

A caregiver tribute

Spring 2013

The MS Society’s Opal Award recognizes caregivers of people with MS who have demonstrated outstanding commitment and caring. Leslie Batten of Fox Trap, Newfoundland and Labrador has lovingly provided care for his wife for over 50 years; he is the deserving recipient of the Atlantic Division’s Opal Award.



"Leslie Batten, recipient of the MS Society Atlantic Division Opal Award, has lovingly provided care for his wife Stella for over 50 years."

When she was just 31 years old, Les’ wife Stella woke up to discover that she couldn’t walk nor see. Stella was taken to the hospital and was soon diagnosed with MS. While Stella was in the hospital, Les took care of their children and continued to work full time. When Stella was discharged, it was nearly Christmas and she came home to a fully decorated house. Les and the kids had put up the tree and made the holiday preparations.

This is just one example of Les’ commitment to caring for Stella. Les is always there to take Stella to doctor’s appointments, do house work, and be Stella’s number one supporter. He makes sure she has an active social life, going with Stella to dances or card games. Les remains committed to supporting Stella in her independence, and to keeping their family life as normal as possible. He retired at age 62 to be home with Stella and continue to give her loving care and support.

Les and Stella remain active with the MS Society’s St. John’s/Mount Pearl Chapter, 50 years after Stella’s diagnosis. This Opal Award recipient is a terrific husband, a great father of three, and a remarkable caregiver. Congratulations Les!

The MS Society congratulates all the Opal Award winners of 2012.

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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 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:
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Listening to People Affected by MS initiative – update

The Listening to People Affected by MS initiative is a multi-pronged evaluation which has the single purpose of hearing from Canadians affected by MS about their quality of life priorities, needs and barriers so that the MS Society of Canada can better inform decisions that relate to our programs, services and advocacy. We have sought your input in a number of ways, including the recent online survey in which over 5000 Canadians affected by MS participated. Several small focus groups are also being conducted (including a caregiver focus group) as well as an environmental scan. All of these elements will help us to further explore aspects of quality of life and MS.

Once the analysis is complete, we will be sharing the results on our website at www.mssociety.ca/listening.



Family caregiving tips: Providing long-distance care

Many people take on the role of designated caregiver for a family member - often an older relative or sibling - while living more than an hour's travel away. Trying to manage a loved one's care from a distance can add to feelings of guilt and anxiety and present many other obstacles. But there are steps you can take to prepare for caregiving emergencies and ease the burden of responsibility.

- **Set up an alarm system for your loved one.** Because of the distance, you won't be able to respond in time to a life-threatening emergency. Subscribing to an electronic alert system will allow your loved one to wear a small device that can be used to summon help immediately.
- **Manage doctor and medical appointments.** Try to schedule all medical appointments together, at a time when you'll be in the area. Make the time to get to know your loved one's doctors and arrange to be kept up-to-date on all medical issues via the phone when you're not in the area. Your relative may need to sign a privacy release to enable their doctors to do this.
- **Investigate local services.** When you're not there, try to find local services that can offer home help services, deliver meals, or provide local transportation for your loved one.
- **Schedule regular communication with your loved one.** A daily email, text message, or quick phone call can let your relative know that they're not forgotten and give you peace of mind.

Source: www.helpguide.org/topics/caregiving.htm

Caregiver news from Manitoba

There is much happening for caregivers living in Manitoba, and we are proud to be part of these exciting times.

Caregiver Recognition Day

The first Tuesday in April is Manitoba's annual Caregiver Recognition Day. This day is part of the Caregiver Recognition Act, which is a recent provincial legislation passed in June 2011. Hosted by the Manitoba Caregiver Coalition in collaboration with the Province of Manitoba, Caregiver Recognition Day is about increasing awareness of the contributions of caregivers. Manitoba is the only jurisdiction in Canada to have a legislated recognition day for caregivers, and also the only province that offers a refundable caregiver tax credit. At this year's event on April 2, we saw the launch of CareAware Manitoba. CareAware Manitoba is a new and innovative initiative developed to raise awareness of Manitobans who provide unpaid care and support to family members and friends through education, information and inspiration.



Manitoba Caregiver Coalition

The MS Society in Manitoba is pleased to be represented on the steering committee of the Manitoba Caregiver Coalition (MCC). The MCC is a group of individuals and organizations that partner with caregivers, service providers, policy makers and other stakeholders to identify and respond to the needs of caregivers in Manitoba. The vision of the Manitoba Caregiver Coalition is a Manitoba that recognizes and respects the integral role of family caregivers in society, and supports this role with the understanding that it is not a substitute for public responsibility in health and social care.

Provincial caregiver advisory committee

As part of the Caregiver Recognition Act, a caregiver advisory committee has been constituted to provide the minister of healthy living, seniors and consumer affairs with information, advice and recommendations. The MS Society in Manitoba is proud to be represented on the committee and is working to bring caregiver issues in the province to the forefront.

Caregiving study results

In 2011-2012, a national study of work-life balance in Canada was conducted. Just over 25,000 employed Canadians participated in the study, which focused on the work-life experiences of employed caregivers. To read the executive summary and conclusions/implications, visit <http://sprott.carleton.co/2013/carleton-releases-national-study-on-the-work-life-experiences-of-employed-caregivers/> (in English only).

Caregiving traps to avoid -Diane Adam,client services coordinator

Reprinted from *MS Quebec*

I am not a caregiver; I am an outsider whose job it is to offer support services to people with multiple sclerosis, their families and caregivers. My goal is to provide guidance so that you can find and maintain a balance between your needs and those of the person you are caring for.

Through various conversations and activities, I have become more aware of the importance of avoiding certain traps in a caregiving relationship so that each partner benefits and preserves their identity.

The overprotection trap: After an MS diagnosis and the possible progression of the disease, the caregiver instinctively tries to figure out how to deal with the care recipient. They ask themselves “How can I help? What should I do?” The caregiver brings his or her own personality and outlook to the situation. The caregiver rallies to the cause, considers the situation and decides to take charge. In any such undertaking, there is a risk of overprotection. By overprotecting the other person, the caregiver infringes on the autonomy of the person with MS and may cause overdependence. Even a person with major limitations and support requirements needs to remain as autonomous as possible. Caregivers who enable the other person to keep the autonomy they have left are less likely to develop a feeling of being all-powerful (an issue for some) or to wear themselves out (a problem for others).

The merger trap: In any caregiver/care recipient relationship, there is a risk of merging. The merger between two people happens when there are no longer any boundaries between them. They become one. The danger in this type of relationship is losing the necessary distance that enables the caregiver to provide enlightened support. By remaining separate, the caregiver can provide the care recipient with objective, lucid security. Furthermore, the care recipient is less likely to feel smothered by concern.

You need to trust the person you are caring for and listen to him/her. By breaking the cycle of overprotection and merger, the caregiver and the care recipient will both grow.

Caregiver updates from Quebec

The government of Quebec is now offering a new toll-free support line for caregivers:

1-855-8LAPPUI. The service is only available in French. For more information, please visit <http://www.lappui.org/lappui-national/nouvelles/lancement-de-la-ligne-info-aidant>

Upcoming caregiver support teleconference (in French only)



May 14, 2013 – My Support System. Caregivers need a support network. This telephone meeting will identify various resources to help caregivers feel less alone and more confident in their caregiving role. Guest speaker: Johanne Lavallée, social worker. To register, call the Care-ring Voice Network Info Line at 1 866 396-2433.

We Care Sponsors Canada Cares' One Wish Award on National Caregiver Day

Do you know a caregiver who deserves special recognition? In a unique initiative, Canadians are being asked to nominate a family member, friend or professional caregiver for a "best caregiver" award and explain what they would do with a \$10,000 prize.

The new **Canada Cares Caregiver Awards** were launched in celebration of National Caregiver Day, which took place on April 5.

It's all part of an innovative program called Canada Cares that supports and salutes caregivers of all kinds across the country. The awards, which will be presented at both a regional and national level, will recognize two exceptional caregivers – one family or friend and one health care professional – in western, Atlantic and northern Canada, Ontario and Quebec. Two national winners will be chosen from selected regional candidates.

Caregiver Award winners will be selected by a national committee of caregivers and health professional organizations, according to such criteria as caregiver strength, commitment to care, community involvement and compassion.



One deserving nominee will also be selected to win the Canada Cares One Wish Award, worth \$10,000, sponsored by We Care Home Health Services. The Canada Cares One Wish Award will be evaluated on the strength of the caregiver's commitment to care, the creativity of the response regarding how the \$10,000 would be used, and the level of need.

"The number of caregivers in Canada is rapidly increasing, with current estimates pegged at over five million," said Caroline Tapp-McDougall, chair of Canada Cares. "It's time to support and recognize caregivers from coast to coast for their tireless, selfless efforts to help improve the lives of others."

Nominations, which can be submitted online, by mail or by video, will be accepted until September 30, with winners announced in November. For details on how to nominate a caregiver, visit www.canadacares.org.

New Caregiving Online Resource

In recognition of National Caregiver Day, a new online resource, "Caring for Family" was launched to provide family caregivers with information and support. An estimated one in four Canadians is a caregiver while in many cases also raising a family of their own. The site features a blog, newsletters, resources, podcasts and an 'ask the expert' section. Please visit www.saintelizabeth.com/family for more information. This website is currently available in English only.

MS Answers: Caregiver Q&A

Question:

My wife has MS and I am her caregiver. Before she required assistance with toileting and bathing, we maintained a healthy sex life. Now that I help her with these daily activities, I feel the romance has gone. Do you have any suggestions as to how we can make this situation work so that she gets the care required but at the same time, the romance in our marriage does not suffer?

Answer:

Playing the dual role of caregiver and intimate partner is difficult to manage for most partners. It is hard to switch off the vision of providing personal bodily care and to view that partner as a sexual being. You are likely fatigued by the additional duties you provide. Your wife may be feeling less sexual and suffering from increased discomfort and fatigue. With fatigue comes less patience and tolerance from both partners. The fact that you are asking this question means that you are making an important effort to avoid the negative cycle that can erode a supportive, loving relationship.

Intimacy is an important component of a relationship. Couples who maintain active sexual relations succeed by doing some of the following:

1. If at all possible and if your wife agrees, hire someone to provide her personal care.
2. Communicate to one another about the best time for intimacy. This may limit spontaneity but it is difficult to enjoy each other if one partner is exhausted.
3. Separate out the time you make for intimacy. Complete whatever personal care chores you can at a different time of the day.
4. Keep medical equipment to a minimum and in an isolated section of the bedroom.
5. Revive the romantic “set-up” to the bedroom that worked when you were first married (i.e., a lit candle, dimmed lights, soft music).
6. Intimacy is more than sexual intercourse. Keep the romance alive by being affectionate during the day.
7. Nurture a loving attitude that allows for new definitions of romance and beauty and that accepts inconveniences and interruptions. If you had children, there were some similar challenges with a baby in the house!



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