

Government relations volunteers and staff take the caregiver message to Ottawa

Deanna Groetzinger, MS Society of Canada

The National Government Relations Committee held successful Day on the Hill advocacy meetings with almost 50 Members of Parliament and Senators on October 24 and 25. This is a record number of meetings for this annual event. Key issues discussed with MPs and Senators included the need for better supports for caregivers.

The MS Society representatives pointed out the need for caregiving is increasing, and meeting the needs of caregivers requires a comprehensive approach. Millions of Canadians provide more than 80 percent of essential care to loved ones with chronic illnesses and disabilities. Their contributions save the health care system billions of dollars each year, equivalent to more than \$5 billion of unpaid labour annually.

Unfortunately, caregiving can have negative effects on the health of caregivers themselves and can drastically affect their own financial security since they may have to leave work or forego promotions to care for their loved ones.

During the meetings, MS Society volunteers and staff thanked MPs from all parties for understanding the key role of families in providing ongoing care. For many years, the MS Society asked that spouses be recognized for their vital caregiving roles. The new Family Caregiver Tax Credit which was included in the June 2011 budget expands the criteria for the tax credit to include spouses.

They also pointed out this credit, as well as other credits for people with disabilities and chronic conditions, could be made even more helpful if they were refundable for people with low incomes.

The MS Society is recommending the Government of Canada act on the following to help caregivers:

- Short term: Make existing and future tax credits (e.g., Caregiver Tax Credit, Family Caregiver Tax Credit, Disability Tax Credit) refundable.
- Longer term: The federal government should engage the provinces and territories, organizations that represent caregivers in a dialogue to develop a pan-Canadian caregiver strategy that should include refundable tax credits, employment protection and cognition of caregivers' vital roles.



In Photo: Eugene Paquin and Paula Moon-Wozney, Saskatchewan Division with Andrew Scheer, Speaker of the House of Commons and MP from Saskatchewan

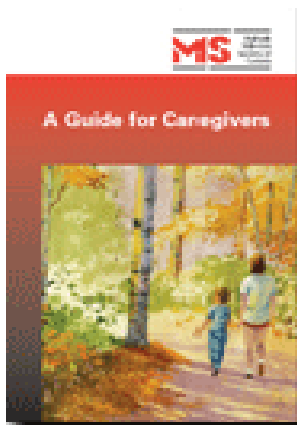
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A Guide for Caregivers



Jennifer Eades, MS Society of Canada

A Guide for Caregivers provides a comprehensive overview of topics related to caring for someone living with MS. Information and practical advice is offered to caregivers from medication administration, finances and life planning and emotional issues, to daily activities such as toileting and dressing. Other helpful MS Society of Canada publications are mentioned throughout the booklet and a resource list containing contact information for government assistance programs and other organizations in support of caregivers is provided.

For more information on this or any other MS Society of Canada publication, please contact your MS Society Division office at 1-800-268-7582.

Top 10 Tips for Caregivers

Guardians Around the Earth, G.A.T.E.



1. Choose to take charge of your life, and don't let your loved one's illness or disability always take center stage
2. Remember to be good to yourself. Love, honour and value yourself. You're doing a very hard job and you deserve some quality time just for you
3. Watch for signs of depression and don't delay in getting professional help when you need it
4. When people offer to help, accept the offer and suggest specific things they can do

5. Educate yourself about your loved one's condition. Information is empowering

6. There's a difference between caring and doing. Be open to new technologies and ideas that promote your loved one's independence and help you do your job easier

7. Trust your instincts. Most of the time they'll lead you in the right direction

8. Grieve for your losses, and then allow yourself to dream new dreams.

9. Stand up for your rights as a caregiver and as a citizen

10. Seek support from other caregivers. There is great strength in knowing that you are not alone.

Share Your Story!

Do you have an inspiring story you would like to share with others?

Submit your caregiver profile to the MS Society today for the chance to be profiled on our National website!

Contact us at abidah.lalani@mssociety.ca for more information.



Caregiving: A Family Affair

Angela Arsenio, The Powerhouse Project

When one person lives with illness, every member of the family is affected. In young families, the person needing care becomes the focus, and children adapt by taking on caregiving tasks. Young Carers are children & youth under 18 years old who provide care for a family member with illness or disability. They may act as the memory for someone with a brain injury or dementia, cook dinner when mom is feeling under the weather, or act as a translator for a parent who can't hear or speak English. Young carers, with the proper supports, become superstars-resilient and compassionate adults in our communities. Without support, young carers can become "overburdened" by their caregiving, which can result in anxiety and stress related conditions, and they are more likely to become adults with addictions and depression. It is important to support caregivers (young and old), in order to ensure happy and healthy children and families.



The Young Carers Initiative (YCI) - Powerhouse Project is a non-profit agency with a mission to promote the well-being of young carers, their families and their community partners. Established in 2008, the Powerhouse Project staff utilizes a holistic approach to assess the needs of the entire family to support families in both the Niagara and Haldimand-Norfolk Regions. The main objectives of all our services are:

- Building resilience in young carers by increasing self-esteem and confidence
- Decrease isolation by assisting in the development of self-care techniques
- Assist in the development of peer relationships
- Provide respite for young carers and their families to decrease the stress and burden which can be associated with caregiving.

Our holistic approach to supporting the families includes programs, special events, one on one home visits and youth advisory meetings bi-monthly in each region. Each season, new programs are offered to our families and include a wide range of activities, from movie nights and homework help to cooking circles and sports activities. We recognize the importance of developing safe strategies to deal with stress, and in response the team has offered scrapbooking, jewelry making, a book club and martial arts classes. The staff involves the young carers in our program development through our advisory committee, where suggested program ideas are incorporated into our offerings in the following quarter. The Powerhouse Project currently serves 297 young carers and their families. Our staff is proud to give young carers a platform to voice their needs and to recognize the care they provide for their family. For more information on our services, please visit our website: www.powerhouseproject.ca

Upcoming Tele-Learning Sessions

January 25, 2012 07:00 PM (EST) (Session offered in English)

How to keep stress from ruining your life

Speaker: Dr. Camillo Zacchia, psychologist, will speak about good stress, and the bad stress which can become a disorder. He will also talk about treatment methods. This will be followed by a question / answer period. This session is reserved for residents of: New Brunswick/Newfoundland/Prince Edward Island/Quebec



To access past tele-learning sessions, download the podcasts [here](#)

Recognizing the Recognition

Sherri Torjman, Caledon Institute of Social Policy

This commentary highlights several measures recently introduced by selected provinces to help recognize the additional health- and disability-related costs that informal caregivers may incur. Unlike the current federal tax provisions, the provincial measures are designed to provide modest financial assistance to lower-income households.

Sometimes governments do the right thing. They recognize a given challenge and introduce measures to address it. Several provinces have taken important steps in recognizing the additional costs associated with informal caregiving. The estimated three million informal caregivers in Canada are unpaid family members and friends who provide substantial assistance and supports to persons with severe disabilities or to the frail elderly. The federal government has in place three tax credits which acknowledge the fact that caregivers may incur additional expenses in respect of their caregiving responsibilities. These are the caregiver tax credit, infirm dependent tax credit and newly-introduced family caregiver tax credit.

The Caledon Institute supports these tax measures but points out a major flaw. As non-refundable credits, they provide no assistance to modest- and low-income households that pay little or no income tax. This weakness can easily be remedied by converting these nonrefundable credits to refundable credits so that all Canadians with disability-related costs receive, regardless of income—some benefit from these tax measures.

Some jurisdictions have heard the message. It is time to recognize their recognition of the problem. Quebec provides a refundable tax credit for caregivers. It is intended to help with expenses incurred in obtaining specialized respite services for the care and supervision of a person with a significant disability. There is a list of eligibility criteria. The care receiver, for example, must have a severe and prolonged impairment in physical or mental functions or must be receiving palliative care. The individual cannot be left without supervision because of the disability. The services must be provided by a person who meets several criteria, including a recognized diploma in health or nursing. Quebec's tax credit for caregivers is worth an annual maximum \$1,560 and is equal to 30 percent of total expenses paid in the year, up to \$5,200. The tax credit that may be claimed is reduced by 3 percent of family income in excess of \$50,000.

Manitoba is also making significant progress on the policy front. The government's last Budget announced a 25 percent increase to the maximum annual primary caregiver tax credit, to \$1,275 from \$1,020 per care recipient. In May 2011, the province also introduced an Act to increase awareness and recognition of Manitoba's informal caregivers. The legislation is part of the Age-Friendly Manitoba Initiative launched in 2008.

Key provisions of the Caregiver Recognition Act include general principles that outline how caregivers should be treated and considered when interacting with health staff and in the workplace. The Act calls for a progress report every two years to evaluate caregiver needs and supports. It establishes a Caregiver Advisory Committee to provide the Minister with information, advice and recommendations.

On the other side of the country, Nova Scotia has in place a Caregiver Benefit (formerly the Caregiver Allowance) that recognizes the vital role of informal caregivers. The program is targeted at low-income care recipients with a high level of impairment as determined by a home care assessment. They must have a net annual income of \$18,785 or less if single, or \$35,570 or less net income if living in a family. Caregivers must be in a regular, ongoing caregiving relationship with the person receiving care, providing 20 or more hours of assistance per week. If the caregiver and the care receiver both qualify for the program, the caregiver is eligible to receive a benefit of \$400 per month.

The federal government has a similar measure for caregivers of children under age 18 with severe disabilities. The Child Disability Benefit is a tax-free payment of up to \$2,504 per year (\$209 per month) for low and modest-families who care for a child under age 18 with a severe and prolonged impairment in physical or mental functions. It is delivered as a monthly supplement to the Canada Child Tax Benefit. These selected measures recognize that modest- and lower-income households can also incur extra costs in respect of their caregiving responsibilities. These programs choose not to direct scarce tax dollars toward the households that least need public assistance.

Of course, the bigger question concerns the overall availability of disability supports – the goods and services that allow people with disabilities and frail elderly individuals to live independently in communities. Access throughout the country varies by jurisdiction, type and severity of condition, age of recipient and household income.

Calling the disjointed and incoherent provincial/territorial systems of disability supports a 'system' is an undeserved complement. But that is another (long) story. Now is the time for deserved compliments – for acknowledging tax measures that take a step forward in providing financial assistance for informal caregivers. Now is the time for recognizing the recognition.

MS Answers - Caregiver Q&A

Have a Question? Send it in.
Visit www.msanswers.ca



Question:

I am 25 years old and provide at least 6 hours of care a day to my mother, I also have a full time job. I am starting to feel really down, and find that I am exhausted all the time. I used to make time for my friends and go to the gym but these days I just don't have the motivation to do either. I have heard about caregiver burn-out. Are depression and fatigue some of the signs and if so what can I do to prevent it getting worse? I don't want to start taking it out on anyone, especially not my mom.

Answer:

Caregiving is a delicate balance between providing safety and comfort to your mother while preserving your own health and quality of life to the fullest extent possible. With a full time job in addition to the six hours of care you provide your mother daily, your life is tipping the scale towards burnout.

If you fail to acknowledge and reduce the chronic stress you are under, the quality of care you can provide will likely deteriorate. As you struggle to cope, your physical and mental health, as well as your job may suffer. You already recognize the toll it is taking on your social life. The depression, fatigue and behavioral changes you described are warning signs that you need to take better care of yourself so that you can continue to provide support for your mother.

Unfortunately burnout can eventually lead to resentment, physical abuse and mental abuse from individuals who never raised a voice or a hand against one another. However, with help this reaction is preventable. Begin by considering all potential resources. Are there siblings, extended family or close friends who might share in your mother's care? Is your mother a member of a church which might be willing to set up a volunteer schedule? Is homecare available? Can your mother afford to hire some additional help? Is there a day centre where your mother can socialize and have some of her personal care needs met? Have you taken advantage of respite care so that you get a break and rejuvenate?

Without knowing your situation I will include questions about your motivation. Does your mother actually need six hours of care daily or is it possible that you give your time out of obligation or "guilt"? Are you dedicated beyond what your own health can sustain? Do you have difficulty asking others to help out because you feel you are the only one who can do the job well?

If none of the questions above help with your particular situation, generate a list of individuals or groups who might better know your situation and be able to provide suggestions or links to helpful resources. Do not shy away from asking for help. You are not alone in this difficult situation. Organizations like the MS Society recognize the plight of the caregiver and are advocating for more resources. Your frustrations are real and your need for help is legitimate. You owe it to yourself and your mother to find a balance in your life that preserves this loving relationship.



Questions, Comments or Suggestions?

Is this newsletter a helpful resource for you? Do you have an interesting topic or suggestion for our next issue? We welcome your questions, comments, and suggestions. Please send your feedback to abidah.lalani@mssociety.ca