

# Does supporting someone with MS make you a caregiver?

By Avril Roberts

It didn't dawn on Barbara Davies that she was a caregiver until two years ago, when her husband Tony's needs reached the stage where she had to give up her job. Temping with the local school board used to give Barbara a break from her care duties at home. "It was nice to have a change." Now that option was gone. This was 11 years after Tony's MS diagnosis had been confirmed with MRI.

Caregiver surveys are finding that most people who do caregiving don't really think of themselves as being caregivers unless the person they are caring for is very, very ill. Most take up to 10 years to recognize their role.

Why is this? Caregivers offer a variety of reasons.

"To me, the word 'caregiver' meant somebody who gets paid," says Barbara, 63. "I married for better or for worse. I see myself as Tony's wife and, of course, I provide care, but I used to think, caregiver... we have none."

Laura Dutton, 24, has similar views. "It's not a job. It's just what we do." Laura and her sister were only eight and 10 years old when their mother was diagnosed with MS. She remembers being scared, at first, and asking the nurse if her mother was going to die. By the time she was 11, she was taking caregiving in her stride.

"I was kind of proud of the fact that I was helping out at home, that I could do something. I didn't see it as a hindrance. It was just what we did as a family."

Laura is also concerned about not hurting her mother's feelings. "I don't want her to feel burdened by the fact that she needs some extra help. I want her to have her independence but I still want to help her in any way possible. I think the word caregiver



just makes it sound more official. It sounds like we're asking for help."

Terry Corcoran, 69, and his wife Maggie, 61, have been married for 37 years. Her MS was diagnosed 15 years ago. Describing their relationship, Terry says, "I never really thought of myself as a caregiver. What we did, from the day Maggie was diagnosed, is we did everything jointly. It wasn't a case of one giving care and

the other accepting it."

This power imbalance implied in the word 'caregiver' may be at the heart of people's reluctance to identify themselves as caregivers and may explain why they don't really accept the title of caregiver until the balance in the relationship has shifted so dramatically that it can no longer be ignored.

Jon Temme, the MS Society of Canada's National Vice-President, Client Services suggests, "To recognize oneself as a caregiver above and beyond other roles, such as spouse, parent, or child, is often a huge shift for an individual."

Yet, the findings of an MS Society of Canada caregiver project suggest that identifying oneself as a caregiver can be a catalyst for positive change.

The MS Society's Family Caregiver Pilot Project ran from 2000 to 2005. A key part of the project provided up to \$300 each, to more than 800 unpaid, family caregivers of people with MS, to choose the types of experiences and activities they felt would give them a break from caregiving. The project was funded by The J.W. McConnell Family Foundation, RBC Foundation and other donors.

"It was not intended to make people better caregivers," says Jon Temme. "It

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was to help them as individuals, knowing that they had this extra role of caregiver to fill.

“One of the unanticipated positive outcomes was that people said it was the first time they had really been given the opportunity or, in some cases, been forced to think about themselves as being more than just a spouse doing it out of love. Many realized ‘I have a particular role I’m fulfilling that has additional challenges. Sometimes it burdens me. Sometimes it’s a joy. But it’s different from being a spouse’.”

With this new-found awareness, people felt free to discover what they needed and what they deserved as someone in a caregiving role.

If you are a family member or friend providing care on a regular basis to someone with MS, realizing and acknowledging that you are a caregiver could be the first steps towards making positive changes to improve your life and protect your health and well-being no matter what level of care you provide.

## How do you live a healthy and happy life?

Caring for someone you love – someone who has multiple sclerosis – can be a big investment of time and energy, but one that so many people make willingly, without a second thought. It is actually harder for people to invest in self-care: things that recharge

their batteries and make them feel good. As the stories that follow show, there is no single solution to self-care. The people who shared their stories with us each found a form of self-care that fits their needs and lifestyles.

Ann Godbold

There aren’t nearly enough hours in the day for Ann Godbold. Her husband Brian, 58, who was diagnosed with MS a month before they married in 1970, has complex caregiving needs. He has weakness on his left side and limited use of his right hand. He uses a wheelchair. He has trouble swallowing.

Before leaving for work, Ann prepares breakfast and cooks lunch. While she is at work, a home care attendant helps Brian with physiotherapy, shaving and eating. Each Wednesday, a friend visits and reads to Brian who has double vision. Conversation can be exhausting because of Brian’s difficulty projecting his voice. At the end of her nine-to-five workday, Ann makes a light supper and by 10 o’clock she prepares Brian for bed.

Brian’s good nature and even temper are a godsend. Ann says he has a more positive outlook than she would have if she were in his place.

Buying a wheelchair-accessible van was a priority. “We gave up other choices for it and I think it is one of the key things keeping Brian out in society.” On weekends,

they visit the farmer’s market in Carp, Ontario or drive to downtown Ottawa where they sometimes sit in the tourist areas and watch the passing parade. They have flown to England to visit her relatives and, last summer, Ann arranged for Brian to go wheelchair paragliding.

Ann pursues her own interests, participating in an

### Quiz: Are you a caregiver?

For some people, it can take years to realize that they have become a caregiver in addition to their “regular” role as a spouse, partner, parent or child of someone with MS. But often people do not seek support or begin investing in self-care until they realize how caring for someone with MS is also affecting them. This quiz is designed to help you answer the question “Am I a caregiver?”

If you answer yes to at least 3 out of the following 6 questions, you may be a caregiver.

1. Do you have responsibility for the physical care of someone with MS?
2. Do you attend medical appointments with someone close to you who has MS?
3. Do you sometimes feel overwhelmed by your responsibilities?
4. Do you help a person with MS manage and/or administer their medication?
5. Do you feel that you have less time for yourself because of the needs of others?
6. Do you carry out your responsibilities with love but feel that you are missing out in other areas of your life?

Irish Ceilidh and a knitting guild. In her quiet time, you might find her sewing, reading, or gardening.

Maria Vink

For the past 13 years, Maria Vink, 69, has been caring for her 37-year-old daughter Cynthia at home. It hasn't been easy. In addition to causing problems with balance and fatigue, MS impairs Cynthia's memory and judgment. In the early years, she would lash out in uncontrollable rage. She is calmer now, thanks to psychiatric help and medication. Maria's caregiving includes managing Cynthia's finances and daily schedule, "keeping track of her outings because she gets very confused."

Maria finds strength in her faith, attending Mass every day, saying the Rosary and prayers with Cynthia in the evenings, "especially when she was so angry," and seeking solace in the chapel on those days when life becomes unbearable at home.

Since retiring six years ago, Maria makes jams – 35 different kinds – and crafts and sells them in retirement homes and hospitals. Twice a week, she drives Cynthia to a recreation centre, where they both enjoy doing water exercises in the pool. She bought a car so that Cynthia wouldn't have to be at the mercy of the public wheelchair transit service.

Once, Maria used to holiday on her own, now she and Cynthia travel together. They visit the shrine in

## Resources

### **Taking Care: A Travel Guide for your MS Caregiver Journey**

[www.mssociety.ca/en/help/caregiverguide.htm](http://www.mssociety.ca/en/help/caregiverguide.htm)

This guide was developed by caregivers for caregivers. It provides information and suggestions on the topics of caregiver self-care and accessing information and community resources. A resource list of related books and websites is included.

### **Caregiver Programs and Support Groups**

Contact the Ontario Division or your nearest chapter for information on caregiver programs in your area.

Ontario Division  
(416) 922-6065  
1-800-268-7582  
[info.ontario@mssociety.ca](mailto:info.ontario@mssociety.ca)

Cap-de-la-Madelaine, QC, each September, and fit in day trips and at least one major vacation a year. So far, they have gone on an all-women's retreat in Hull, QC, a pilgrimage in Mexico, stayed at a resort in the Dominican Republic and plan a cruise this year to the Mexican Riviera, if Cynthia's health allows. Wheelchair accessibility has become less of a barrier, over the years.

Laura Dutton

It took a mishap for the Dutton family of Burlington

to consider bringing in outside help. Laura's mother, Barbara, fell one day and broke her ankle. Laura's father was at school, teaching. She and her sister were away at university. For the first time, the family realized that perhaps it wasn't safe for Barbara to be at home on her own. They looked into home care as a short-term solution. Now it's ongoing. "As the years have gone by, we have begun to realize that we need a break sometimes to do what

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Laura Dutton and her mother, Barbara

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we need to do. Someone else can handle the routine things like housework.”

Laura appreciates it when her mother’s friends take her out to lunch, giving her recently-retired father time for himself.

Her advice to young people whose parents have been diagnosed with MS is to be open, talk about it with each other, have activities you enjoy with your friends and volunteer with the MS Society. “Volunteering made a big difference. I felt I was helping someone else in a similar situation, even if I couldn’t help Mom in a certain way.”

For young families, where a parent has MS, she recommends participation in the Super Cities WALKs for MS as a fun way for kids to meet other children who can relate to their experiences and for families to expand their network of support.

Barbara Davies

Barbara Davies looks forward to dinner at a restaurant one evening each month. That’s when her caregiver support group meets. When her sister-in-law first suggested it, she resisted: “I’m not one to sit in a circle and commiserate. I have wonderful friends and neighbours. I don’t need this.” A caregiver weekend hosted by her Ottawa MS Society chapter changed her mind.

Now, Barbara considers the support group a great way to get out of the house, to get out of the environment.

It’s a place to exchange ideas and share information about equipment and vendors, first-hand. Also, to just relax and chat about things that have nothing to do with MS. “It’s a meeting amongst friends with the same interests.”

A brush with cancer last fall has made Barbara more aware of the need to look after her own health. She has decided to keep her father’s condo in Germany as a sanctuary. She had planned to sell it after winding down his estate. Now, it will be a place she can go to once a year, visit with old school friends and relatives and come back refreshed.

Terry Corcoran

Terry and Maggie Corcoran have adjusted their recreation activities to Maggie’s abilities. Before her MS, they played tennis regularly. Then they started going for walks. Now they drive to areas like the Brickworks, just off Toronto’s busy Don Valley Parkway, where they can sit, enjoy the scenery and watch the birds. “You can drive by it so fast you wouldn’t even know it’s there. But when you slow down and go in, you find there’s a lot of beauty you’ve been missing. So that’s what we’ve tried to do to make every day enjoyable.”

Playing squash five days a week keeps Terry fit physically and emotionally. “You go down to play and you leave the court fatigued. You have cleared your head and away you go.”

With 15 years of care-

giving behind him, Terry offers some strategies for spouses and partners who are new to the role:

- ♦ Get a reasonable understanding of what’s involved in MS, including knowing the kinds of upheaval people experience after getting the diagnosis.
- ♦ Analyze your personality and your partner’s personality to decide the best way you can handle this as a team.
- ♦ Chat with your partner to find out what he or she feels is the best approach and to find out what is needed.
- ♦ Be aware that your solutions may not be the same as another couple’s.
- ♦ Learn how to provide support and help without undermining confidence.
- ♦ Aim for a positive mental attitude.
- ♦ Do silly things together and have fun.

*[All names and personal details used with permission.]*

*Avril Roberts is a Toronto-based health writer with an interest in neurological disorders.*

### Caregiver Strategy - Online Survey

The Multiple Sclerosis Society of Canada is developing a strategy to support caregivers of people with MS. Add your voice to the strategy. Visit [www.mssociety.ca](http://www.mssociety.ca) to provide your feedback by completing the online survey. Call 1-800-379-2166 for a print version of the questionnaire.