

## Caregiving over the holidays

Fall 2013

The holiday season can be a wonderful time to meet with friends and family. For those caring for a friend or family member, the season may come with special challenges. In addition to the tasks of caregiving, the extra energy needed to take part in social celebrations can be taxing.

**Take stock** of how much energy you have and how much you can expend. It may mean that you can't attend every function. It may mean that you can't bring that special dish, which you're famous for, to the pot luck. It may be a time to draw on resources you don't normally use. For example visiting family members may be able to take the person you're caring for on a special outing. The key is to be aware of what your body is telling you.

Also, try to **arrange respite care early**. It's a busy time for everyone, whether you are asking a neighbour or a health care professional. Putting in a timely request can ensure you get a reserved spot in their datebook.

The holiday season can be a good opportunity to **communicate with family members** and to gain support from them. Friends and relatives may not realize the impact that caregiving is having on your life. Give yourself permission to discuss your feelings both positive and negative about being a caregiver without blame. Many of us are hesitant to share our feelings for fear of causing worry or conflict. You may find that simply sharing your experiences may make the load lighter.

The holidays are traditionally a time that center on family celebrations and traditions. Being unable to celebrate in the same way you always did can be a loss in itself. But it's an opportunity to relive those past celebrations and traditions with conversations and photographs. It may be a good opportunity to **start a new family tradition**, such as gather the family for a home-movie night. While you may not be able to recreate past traditions, it's a good time to create new ones or to pass on the responsibility to younger family members.

Don't forget to think about your own needs and to **make up your own holiday wish list**: lunch with your child or grandchild, a gift certificate for a massage, a bestselling mystery novel— whatever will bring you enjoyment and renewal.



The December holidays may be one of life's ways to brighten winter, to create opportunities to gather with friends and family and to enjoy good food. What's important is to **give yourself permission to simplify the season**, to be aware of your limits and to care, not only for others, but also for yourself.

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# Bill 21 Passes Second Reading

On September 25, Bill 21, the Employment Standards Amendment Act (Leaves to Help Families), 2013, passed second reading after debate in the Ontario legislature. Caregiver supports remain a priority for the MS Society of Canada, and we are pleased to see this Bill move forward.

If passed, the Bill would allow caregivers to focus their attention on providing care and support to their loved ones, without the fear of losing their jobs. The Family Caregiver Leave will provide up to eight weeks of unpaid, job-protected leave for employees to provide care and support to a family member with a serious medical condition.

The Bill has now been referred to the Standing Committee on General Government and public hearings will occur during the week of December 4, 2013. The Ontario Caregiver Coalition, which the MS Society of Canada plays a leadership role, has been invited to present to committee, and will advocate for the following changes in order to enhance the ability of this Act to assist caregivers:

- Allowing caregivers to bank unused days if they do not take the leave in full week increments
- Waiving the fee for obtaining a medical certificate

Currently the Act requires caregivers take leave in full week increments however we recommend that the caregiver be allowed to bank the unused days of the leave. For example, if a caregiver wishes to take leave for three days, we would like them to be able to bank the remaining two days rather than have a full week deducted from their total amount.

The Act also requires the caregiver produce a medical certificate to apply for leave. These certificates can average \$50, which creates a barrier for many caregivers. Caregivers take on additional financial obligations when looking after their loved ones. Many of the costs associated with care are not reimbursed through existing federal and provincial social assistance programs.

## Video resource: You are not alone

North Shore Community Resources in BC has a series of videos on their website for caregivers including one emphasizing the importance of reaching out to others to alleviate the stresses of being a caregiver. You can watch the video here: <http://www.nscr.bc.ca/information/caregiver.html>



# Look after yourself without feeling guilty

Reprinted from *MS Quebec*

You invest your time and energy in a caregiver/person with MS relationship and experience it at an emotional level. You also receive satisfaction from it. You probably feel useful and appreciated. Despite these positive aspects of your caregiver role, it is very demanding. At times you feel overwhelmed, exhausted, or even impatient, which may lead you to feel guilty. To compensate, you may try to do even more and exceed your limits. How can you stop this vicious circle?

## It doesn't help to feel guilty

To release yourself from guilt, learn how to accept your right to happiness, rest and making mistakes. Be aware of prejudices and beliefs which feed your guilt. Sweep away thoughts such as “Don't give up”, “I am healthy, and he or she isn't”, “I owe him or her that much”, and “I am the only person who can do it.” You are first and foremost responsible for yourself before being responsible for the other person. You cannot help the other person if you are unable to look after yourself. How can you re-establish the balance between your needs and those of your loved one?

## How to re-establish balance

Here are a few hints for family caregivers to help you re-establish the balance between your needs and those of your loved one. Most caregivers recognize the importance of taking better care of themselves. However, it is not always easy to actually do it. The fear of being viewed as lacking in empathy for the person with MS, and the problems you have finding time for your personal activities when the schedule is so busy are very daunting! First, admit that taking care of yourself is an essential need and that no one can do it for you. Then, recognize the need for some planning. Learning to effectively manage priorities is key to preserving balance. Identify an activity that you like and include it in your schedule. Accept the fact that you cannot change some things. You can change your attitude and the way that you deal with the situation. Openly express your needs to those around you, especially to the person with MS, and encourage your loved ones to do the same with you. Seek support from other people who will validate and support your initiative.



## Share your story!

Do you have an inspiring story you would like to share with others? Submit your contributions to the MS Society 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: [andria.samis@mssociety.ca](mailto:andria.samis@mssociety.ca)

# MS Answers: Caregiver Q&A

## Question:

My wife has multiple sclerosis. As the days go by, it is becoming more difficult for me to care for her on my own. She is in her forties and still young. Is there a place besides a seniors' residence where she may live and receive the care she needs?



## Answer:

If you no longer have the resources to care for your wife – and your attempt to provide her constant care is putting your health at risk – it's time to consider other options. Placement options for people with chronic illnesses vary across Canada. In your community, there may be a group home that can provide constant care and is more personable than a “seniors’ residence”.

Another option is Self Managed Care, a government-funded program that would allow your wife to hire her own caregiver and remain at home. In 2006, Health Canada published a report, *Self Managed Care Programs in Canada: A Report to Health Canada*, identifying publicly funded self managed home care programs at federal, provincial and territorial levels across Canada. To find out which programs are available in your province, [click here](#).

Visit [msanswers.ca](http://msanswers.ca) to read more answers to MS-related questions.

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