

## Active, informed approach to MS can make the difference

by Sharon Crawford

The year 1991 was a landmark year for Derek Lunden of North Vancouver. At 35, he was engaged to be married and had started a software-consulting firm. He was also diagnosed with primary-progressive MS.

His MS came fast and furious. In 1990, his knees started giving way when he played squash. He saw a neurologist and had a CAT scan, but the neurologist "believed it was all in my head." Then, in May 1991, after returning from a friend's bachelor party, "I lost the ability to urinate. I ended up in the hospital that night pleading to be catheterized."

Now, the testing became very aggressive. Urodynamic testing showed he had a neurogenic bladder, and an MRI showed plaque in his brain. "MS Positive. Maria, (his fiancée) and I were in shock." By February 1992, he was using a wheelchair. He could still walk with canes but found it too slow. "I didn't resist the chair; I saw it as an opportunity." Maria and Derek married in May 1994. Their son, Mark, was born in 1998.

Across the board, MS is difficult to manage, "because it has a wide variety of symptoms," says Dr. Paul O'Connor, neurologist and director of the MS Clinic at St. Michael's Hospital, in Toronto. These symptoms may include numbness, cognitive dysfunction, balance problems, limb weakness, fatigue, and bladder and bowel dysfunction - all of which can lead to anger, denial, and depression.

Typically, MS hits people in their 20s and 30s when they're most productive in their careers and starting families, says Dr.

O'Connor. Many people have difficulty dealing with the losses associated with the disease.

Managing MS after diagnosis really depends upon the type of MS someone has developed. While statistics vary, there is general agreement that 75 to 85 percent of people initially have relapsing-remitting MS. About half will go on to develop secondary-progressive MS, in which relapses (MS attacks) become less frequent and there is steady progression (worsening of the disease).

A much smaller number of people with MS - about 10 to 15 percent - have primary-progressive MS from the beginning. This is the kind that Derek Lunden has.

Complicating the management of MS, both for people with MS and their physicians, is the existence of benign MS. Twenty to 25 percent of people who were originally diagnosed with relapsing-remitting MS will do well. They will have few attacks with long periods of remission and limited disability after 15 years.

The complication arises from the generally accepted recommendation that relapsing-remitting MS should be treated as early as possible with one of the disease modifying therapies (beta interferons (Avonex®, Betaseron® or Rebif®) or glatiramer acetate (Copaxone®)). Some MS neurologists have questioned whether all people with relapsing-remitting MS should be treated immediately upon diagnosis (or even before if MS is suspected because of one attack and MRI evidence). They argue that this approach means people who have

**“The key to successful treatment of MS is patient education”**

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benign MS will be injecting themselves with one of the disease modifying therapies for years when it would not have been necessary.

This debate reached the pages of the prestigious scientific journal *Archives of Neurology* in April. It published two articles: one arguing in favour of early treatment and another suggesting not all people should be treated at the time of diagnosis. The journal editorial weighed both sides and concluded treatment with one of the disease modifying therapies should be started as soon as possible since, at this time, it isn't possible to determine which individuals will have a benign course of MS and which will have a more severe course.

While choosing a therapy is the first step in managing relapsing MS, the second, and equally important, is sticking to that therapy. As Dr. C. Everett Koop said in a 2003 World Health Organization (WHO) report, "Drugs don't work in patients who don't take them."

According to the European Multiple Sclerosis Platform *From compliance to adherence in long-term MS therapies* (2004, Brussels), the goals of treating MS with the disease modifying therapies are to: decrease the rate of relapse; decrease the inflammation; decrease brain atrophy development; slow down accumulation of permanent disability; and improve quality of life.

The WHO also reported that up to 45 percent of people with MS don't adhere to the course of medication prescribed to them. This is certainly understandable since people are not only dealing with roller-coaster lifestyle changes, now they must inject drugs.

"Some patients don't like the medication," says Dr. O'Connor. "A lot of people have trouble putting up with self-injection or the side effects." These side effects include flu-like symptoms, redness, swelling and local discomfort at the injection site, mood alteration, headaches and fatigue.

According to a recent European conference on adherence to MS drug therapies, during the first three to six months of treatment, the main reason that people stop therapy is unmanaged side effects. In the longer term, patients stop because they question whether the treatment is working.

Dr. O'Connor believes the key to successful treatment of MS is patient education. Knowing what to expect from a therapy, what the side effects might be and having effective strategies for managing those side effects can make a tremendous difference.

Unfortunately for Derek Lunden, treatment of primary-progressive MS with one of the disease modifying therapies is not an option because, as Dr. O'Connor explains, "patients with purely progressive disease do not respond to these drugs." Instead, Derek focuses on managing his MS symptoms.

When it became apparent that caring for bladder and bowel dysfunction was vital to managing his MS, Derek became proactive and informed.

That's an attitude that Colleen Harris, RN, coordinator, MS Clinic at Foothills Hospital in Calgary, would applaud. Too often patients, especially younger patients, "don't want to sit down and discuss it (bladder problems) with the physician." But "it's a common symptom" and has to be dealt with.

### ***What is a doctor or nurse to do?***

Enter Dr. Rosalind Kalb, director of the Professional Resource Centre, National MS Society USA. Seven years ago at a convention, a neurologist challenged her to develop some practical communication tools for doctors. So, Dr. Kalb sat down and created a series of booklets called *Talking with your MS patients about difficult topics*. The booklets, which have been adapted by the MS Society of Canada, are set-up in question/answer format to act as a simple tool for healthcare profes-

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sionals. The booklets cover a range of topics, from elimination to sexual dysfunction and depression.

Dr. Kalb says, "It's a very comforting message (to patients) when doctors bring up the tough stuff and talk about it." It also gives patients "a comfortable vocabulary."

And it gives people comforting answers, such as finding out that bowel and bladder changes are common with MS. This "safety in numbers" syndrome can diminish feelings of embarrassment and isolation. People also need that comfort because dealing with bladder issues "often involves self-catheterization," says Colleen Harris.

Right from the get-go, Derek Lunden was introduced to intermittent catheterization to completely empty his bladder and prevent urinary tract infections. Overall, this has been a successful management technique for him.

Dealing with bladder and bowel issues also includes diet, fluid intake, exercise and routine. Eating lots of fibre is vital to keeping the bowels moving because it adds bulk to the bowel, although "too much bulk product may irritate the bowel," Colleen Harris advises. This irritation could be gas, bloating or diarrhea. Fibre is found in whole grains (breads and cereals, vegetables and fruit).

In *Understanding Bowel Problems in Multiple Sclerosis*, Nancy Holland, R.N. and Robin Frames advise that people with MS who have limited mobility might require 30 grams of fibre daily. Eating a bowl of bran cereal or four slices of bran bread can help fulfill this requirement.

In addition, drinking water will soften the stool and help with bladder problems so drinking eight glasses of fluid a day is big help. To avoid or limit leakage, drink fluids when you are near a bathroom and can catheterize. Reduce or eliminate liquids containing bladder irritants such as caffeine, aspartame and alcohol. To minimize urinary tract infections, drink cranberry juice and decrease citrus juices.

Routine is also important with bowel

movements. Colleen Harris advises, "Go to the bathroom regularly." "Regularly" is a complete evacuation every day or every other day. Go to the bathroom after breakfast because that's when the emptying reflex is the most powerful. Sometimes "introducing Metamucil, stool softener, or a suppository" is helpful. "You have to follow a regular lifestyle to be regular," she says.

Your emotions can also affect bowel movements. Depression can cause constipa-

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### **Sticking to a therapy is key to success**

Whether you are taking one of the disease modifying therapies, or managing a complex MS symptom, here are some general guidelines that can help you communicate with your healthcare providers:

- ✓ Make sure you understand what the therapy is meant to do.
- ✓ Find out what side effects you might expect, especially if you are starting a new drug.
- ✓ Ask about how to best manage the side effects.
- ✓ If you are making changes to your lifestyle (e.g., diet or exercise) ask how long it will take to see positive outcomes.
- ✓ Take a family member or friend with you to be a second set of eyes and ears.
- ✓ See your healthcare providers regularly and be sure you have an open two-way dialogue with them.
- ✓ If you are taking one of the disease modifying therapies, use the telephone information service offered by the pharmaceutical company as a resource.

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tion and start another spiral of being upset. Stress also interferes with bowel movements.

Regular exercise is important for the bowel too. Colleen Harris advises trying exercise programs on TV or tapes. These exercises can be adjusted for people using wheelchairs.

"I try to stay as healthy as possible," says Derek Lunden. "The thing for me is to drink lots of water and exercise." He lifts weights, "rolls" in his wheelchair, Sit-Skis and golfs using a single rider golf cart. He eats lots of fibre and stays away from processed foods.

Much of steering through MS is attitude - of healthcare providers and people with MS. "We don't instil they are sick," says Colleen Harris "we instil they are healthy. The main goal is to have as high a quality of life as possible. And if things are getting them down, they need to seek other resources, whether advocacy or education."

Dr. O'Connor also stresses the importance of patient education because "knowledge is power." The informed person can make intelligent decisions. The uninformed person won't be able to differentiate if symptoms are MS-related or caused by something else.

For Derek Lunden, "one of the challenges with this disease is it's a progressive disease. I lose a little every day. You have to go through your stages - anger, denial, depression. The last is always acceptance. The key to my life is acceptance. The more you resist something, the more it will persist."

"I don't think I've ever said 'Woe is me.' I'm not a victim of this disease. My whole goal is to help make a difference. If you believe you can't, you won't, but if you believe you can, you might."

*Sharon Crawford is a Toronto-based freelance writer and editor specializing in healthcare issues.*

## Additional Resources

### ***MS Disease-Modifying Therapies in Canada***

Booklet describing the four medications available to treat relapsing MS.

Available at [www.mssociety.ca](http://www.mssociety.ca), key search word "managing practical issues"

### ***Understanding Bladder Dysfunction***

Illustrated article describing various ways to manage bladder problems.

Available at [www.mssociety.ca](http://www.mssociety.ca), key search word "managing MS symptoms"

### ***Understanding Bowel Problems***

Describing impact of MS on bowel function with suggestions for management.

Available at [www.mssociety.ca](http://www.mssociety.ca), key search word "managing MS symptoms"

### ***Talking with your MS patients about difficult topics***

Series of booklets for healthcare professionals to assist with discussing the diagnosis of MS, progressive disease, elimination problems, sexual dysfunction, depression and other emotional changes and cognitive dysfunction.

Available at [www.mssociety.ca](http://www.mssociety.ca), key search word "managing practical issues"

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