



# Caring for the Caregiver

Fall 2015



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## Mobilizing Action: Family Caregivers in Canada

Source: [www.ccc-cccan.ca](http://www.ccc-cccan.ca)

The goal of *Mobilizing Action* is to develop a concrete action plan that will address the physical, psychosocial and financial needs of family caregivers. The two year pan-Canadian project builds on the findings from a number of influential events: the 2011 Canadian Caregiver Strategy, the 2013 Action Table on Family Caregivers and the 2013 Way Forward Caregiver Consultations. A success of this project will bring us closer to a Canada that recognizes, respects and values the integral role of family caregivers.

The project will move discussion into action. By bringing together a broad range of stakeholders with diverse perspectives and expertise, *Mobilizing Action* will identify actions to support family



caregivers and gain commitment from stakeholders to:

- Enhance awareness of caregiver needs and facilitate their voice in care provision and the health care system.
- Improve access to caregiver support services and patient care resources.
- Alleviate the financial burden placed on family caregivers.
- Create flexible workplaces that recognize caregiving obligations.

To learn more about this project, please download the Mobilizing Action Plan here: <http://www.ccc-ccan.ca/media.php?mid=463>

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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 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](mailto:emily.knight@mssociety.ca)

**MS** PEER SUPPORT PROGRAM

**You are not alone in living with multiple sclerosis.**

I need someone to talk to about my MS

I have some questions and I want to connect with someone who's been there

No one understands what I'm going through

The MS Society of Canada is pleased to offer a confidential peer support program to connect you with trained volunteers who also live with MS.

For more information, contact [peersupportprogram@mssociety.ca](mailto:peersupportprogram@mssociety.ca) 1-800-268-7582 x3149

**MS** Multiple Sclerosis Society of Canada

## MS Nationwide Peer Support Program

The MS Society is pleased to offer a telephone/internet peer support program for individuals living with MS. In addition to the evidence based information and support that individuals can already receive from the MS Society, this program will allow an individual to be connected with someone who has had a similar experience - someone who has "been there" by matching trained volunteers with peers who approach the MS Society looking for support. Volunteers from across Canada are provided with extensive training to ensure they have the skills to provide support. This program is confidential and will be flexible so that support can be provided over the phone/skype at a time that works best for the volunteer and the peer.

### How does it work?

- Contact the MS Society of Canada, Peer Support Program at [peersupportprogram@mssociety.ca](mailto:peersupportprogram@mssociety.ca) or 1-800-268-7582 x3149 to request more information or an application

- You will fill out an application and have a conversation with the program coordinator to ensure we can properly match you with a volunteer
- Once a volunteer is secured, you will be notified by the program coordinator and the volunteer will contact you. Together you will decide on the frequency of communication – some people want to chat just a few times and others maintain an ongoing connection. The MS Society will monitor matches up to 6 months

### Want to volunteer with the MS Peer Support Program?

The MS Peer Support Program invites applications from interested volunteers who have been living MS or an allied disease for 2 years or longer. We are looking for individuals who are at a place in their own experience where they feel they can effectively support others.

Please note that given potential interest and the need to ensure diversity in the volunteer pool, not all applications will result in acceptance to the program at this time.

We are looking for volunteers who meet the following criteria:

- Must be 18 years or older and diagnosed with MS (or an allied disease) for a minimum of 2 years;
- Be at a point in your journey where you can provide support to others;
- Sign volunteer and confidentiality agreements;
- Submit documents for a criminal records check before starting as a volunteer
- Be available to participate in online volunteer training
- Agree to a one year minimum commitment to the program

### FOR MORE INFORMATION

For more information, please contact [peersupportprogram@mssociety.ca](mailto:peersupportprogram@mssociety.ca) or 1-800-268-7582 x3149

# Caregiver Webinar: Taking Care of Yourself through the Ups and Downs of Caregiving

Caregivers play a major role in providing care to family members with neurological health conditions such as Alzheimer's disease and other forms of dementia, Parkinson's disease and Multiple Sclerosis. While many wouldn't have it any other way, it is important that caregivers focus on their own needs as well, ensuring a better quality of life for themselves and their diagnosed family member.

On **Thursday, December 10th at 6:00 PM EST** the Alzheimer Society of Canada, Multiple Sclerosis Society of Canada and Parkinson's Society Canada are proudly co-hosting: ***Taking Care of Yourself through the Ups and Downs of Caregiving***, a webinar event that will provide an opportunity to learn about the various stages of caregiving, the emotional ups and downs that can come with each stage and tips for managing stress and staying well.

For more information and to register for this event, please visit: [tinyurl.com/caregiverevent](http://tinyurl.com/caregiverevent)

The Parkinson Society of Canada, Multiple Sclerosis Society of Canada and Alzheimer Society of Canada gratefully acknowledge the support of Biogen who provided an unrestricted education grant for this webinar.



Alzheimer Society



## FOR MORE INFORMATION

For any questions or for more information about the event, please call 1-800-267-7582 x 3149



## Elizz: Caregiver Helpline

Source: <https://www.saintelizabeth.com/Caring-for-Family/Health-Resources/Ask-Elizabeth.aspx>

*Elizz* offers a phone service for caregivers who are looking for support and don't know where to turn. Whether you need information on helping Dad live independently, getting Mom to doctors' appointments, arranging for a volunteer or what's worrying you about your sick sister, you can talk to our health professionals for the personalized support you need.

Call 1-855-Ask-Eliz (275-3549) or chat online for free, trusted

information and support on caring for others.

*Ask Elizabeth* is available during business hours from Monday to Friday, 8:30am - 4:30pm ET.

Some questions that they have answered:

- "I am needing help with caring for my dad - where can I turn?"
- "My sister is really struggling with coping at home on her own - is there someone she can talk to?"

- "I can't take any more time off work to care for my mom - is there anyone who can help me?"

## FOR MORE INFORMATION

To chat online and for more caregiver services and resources, please visit: <https://elizz.com/>

# Health NGOs endorse premier think tank's roadmap for economic integration of Canadians with serious illness

Source: <http://bit.ly/1JB1zvG>

The Multiple Sclerosis Society of Canada (MS Society) and Canadian Caregiver Coalition are pleased with the recommendations in the Institute for Research on Public Policy (IRPP)'s report, titled "Leaving Some Behind: What Happens When Workers Get Sick." This report highlights the need for a fundamental renewal of Canada's income, disability and employment support system and calls on the federal government, and roundtable participants to champion the renewal. This report was based on a sponsored discussion by the MS Society, Canadian Cancer Society and Canadian Caregiver Coalition, on the burden and household impact of serious illness in Canada which included 33 participants from academia, think tanks, government, employers, and private insurance along with 7 health NGO's. The meeting took place this past June in Ottawa and was convened by the Institute for Research on Public Policy

"The burdens faced by Canadians with serious illness and their loved ones need to matter to governments. This report is the first major effort to quantify the issue of employable, ill Canadians being excluded from the labour market by public policy," says Neil Pierce, National Vice President, Government Relations, MS Society of Canada. "It speaks to the impacts and high cost in the billions to Canadian households, governments, and employers. And perhaps more importantly, this report's recommendations show a

constructive way out of this predicament. It's life-changing."

"Key issues are outlined in this report such as the exhaustion of short-term benefits without access to longer-term supports and poor coordination among public programs, which echo what people living with multiple sclerosis have told us about their interaction with support systems when they have needed them," says Sylvia Leonard, Vice President, Talent, Programs and Services, MS Society of Canada.

Containing both long-term directions and immediate reforms, the report calls on the federal government to act as a champion for these identified and necessary improvements. Reforms include improving the coordination of basic definitions and program parameters across the disability support system and enhancing the breadth and quality of disability insurance coverage within the labour market. The federal government can extend the duration of EI benefits and create a flexible work-sharing program, so that a person can reduce work hours while receiving EI income. Additionally, it can create a system for the expert dissemination of information and hands-on support to employers on roles, best practices and resources when an employee is diagnosed or have to care for someone with an illness and may require time away or accommodations so they can continue to work.

"For family caregivers this report acknowledges that, just like those who are sick, job protection, flexible work arrangements and income replacement while on leave are critical for helping them balance their work and care responsibilities," says Nadine Henningsen, President, Canadian Caregiver Coalition.

The sponsor-NGOs and nearly 90 partner organizations will work closely with the federal government and roundtable participants to ensure no one who has a serious illness or disability, chronic or episodic, who needs supports is left behind.

## FOR MORE INFORMATION

For more details and to download the full report, please visit:  
<http://irpp.org/research-studies/report-2015-09-03/>



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Research on  
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recherche  
en politiques  
publiques*

## Thanks for Electing to Fight!

Thank-you for joining thousands of Canadians who chose to fight in this election. With your participation over 14,000 letters were sent to candidates all across this country asking for their support in the fight to #endMS.

Thanks to our united voice, our new MPs from coast to coast know what we need:

- More flexible employment programs to help people with MS keep working
- Improved income security programs that are accessible to people affected by MS
- Increased investment to accelerate research on innovative and effective therapies for progressive MS

As you know, the fight does not end here. We have raised awareness that we are the country with the highest rates of MS. Now we need to continue our efforts by engaging with the newly elected MPs in every constituency across Canada.



Try to meet with your MP in person and ask them to champion improved job and income security for people living with MS. They should press the new government to follow the recommendations outlined in this campaign and highlighted in the recent report from the Institute for Research on Public Policy "**Leaving Some Behind: What Happens when Workers Get Sick**".

Also ask them to support stepped up research investments for progressive MS. And let us know what you learn by emailing us at [advocacy-support@mssociety.ca](mailto:advocacy-support@mssociety.ca)

### FOR MORE INFORMATION

To read more about the Leaving Some Behind: What Happens when Workers Get Sick report, please visit: <http://irpp.org/research-studies/report-2015-09-03/>

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