others, sons or daughters." Richard received the MS Society's highest caregiving award, the National Opal Award for Caregivers, in recognition of his commitment in caring for his wife, Teresa, who was diagnosed with MS in 1986.



The reception culminated Day on the Hill advocacy meetings for national government relations committee members from all across Canada. They met with almost 60 members of parliament and senators— a record number. Key issues discussed included the need for better supports for caregivers including making existing and future tax credits (e.g., Caregiver Tax Credit, Family Caregiver Tax Credit and Disability Tax Credit) refundable for people with low incomes.

## Do you live in Ontario? Tell your MPP to bring back the Family Caregiver Leave Bill

Bill 30, the Family Caregiver Leave Act, is a critical piece of legislation that would provide job protection for caregivers to take up to 8 weeks of unpaid leave from work. The MS Society, together with members from the Ontario Caregiver Coalition (OCC), has been working to make revisions to the bill that include flexibility on how leave is taken and supplemental income through extending federal employment insurance (EI) benefits.

Unfortunately, the decision to prorogue the Legislature has meant that all bills put before the house have ended. Regrettably this includes the Family Caregiver Leave Act that working caregivers so desperately need. There is hope however; the government could propose to carry this bill forward to the next session.



Let your MPP know that you want to bring back the bill on the Family Caregiver Leave Act to committee. By the click of a button you can send a letter to your MPP now and ask them to take action to support caregivers. To send a letter and learn about other advocacy issues for the online campaign please visit:

<http://mssociety.ca/ontario/action/>

# Developing a care plan: a family matter

(adapted from MS Canada 2007)

Caregiving can be overwhelming- especially when there is no plan of action. Developing regular routines and identifying clear roles for all involved can relieve some of this pressure, assist with the day-to-day management of the household and provide primary caregivers with a little respite.

If you are a primary caregiver, begin developing your care plan by making three separate lists. The first list should include your daily **caregiving** responsibilities. The second list should include your daily **self-care** activities (i.e. physical, emotional and spiritual activities). The final list should include **household management** activities that take place on a daily, weekly or monthly basis (i.e. grocery shopping, house cleaning and yard maintenance). You may find that when you compare your lists, the amount of time you spend caring for yourself is minimal.

The goal of a care plan is to achieve balance between your caregiving, household and self-care activities. Here are a few tips on achieving this balance:

- Hold a family/friends meeting to discuss responsibility sharing, and where possible, delegate responsibilities so that everyone is involved somehow
- Adapt spaces around your home to encourage the independence of the person with MS and other family members

Some caregivers take on more than they need to because family members fail to communicate effectively; don't be afraid to ask for help. Everyone has a limit, you need to recognize and communicate your boundaries.

## Family Caregivers Unite!

Family caregivers are the people who provide care to partners, parents, children, brothers, sisters, cousins, friends, neighbours and even co-workers. They are the people who provide care when everyone else has gone home. Dr. Gordon Atherley, host of the Family Caregivers Unite! talk show, and Amy MacFarlane, Founder and CEO of [Recreational Respite](http://www.recreationalrespite.org/), partner in their passion for family caregivers and family caregiving. Through the talk show they provide family caregivers with ways to combat loneliness, and with information that is trustworthy, understandable and useful. They enable family caregivers to tell their own stories and discuss their own experiences. Browse compelling episodes in the show's On-Demand Library, <http://www.familycaregiversunite.org/>.



# Healthy communication

By: Diane Adam  
Reprinted from MS Quebec

For some people, communicating and talking with their significant others comes naturally. For others, it is more difficult. For them, they might have a lot to say, but they can't find the words to express themselves.

Multiple sclerosis seems to overshadow everything. Talking becomes more difficult. The diagnosis has been made so what can you say that has not already been said?

Nevertheless, in a relationship of caregiver and care recipient, healthy communication makes it easier to get along together. You can say anything, listen to everything: the secret is in how you do it. It is normal to not always know what to say to someone who has been diagnosed with a chronic progressive disease. The caregiver, just like the care recipient, is trying to protect the other person by refusing to express his or her emotions.

To avoid having two solitudes under the same roof, let's look at a few avenues that will facilitate your communications with the care recipient and thus develop the basis of a solid partnership.

- Create a good atmosphere – Find a good time to talk. It is better to wait until you are more relaxed to discuss sensitive subjects. Don't try to start a conversation as you are on your way out. Ensure that you are comfortable and relaxed.
- See if the care recipient is willing to talk or not – It may be a good time for you, but what about the other person? The best way to find out is to ask the question directly: "I would like to talk, is that OK with you?" or "Do you feel like talking?"
- Listen and show the other person that you are really listening – Avoid thinking of what your answer will be. Knowing how to listen is just as important as the words you say during a conversation. Don't interrupt the speaker; give the person time to express himself or herself.
- Know how to listen and respect silences. Non-verbal communication is just as important as verbal communication. A silence may indicate a feeling that is painful to express. Your listening, your presence and some form of encouragement from you, such as touching the person's hand, are signs of your support to continue and to open up to you.
- Don't hesitate to talk about your feelings and emotions – It is legitimate to talk about your feelings when a situation is difficult to manage. Expressing the emotion you feel may help lighten the atmosphere. By recognizing that the situation is difficult, you open a door to the other person, make room and give him or her the opportunity to respond.
- Don't change the subject – During a conversation, certain things that the care recipient says may catch you off guard. Some fears may be exacerbated or you may feel powerless. If the subject is painful for you, don't forget that the subject is probably very important and possibly painful for the care recipient as well. So what can you do? Simply listen, but, if you can't take any more, just say so. Tell the care recipient that, for the moment, it's too difficult for you and you would like to talk about it later.
- Avoid giving advice – Giving advice may be reassuring, but it may also short-circuit communications. Giving your opinion and asking questions about a subject will encourage speakers to develop their thoughts and perhaps find a solution or, at least, an opening.



- Humour – Don't forget to include humour in your conversations as long as it is the right moment. It is good to laugh.

In conclusion, for healthy communication, have faith in yourself, speak in the first person ("I"), consider the other person an equal, trust him or her, and open your mind. In other words, talk, listen to silences and pardon your errors. Having said that, caregivers and care recipients – this is meant for you. Happy reading and good communications!

# MS Answers - caregiver Q&A

**Question:** My responsibilities as a caregiver are increasing and I am not sure how to manage them without affecting my career. How do I address this with my boss?

**Answer:** Managing both roles can be challenging and each employer will have a different level of understanding and acceptance of the situation. Review the Human Resources policies related to family or personal situations. Once you know the policies, speak honestly with your manager about your situation. Hopefully you will be able to work out a schedule together that will provide more flexibility in fulfilling both of your roles. Try to have specific examples of what would be helpful to you, for example, working from home a few days a week. If your manager is not familiar with MS, share some information about it with them. Because MS can be so unpredictable, it's important that they understand that you may need to make adjustments to your work situation according to changes MS has caused for your loved one.

Try to 'be where you are'. When you are at work, whether it is from a home office or the company office, focus on your work. If you have chores to do, get to them on your lunch break. One way to manage your time efficiently is to keep to-do lists and calendar reminders. Most mobile devices can help you stay organized. Prioritize your activities and delegate where possible; this includes accepting help from other family members, friends and colleagues.

Have a question? Send it in. Visit [www.msanswers.ca](http://www.msanswers.ca)



## Reminder for tax filing



The Family Caregiver Tax Credit takes effect for the 2012 tax year. For the first time, spouses can claim a tax credit for the caregiving they provide. The government introduced the tax credit in response to urging by the MS Society of Canada and other organizations that spouses and common-law partners should be able to claim a tax credit.

The new Family Caregiver Tax Credit is a 15 percent non-refundable credit on an amount of \$2,000 for the 2012 tax year. When preparing to file your tax return for 2012, please keep this credit in mind if you are a spouse or common-law partner and provide caregiving support.

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