

## Getting the most out of MS therapies

by  
Avril Roberts

Even before her first MS clinic appointment, Colleen McDonald-Hedlund of Winnipeg knew which MS treatment she wanted to take. She had done her homework. She had called her local MS Society office to get a newly diagnosed information package and searched the Internet for news about therapies for MS and their performance in clinical trials.

It was the armour she needed to help rewrite family history. "My mother had MS quite progressively. She succumbed to her illness at 47. I had grown up with MS, but I didn't know it in the fashion I'm living it today."

There are now drug treatments for MS, since the approval of the first medications shown to reduce the frequency and severity of MS attacks by about one-third in people with relapsing-remitting MS. These disease-modifying drugs – Avonex, Betaseron, Copaxone and Rebif – are prescribed early in MS to give people a fighting chance at slowing down the

progression of disability.

Where severe relapsing-remitting MS has not responded to other treatments, mitoxantrone (Novantrone) is available off label. Mitoxantrone is also prescribed for some people with rapidly progressing MS.

This good news about treatments is tempered by the fact that the current medications are not cures. The positive benefits are not immediately apparent and are best determined over time. In addition, mitoxantrone can be taken for a limited time only, due to its potential for heart damage. As yet, there are no drug treatments for primary-progressive multiple sclerosis.

For people wanting to optimize their well-being, the challenge is how to get the maximum benefits from available treatments, keep as well as possible and enjoy a good quality of life.

First steps include choosing the right



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health care team – family physician, neurologist, MS nurse, and other health professionals; becoming an active participant in all aspects of care; learning about treatment options; selecting treatments that fit your values and lifestyle; and taking charge of your life and health.

“It's really a team approach, with many different health care professionals trying to help people with multiple sclerosis... keep their MS stabilized,” said Dr. Mary Lou Myles, an Edmonton MS neurologist.

“If someone is starting on one of these immunomodulatory therapies, neurologists spend a lot of time going through the pros and cons of each treatment, realistic expectations and what's involved. The person meets with an MS nurse. There is also literature and videotapes.”

“We make an active decision together because, as far as we know, there is no one right treatment. We try to balance people's values and make sure they are committed to treatment so they can benefit in the long term. We also want people to know exactly what side effects to expect so if they experience them they can handle them well and understand that they should remain on the treatment until we get

something better or until it becomes apparent that it's not working as well as it should.”

Factors that could require a change in treatment include: severe attacks from which there isn't complete recovery; a persistent and measurable increase in the level of disability;

and adverse responses, such as infections or the development of neutralizing antibodies, proteins that, when present in high numbers, may work against a treatment and reduce its effectiveness.

By teaching people how to manage and monitor MS symptoms and therapies, the MS nurse helps bridge the gap between neurologist and family physician. In 20 years as a Calgary MS clinic nurse, Colleen Harris has seen a growth in outpatient care, including rehabilitation services and treatment for relapses and a shift to patient-centred care, focused on healthy lifestyles and taking control of MS.

“We teach people how to titrate (manage) medications, bowel and bladder problems, and exercise. Also, how to take medications appropriately to minimize adverse effects.”

The nurse also shows how to deal with injection sites and side effects and advises what's normal or abnormal. “It is

### New recommendations assist neurologists in optimizing MS treatments

Now that people are taking disease-modifying therapies for MS (Avonex, Betaseron, Copaxone and Rebif) how do you know if people are benefiting from any of the drugs? How do you know when it is time to adjust the dose or switch to another therapy?

These questions prompted a group of Canadian neurologists to come up with evidence-based recommendations for treatment optimization in MS. The recommendations were developed by the Canadian Multiple Sclerosis Working Group and published in the May 2004 issue of the *Canadian Journal of Neurological Sciences*.

“There are proven therapies out there and they need to be used to the best of their abilities,” says Dr. Mark Freedman, principal author of the article, *Treatment Optimization in Multiple Sclerosis*. “Our recommendations are there to help guide the use of these drugs, to optimize which drugs should be used in which patient, and to recognize when someone is having a suboptimal response.”

The Working Group defined optimal response as no attacks, no disease progression (as measured by the Expanded Disability Status Scale) and no MRI changes. To determine suboptimal responses to the four available drugs, the group analyzed published literature on the disease-modifying therapies and the experiences of people who did or did not benefit from the treatments in research and clinical trials.

important to know if the treatment is working. We teach people to recognize changes in their MS.”

This intensive preparation pays off, according to Dr. Myles. “People who have been involved in that type of educational process concerning their treatments end up with a better understanding, a bigger commitment and tend to do better. The majority of my patients on treatment are leading full lives. They’re travelling. Eighty per cent are working full time. Their lives are much better than before they started. It’s possible to stabilize people so they can get on with their lives.”

Colleen McDonald-Hedlund, 26, started on a disease-modifying therapy immediately upon her diagnosis, in February 2001. Fear and anxiety were strong motivators, but so, too, was the desire to live a good life while raising her two little girls.

“It was a matter of what was going to give me my strongest defence against my disease. If it was going to make me feel bad the next day that was okay. Just being able to do well with MS was an incredibly driving force.”

She has had typical side effects – flu-like symptoms that wore off after a year, enabling her to stop taking ibuprofen with her dose, and low energy the day after the injection. She has recently had to adjust her dosage, which isn’t uncommon. She developed problems with her blood work after two years. Her blood work returned to normal during a two-week drug holiday so she is now on a lower dose and anticipates moving to a higher dose again.

To optimize her health, Colleen (and her

family) follows a low-fat diet, emphasizing whole grains, organic foods, low saturated fat intake and good fats. She maintains an exercise routine incorporating yoga to keep her muscles toned. “If a relapse does take place, you want those muscles in the best shape you can.”

### Tips for communicating with health care professionals

- Find a neurologist, family physician and MS nurse with whom you feel comfortable discussing your condition and treatment.
- Learn about MS and treatment options.
- Keep a diary (written or electronic) of your MS. Record:
  - changes in your MS
  - relapses – frequency, severity, treatment, degree of recovery
  - new symptoms that might need management
  - trouble with or concerns about treatments, managing injections or side effects
  - feelings of depression
- Keep an ongoing list of questions and concerns. Use it as a guide for the visit to your doctor.
- Know what you want to achieve from your appointment.
- Take someone with you to be your eyes and ears during the visit.
- Take a list of medications and complementary therapies.
- Say if you have seen any specialists since your last appointment.
- Talk to your neurologist and MS nurse about realistic expectations for your therapy.
- Ask about other helpful medications and treatments.

When stretching and exercising wasn’t enough to combat some lower leg spasticity, she took baclofen, but has weaned herself off it. “It feels good to be able to do that. You feel a little in control.” She keeps depression at bay with talk therapy. “It’s incredibly beneficial.” She is living well with MS in ways her mother could scarcely have dreamed of.

Greg Walker, 40, of North Bay, Ontario, has a different experience, having been diagnosed 19 years ago. Apart from eye damage from his initial bout of optic neuritis, he had few symptoms during the first 12 years and only a few attacks, for which he took steroids, such as prednisone. By the time the disease modifying drugs became available, his multiple sclerosis had begun a gradual downhill slide. He would have welcomed an aggressive approach to treatment but was told all he could do

was live a healthy lifestyle.

“That wasn’t acceptable to me. I wanted to try whatever I could. The neurologist who treats me now has that same mindset. He’s the type of person who says, ‘well that didn’t work, let’s try this.’ That’s what I needed.”

From 1999 to 2000, he participated in a phase two clinical trial of a drug that did not

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proceed to phase three. He spent two years on mitoxantrone, administered intravenously once every three months. He believes it helped slow the progression of his MS but he reached the dosage limit. He now takes an interferon drug he hopes will keep his multiple sclerosis stabilized.

“Over the last two or three years, I've reached the point where, if I'm progressing, it's at a slower rate than three or four years previous to that. I was losing my ability to walk at a fairly rapid rate compared to now. Whether that's the natural course of the disease or the drugs I've used, it's impossible for me to know.”

He uses a walker at home and a power scooter to get around the city. He is conscientious about his diet and takes medications for MS-related bowel problems. With a busy wife and two energetic teenaged daughters, it isn't always possible to plan his day around fatigue; sometimes he forgoes family outings but his daughters understand.

“If they've learned nothing else from their father having MS, they have learned how to be around someone with a disability and learned not to feel embarrassed, uncomfortable or nervous about offering help.”

Greg Walker is realistic about his treatment goals. “I don't think they can turn things around based on the available treatments, but the hope is to suppress the disease, have it calm down and slow what it's doing.”

Anne Belohorec, 51, of Edmonton, takes a holistic approach to optimizing well-being in MS. “The physical, emotional, mental and spiritual aspects of who we are affect our health. When you have a disease that doesn't have a cure, you need to explore all of those. That means looking into treatments for the physical and the emotional, reviewing your thoughts, spiritual beliefs and blocks and finding ways to connect to spiritual forces to help you.”

This mind-body approach to wellness includes taking responsibility for finding out who and what is good for you. For the person with digestive imbalance, that may mean a nutritional consultant or a good health food store. Someone dealing with depression may need a psychotherapist and antidepressants or other medications. For

people dealing with grief – anger, loss, sadness – a social worker or pastoral counselling may be affordable options.

Anne Belohorec is a holistic health practitioner. After she was diagnosed at age 29, her MS progressed rapidly, five severe attacks in a year and a half, then stabilized. For 12 years, she was unable to stand or walk and had only partial use of her arms. She worked at recovering her physical mobility through physiotherapy and tai chi and explored complementary therapies to balance her body's energies.

Today, she is fully mobile. She still deals with pain, tiredness and weakness and doesn't function well with crowds. Her full-time holistic health practice is based in her home where she can set her own hours, meet clients one on one and use the best of her abilities. She takes great joy in caring for her grandchildren.

She says complementary therapies suitable for MS include: the gentler types of massage to help relax muscles, improve circulation and enhance body awareness; craniosacral therapy, using a light touch, for pain relief, stress release and deep relaxation; and therapeutic imagery and dialogue for emotional awareness and release.

“If you can, you clear some of the impediments to healing, you put your body in a better position to heal itself. The key is to believe that it's possible to be in better health and to work towards it one step at a time.”

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

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