



Caring for the Caregiver

Fall 2014



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MS Society Advocacy Reaches MPs in Ottawa

At the end of September, 2014, MS Society staff and volunteers met with nearly one hundred members of parliament and senior policy advisors in the federal government to discuss our priorities and the support that we are requesting of government. Key areas of focus were identified in the Society's pre-budget submission and expanded on in our discussions. These key areas included:

- Job retention
- Income security
- A national caregiver action plan

Feedback has indicated that the MS Society made a positive and meaningful impression and follow up is underway.

The MS Society requests that the federal government take action for better caregiver supports for people affected by MS.

The federal government needs to initiate the development of a National Caregiver Action Plan working with provinces, territories, caregivers, employers and other organizations to reduce financial burden, improve access to resources, create flexible workplace environments, and recognize caregivers' vital roles.

- Make caregiver tax credits (family caregiver and caregiver tax credits) fully refundable to help provide essential income for people sacrificing time and income to care for people with MS
- Increase the caregiver tax credit amounts (family caregiver and caregiver tax credits) to help alleviate the immense financial burden faced by Canada's caregivers

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How to stay involved when caregiving from a distance.

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: emily.knight@mssociety.ca

Going to the Doctor

From: Caregiver Action Network

You may want to accompany your care recipient to doctor's appointments. This way, you and your care recipient can work together as members of the health team to ensure that you both understand the recommended medical course of action. This is an especially important role if your care recipient is cognitively impaired. Here is a checklist to help you make the most of your doctor's visit:



Before the Visit

- ➔ Write down all questions or any concerns you might have so you don't forget them. Regardless of how insignificant you feel the doctor may think it is – ASK!
- ➔ Identify current symptoms
- ➔ Update the care recipient medication list
- ➔ Call to confirm appointment

During the Visit

- ➔ Bring an updated medication list
- ➔ Clearly report all of your loved one's symptoms; don't try to diagnose the problem
- ➔ Ask your questions and record the answers
- ➔ Record doctor's instructions
- ➔ Discuss recommendations
- ➔ Verify follow-up

After the Visit

- ➔ Review your notes
- ➔ Check prescriptions
- ➔ Discuss the visit
- ➔ Update your calendar
- ➔ Call for test results
- ➔ Update care recipient file (see below)

Creating a Care Recipient File

From: Caregiver Action Network

The single most important thing you can do to function effectively as a caregiver is to create and maintain a comprehensive file of information about the person you are caring for.

There is a variety of ways to create and maintain a care recipient file. Some people prefer paper, some electronic, some a combination of both. You can keep this information in any form that works for you, although most people simply put it in a binder or folder. It doesn't have to be pretty; it just has to work for you. The important thing is that it provides easy access and can be efficiently updated and shared when needed.

Select a place to store the file that is logical to you – where you can grab it quickly in an emergency or on your way out the door to an appointment

Keep it up to date – an outdated file won't do you much good when you are standing in an emergency room at midnight!

Suggestions for what should go in the care recipient file:

- ➔ Care recipient's medical history
 - Diagnosis
 - Physician contact information
 - Allergies
 - Health history
- ➔ Medication List
- ➔ Insurance information
 - Medical insurance
 - Prescription coverage
 - Long term care insurance
 - Dental and vision insurance
- ➔ Legal documents
 - Living will
 - Power of attorney for Health Care
 - Power of attorney for finances
 - Contact information for care recipient's lawyer

REFERENCE

Article was sourced from the Caregiver Action Network: <http://www.caregiveraction.org>

Canadian Employers for Caregivers Plan

Recognizing that informal caregiving costs employers approximately \$1.28 billion annually in lost production, the Government of Canada (as part of the 2014 federal budget) committed to launch the Canadian Employers for Caregivers Plan (CECP).

This plan is designed to engage with employers on cost-effective workplace solutions to help maximize the participation of caregivers in the labour force. There are three key elements:

- ➔ Employer panel for caregivers - a panel of leading employers who will connect with other employers to identify successful ways to support caregivers in the workplace
- ➔ Business cases – the development of business cases which will outline various workplace supports from a cost-benefit perspective
- ➔ Sustained engagement – exploration of ways for ongoing employer engagement in the area of caregiver supports

As an employer and as an organization who supports workplace awareness and accommodation to support caregivers, the MS Society of Canada participated in one of the recent panels in Toronto. We will provide updates when further information is provided on the outcomes of the CECP.

FIND OUT MORE

For more information, please visit: <http://www.esdc.gc.ca/eng/seniors/cecp/index.shtml>

[blankMS]

Your idea to put MS in the spotlight

With the highest rate of multiple sclerosis in the world – MS is Canada's disease. Many Canadians are unaware of this fact, and this is why we need YOUR help.

The Multiple Sclerosis Society of Canada is on the search, far and wide, for people with innovative design talent to send their proposals on **unique and creative ways in raising awareness of multiple sclerosis** – Canada's disease.

The possibilities are endless and we know that the winning idea is out there! The winning entry has a chance of being part of an MS awareness initiative and the winner will receive \$500.

Have the winning idea? Great! Read up on what you need to know (aka [official rules and regulations](#)) to get

you started with your entry, and your quest to help the 100,000

Canadians with MS. Be part of our country's fight to end the disease!

Remember, we are looking for fresh approaches in raising awareness of MS. Judges will select the winning entry that they consider will have the **greatest impact** on increasing Canadians' knowledge of multiple sclerosis.

What you need to know

- ➔ Competition name: [blank MS]
- ➔ Deadline: December 5, 2014
- ➔ Goal: Design a fresh approach to raise awareness of MS in Canada
- ➔ Prizes: \$500 and winning entry has a chance of being a part of an MS awareness initiative

[blank MS]

FIND OUT MORE

For more information, please visit the following links:

Official Rules and Regulations: <http://blankms.ca/terms>

Team Participant Release Form: http://blankms.ca/files/TeamParticipantWaiver_BlankMS.pdf

How to apply: <http://blankms.ca/submit>

Asking for Help

by Susanne Mintz

Our neighbor Allen, who lives directly across the street, is tall, well over six feet. He carries his height on a solid frame. I see him out jogging from time to time and working in the yard.

My husband Steven is average height, about 5'8", and he weighs about 135 lbs. That in itself is a not problem. In fact, it is actually a good thing because Steven has multiple sclerosis and can no longer walk. Now and then, especially during transfers from toilet to wheelchair, Steven's legs give out and he ends up on the cold tile floor, caught between the wall and the wheelchair in the confined space of our bathroom which was designed long before the Americans with Disabilities Act was ever dreamed of. It is in just those moments, after I've determined that Steven is in no immediate danger, and I have done my best to at least cushion the bony parts of his body, that I think of Allen.

Somehow, miraculously it seems to me, Allen is usually available when I need his help. Despite a busy travel schedule, he's at home more often than not when I call.

I've come to think of Allen as my white knight who comes over at a moment's notice and with a few deft strokes manages to pick Steven up and right him in his wheelchair. There's no way that I can do it by myself. I've tried. At 5'1" and 109 lbs., I just don't have the strength or the leverage. It's such a comfort knowing that Allen lives across the street and is so willing to literally lend a hand. Everybody, or at least every caregiver, needs an Allen – someone to call on for immediate assistance in times of crisis.

I'm actually very lucky. If Allen isn't home, or I'm concerned about having called too often, I know I can always turn to Tony who lives next door. Tony isn't quite as tall as Allen, but he is younger and very strong, and most importantly, always so willing to help at a moment's notice.

The other day when Steven had a fever of 102 degrees and was so weak he could barely move his fingers, it was Tony who I called at 6:30AM. He came over in an instant, helped me get Steven out of bed and into his wheelchair so we could drive to the emergency room. He also called that night when he got home from work to find out how things were going.

I recall one Sunday afternoon when Steven had slipped out of his wheelchair during a transfer and neither Allen nor Tony was at home. It seemed we were the only ones at home on that lovely sunny Sunday. Bereft of neighbors (or at least those I felt comfortable enough asking), I called the fire department. If people ask them to get cats out of trees, I surmised, they can surely help lift a man off of the floor. Sure enough, three members of the rescue squad showed up within fifteen minutes. "Any time ma'am" they said with a smile.

I've become very good at asking for help, in putting necessity first and pride last. I've learned that caregiving is more than a one-person job, and that you need to know when something is beyond your capabilities. I've learned how absolutely critical it is to make a conscious effort to put a network of support in place, to have people you can call on in an emergency.

I've also learned it doesn't just happen. It requires an effort and a breaking down of barriers. You have to let people into your life, to tell your story, to let them see your vulnerability as well as your strength.

We didn't know that Allen lived across the street when we bought our house, or that Tony would move in next door a few years ago, but as Steven has become increasingly disabled, we have come to realize how critical it is to establish a core group of people that we can rely on. Every caregiver needs an Allen or a Tony. Every caregiver needs a few people to call on who can respond quickly in an emergency. Across the street or next-door is ideal, but even five or ten minutes away can work.

I've learned that many people do actually want to help. They need to be asked and then told what kind of help they can actually provide, and once they've provided it, they need to be heartily thanked.

We need to let other people into our lives, and perhaps that is the hardest part, to let them see the intimate difficulties with which we deal. But once we do, life isn't quite so scary anymore, and we don't feel so alone. For a caregiver, or at least for this one, that is very, very important. My wish for you is this – that you find the courage and the strength to reach out for help and find an Allen or a Tony to respond.

REFERENCE

Article was sourced from the Caregiver Action Network:
<http://www.caregiveraction.org/profiles/too/asking-for-help/>

Question and Answer

Question: I am caring for my mother from a distance, how can I keep up with her medical care when I can't be there for everything? I don't know where to start.



Healthcare experts recommend that you start by learning as much as you can about your parent's illness, its likely course, and current treatments. This information will be essential as you help your parent and the primary caregiver cope with day-to-day concerns, make decisions, and plan for the future. You can do this by discussing your mom's diagnosis with your own healthcare provider or gathering reliable health information. Contacting a government agency or visiting its website is a good way to find information you can trust.

When you visit your parent, consider going along on a doctor's appointment—first check that your parent does not mind having you there.

You must have your parent's permission to have any conversation with his or her doctor or to discuss healthcare bills with their health insurance provider. Ask your parent to complete a release form that allows the doctor to discuss his or her medical care with you. Be sure the release is up-to-date and that there's a copy in your parent's medical records, in addition to keeping a backup copy for your files.

Some long-distance caregivers say that making a separate appointment with a doctor allows them to seek

more detailed information and answers to questions.

You could also see if the doctor will agree to provide email or telephone updates to you or other family members who live out of town.

FIND OUT MORE

For more questions and answers regarding caregiving from a distance, please visit:

<http://www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving/things>

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