Caring for the Caregiver

Spring 2015

Multiple
Sclerosis
Society of
Canada

MS My Story Youth Videos

The MS Society is pleased to announce the release of an exciting project supporting youth affected by MS! *MS My Story* is a series of 18 videos featuring personal stories, feelings and experiences of young people living with or affected by MS.

One video features Noah. His mom has MS and he provides support to her by taking care of things around the house. Click here to watch Noah's story.

This video project is youth volunteer driven. It is made possible by a generous sponsor and by people inspired by the idea that no young person affected by MS should feel as if they are alone in their struggle. These videos shed light on some areas of being affected by MS that are not always discussed like dating, 'going public', and feeling the burden of providing care.

Young people are very much directly affected by MS and by sharing their stories, they are standing up and taking action. We encourage people to find support in these videos and hopefully viewers will share this project on social media (#msmystory) and share their stories (written or video) in return!

We thank the estate and family of Stella Shein for making this project possible.

Noah getting ready to film his portion of the MS My Story videos.

MS MY STORY

IN THIS ISSUE

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

Alzheimer Society, MS Society of Canada & Parkinson Society Canada Collaborate on Caregiver Project

As health charities supporting individuals with neurological conditions, the Alzheimer Society, the Multiple Sclerosis Society of Canada, and Parkinson Society Canada have common aims to serve and support individuals in our communities. A key stakeholder is the caregiver, who provides support to a family member, a friend or a person living with these respective diseases. We recognize that there are common topics which appeal to many caregivers in the broader disease community.

That's why our three organizations have partnered to offer online education initiatives to meet your common needs.

We are conducting a short survey to identify what information and topics are currently of interest to caregivers who provide support to people living with Alzheimer's disease or other dementias, Multiple Sclerosis, Parkinson's disease, or other related neurological diseases.

To complete the survey please visit the following link:

https://www.surveymonkey.com/s/3FWQXMN

The survey should take no longer than **10 minutes**, and will be open until **April 30th, 2015**. The information collected will determine specific topics for upcoming online education sessions (webinars), as well as additional projects and resources. We value your voice and we thank you in advance for your time and participation.

The Family Caregivers' Network Society

By: Family Caregivers' Network Society

The Family Caregivers' Network Society (FCNS) is a registered charitable organization in BC whose mission is to inform, support and educate to improve quality of life for family caregivers. The society provides leadership to strengthen the voice of all family caregivers and promotes the significance of the family caregiver role.

Currently, FCNS is taking a strong leadership role to increase the visibility of family caregivers and the vital and increasing role they play in health care. With funding from the BC Ministry of Health Patients as Partners initiative, they have been able to scale up their operations with the Provincial Family Caregiver Program.

The 3 pillars of the BC provincial program include:

A Resource Center for Family Caregivers

A family caregiver anywhere in BC can find 1-1 support for a variety of issues including emotional support, help navigating the system and referrals via a toll-free line, Skype or MSN chat. FCNS is working on expanding and improving the online portion of the Resource Center, offering information 24/7 - recorded educational webinars, articles, links to BC resources, upcoming events and a blog feature. FCNS leads the BC Family Caregiver Week annual awareness campaign (this year is May 4-10) in partnership with other organizations.

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Education for Family Caregivers and Health Professionals

Education is an important part of the program, focusing on both family caregivers and health professionals. Webinar (or phone-only) sessions focus on practical solutions to the many issues that caregivers face. Health professionals will be able to learn more about these issues and gain ideas for including and supporting family caregivers in their work.

Caregiver Engagement & Health Sector Collaboration

The first ever Provincial Caregiver Collaborative Action Roundtable was held on February 27, 2015 with over 50 organizations and key stakeholders. This inspiring day of brainstorming and action planning focused on gaining a common understanding of the current state of caregiver support; enhancing connections among service providers; generating concrete ideas and action to close gaps and avoid duplication; and maximizing our collective strengths to improve recognition, support and education for family caregivers.

FCNS is representing family caregivers at regional and provincial tables, including the Patients as Partner Provincial Committee, and is creating a pool of family caregivers for health system engagement efforts across the province. They are also partners in the Canadian Caregiver Coalition and are very pleased to be working together with the MS Society of Canada and many other organizations on the pan-Canadian Family Caregivers: Mobilizing Action initiative.

FOR MORE INFORMATION

For more information or to get actively involved in collaborative action, please contact us at:
caregiversupport@fcns.ca

Education & Resource Center:
www.familycaregiversnetwork.org

National Survey on Balancing Work, Family and Caregiving

By: Linda Druxbury, Carleton University

The National Survey on Balancing Work, Family and Caregiving is looking for participants who are working and caregiving at the same time. The goal of this survey is to increase awareness at both the public policy and employer level of the challenges faced by those combining work, caregiving and perhaps childcare. The study also seeks to identify differences in caregiving challenges faced by employed caregivers caring for someone with various forms of dementia versus those caring for relatives with chronic non-dementia conditions.

To participate in the survey go to:

http://sprott.carleton.ca/2015-caregiver-study

All of your responses are anonymous and it takes 45 to 60 minutes to complete the survey.

This study is funded by the Canadian Institute for Health Research (CIHR) and is part of the Canadian Consortium on Neurodegeneration in Aging. It has been reviewed & cleared by the Carleton University Research Ethics Board (613-520-2517; ethics@carleton.ca)

FOR MORE INFORMATION

Any Questions? Please contact:

Linda Druxbury PhD at:
linda_druxbury@carleton.ca

Maggie Stevenson PhD at:
margaret_stevenson@carleton.ca

Or visit:
http://sprott.carleton.ca/2015-caregiver-study

Join us for the 2015 MS Walk!

By: Andrea Mears

With the MS Walk season quickly approaching, I wanted to share a little bit about my walk experience last year! My name is Andrea and I'm 24 years old. After being diagnosed with MS in December of 2013, I decided to create a team for the MS Walk so my friends and family could come together to support the MS Society. Being diagnosed with MS has changed the way I value things in life, specifically my health and wellness. There are difficulties I face on a daily basis that may not be visible to others. Despite the negative impacts MS has on my life, it has taught me about personal strength and resilience the way no other experience has before. My experience with the MS walk in 2014 was a really positive one although I was hesitant about participating, since the reality of my MS diagnosis was still fresh.

Overall, it was a great experience where I was surrounded by family and friends, and a whole new community of supportive people. Participation in the MS walk has been a fundamental factor in bringing optimism to my life. When I was first diagnosed all I felt was confusion, hopelessness and fear. By becoming a part of the MS Society and participating in the walk, it made me realize that I am not alone and I really am surrounded by so much hope and support. To me, hope means staying positive even when you feel like all forces are against you. Throughout my own diagnosis, being hopeful and thinking positive has been paramount to my health and overall happiness. With so much breakthrough research taking place, there really is hope for people living with MS.

Andrea with her friends and family at the 2014 Mandarin MS Walk in Toronto

One of the greatest benefits of doing the walk as a team is getting to see that you are not alone and that you are walking with a community of people who all want to end MS. Seeing all my family and friends come together to support myself and the MS Society really means the world. Last year my team fundraised over $12,000 for the MS walk, and this year we are hoping to beat my record and fundraise over $15,000! I'm working hard to keep in contact and motivate everyone via social media. After last year, that's one piece of advice for fundraising – take advantage of social media! This year I am creating a team called Chicks with Kicks to EndMS, with 2 of my friends who also have MS – check out our team page here! The 3 of us are bringing together all of our family and friends and we have high hopes for our success in the 2015 walk! Spread the awareness because a cure is in sight!

By coming together at the MS Walk and through your fundraising efforts, we make a tangible and life-changing difference to the 100,000 Canadians living with MS. This is an excellent opportunity to interact with members of the community and other caregivers while supporting a great cause!

FOR MORE INFORMATION

To find out more about MS Walk events near you, or to register for an event, please click here

It's Time to Care for the Caregiver

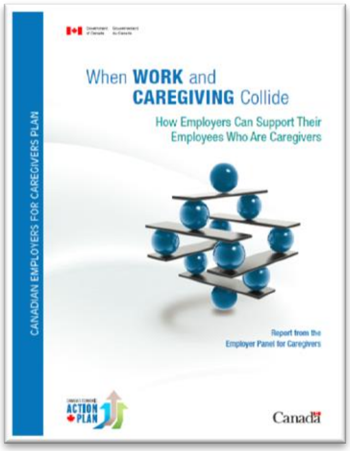
By: Neil Pierce, President of MS Society Alberta and Northwest Territories Division & Vice President Government Relations

I recently heard the struggle of one family through social media, of the immense stress and financial strain they endured when one parent assume the role of full-time caregiver while also working full-time. The impact on the couple's children, who became caregivers themselves, was distressing.

Their story is unfortunately not a unique story. Through our Listening to People Affected by MS initiative, we learned that three out of four caregivers do not have the support they need and that people living with MS worry most about the impact their disease will have on the family.

Thank you for sharing your stories through social media. Please continue to share them on our Facebook page and on Twitter. Your experiences will help the MS Society drive change.

In January, the Honourable Alice Wong, Minister of State (Seniors), announced the release of the Employer Panel for Caregivers' report called When Work and Caregiving Collide – How Employers Can Support their Employees Who Are Caregivers. I would encourage you to read the report and share it with employers across the country.



CANADIAN EMPLOYERS FOR CAREGIVERS PLAN

When WORK and CAREGIVING Collide

How Employers Can Support Their Employees Who Are Caregivers

Report from the Employer Panel for Caregivers

ACTION PLAN

Canada

This report is a great start to raising awareness of caregivers' experiences in the workplace. Many caregivers of people living with MS are still working, like Teresa Fortin whose husband Doug lives with secondary progressive MS.

"She takes time off work to drive me to medical appointments and to be there for my many rounds of treatment. She helps care for me, and I want the government to recognize the vital role she plays in our family…I want better care for my caregiver," Doug says.

While we are pleased to see this recent announcement addressing the needs of caregivers in the workplace, we need the federal government to go further. We need a national caregiver action plan to reduce caregiver burden, improve access to resources, recognize caregivers' vital roles, and create flexible workplace environments and support systems.

We look forward to the federal government addressing these needs and ensuring Canada cares for the caregiver.

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