Disease-Modifying Therapies — Part 2

Switching Therapies

People with MS should discuss their disease management plans with their neurologist. It is important to keep in mind disease history and treatment goals, when determining whether or not changing therapies is a suitable option for them. Due to the large number of different MS therapies currently available, as well as the fact that each therapy may have a different mechanism of action, people with MS should discuss their disease management plans with their physician.

Drug costs and reimbursement

The base cost of disease-modifying therapies for MS varies widely and typically falls in the range of $20,000 to $40,000 per year. The total cost of the medication will depend on the treatment selected, the dosage, provincial drug program pricing, pharmacy or clinic costs and dispensing fees.

The level of drug reimbursement and access criteria varies from province to province and the MS Society is working to ensure that people who could benefit from treatment have access. The Common Drug Review (CDR) at the Canadian Agency for Drugs and Technologies in Health (CADTH) is a pan-Canadian process for conducting objective, rigorous reviews of the clinical, cost-effectiveness, and patient evidence for drugs. Depending on the province, this can take anywhere from 8-24 months from initial submission to final recommendation. It should be noted that Quebec conducts its own review, independent of the CDR.

For more information about these therapies or for other information about MS management, please contact your physician, or the Multiple Sclerosis Society of Canada at 1-800-268-7582.
Legend:

RRMS—relaxing remitting MS
CIS—clinically isolated syndrome
MRI—magnetic resonance imaging

Brand (Generic Name) Health Canada, Indication, Administration and Dose

**Aubagio®** - (teriflunomide) - Relapsing remitting MS; One 14mg tablet taken orally daily.

**Avonex®** - (interferon beta-1a) - Relapsing-remitting MS; Secondary-progressive MS with relapses; Clinically isolated syndrome (CIS); One 30mcg injection into the muscle once a week.

**Betaseron®** - (interferon beta-1b) - Relapsing-remitting MS; Secondary-progressive MS with relapses CIS; One 250 mcg injection under the skin every other day.

**Copaxone®** - (glatiramer acetate) - Relapsing-remitting MS CIS; One 20 mg injection under the skin daily.

**Extavia®** - (interferon beta-1b) - Relapsing-remitting MS; Secondary-progressive MS (with relapses); One 250 mcg injection under the skin every other day.

**Gilenya™** - (fingolimod) - Relapsing-remitting MS. Recommended for people who have not responded adequately to other disease-modifying therapies or who are unable to tolerate them. One 0.5mg capsule taken orally daily.

**Lemtrada™** - (alemtuzumab) - Relapsing-remitting MS, with active disease in people who have had an inadequate response to other disease-modifying therapies. One 0.5mg IV infusion daily for five consecutive days in year 1 of treatment, and one 0.5mg IV infusion for three consecutive days in year 2.

**Rebif®** - (interferon beta-1a) - Relapsing-remitting MS; Secondary-progressive MS with relapses CIS; One 44 mcg injection under the skin three times per week; or One dose of 22 mcg injected under the skin three times per week. Also available in a pre-filled syringe.

**Tecfidera™** - (Dimethyl fumarate) - Relapsing-remitting MS; Two 120mg capsules taken orally, twice daily; or One 240mg capsule taken orally, twice daily.

**Tysabri®** - (natalizumab) - Relapsing-remitting MS. Recommended for people who have not responded adequately to other disease-modifying therapies or who are unable to tolerate them. One 300mg IV infusion every four weeks.
Hello!

Everything we do at Can Do MS is driven by one simple belief: you are more than your MS.

It's no secret that living with multiple sclerosis (MS) can be overwhelming: from having to manage the challenges of everyday life to scheduling regular doctors' visits and remembering to take your medication, it may be difficult to find time for yourself and focus on the positive aspects of life. That's why Can Do MS has partnered with Biogen Idec to launch MS Blueprint™, a program to encourage those impacted by MS to find activities that will bring joy and happiness to their lives every day.

MS Blueprint was inspired by happiness expert Gretchen Rubin's approach to creating a happier life, which she details in her New York Times best-selling book, The Happiness Project. As program ambassador, Gretchen is sharing her own tips and advice for getting the most enjoyment out of each day, and hopes to motivate those impacted by MS to address their challenging circumstances, focus on what makes them happy and live in the present.

We encourage you to visit MSBlueprint.com to set goals and create personalized activity plans, called MS Blueprints, filled with simple, fun activities to help you attain a more positive life. Take it a step further by suggesting new activities to add to the MS Blueprints on the website.

The website also features frequently asked questions about living with MS, and a blog from Gretchen on how to incorporate happiness into your daily routine.

We work collaboratively with our partners to make sure you have the resources and support you need to live your best life with MS.

Enjoy!

Sincerely,

Your Friends at Can Do MS

A national nonprofit organization, Can Do MS is a leading provider of innovative lifestyle empowerment programs that empower people with MS and their support partners to transform and improve their quality of life. Visit www.mscando.org
Fatigue is perhaps the most prevalent and disabling symptom experienced by persons affected by MS. An overpowering feeling of fatigue can severely affect daily functioning particularly when compounded by other symptoms of MS, impairs performance at work or school and affects one’s interactions with friends and family. While the cause of fatigue in MS is still unknown, one hypothesis that is gaining ground among scientists and clinicians alike is that underlying sleep disorders may play a larger role than previously thought. Promising data out there suggests that identifying and treating sleep disorders can go a long way towards alleviating fatigue and improving quality of life in people with MS. This is good news, since fatigue is generally resistant to the frontline treatments that are the mainstay of MS symptom management.

In this article, I’ll talk about some of the most common sleep disorders identified in people living with MS, discuss the evidence linking sleep disorders with fatigue, and identify potential strategies that people with MS can pursue to manage fatigue.

Some common sleep disorders
Disorders affecting sleep and waking are numerous and complex: however, one feature they almost invariably share in common is a reduction in sleep quality at night along with an increase in sleepiness during the day. Here are some of the most common sleep disorders, found in both people with MS and among the general population.

Insomnia: Certainly the most widespread and well-known sleep disorder, insomnia is defined as difficulty in falling asleep or staying asleep, despite adequate opportunity. According to the Canadian Community Health Survey from 2002, more than 3 million Canadians, or 10-15% of the population, experience insomnia. Among people with MS that proportion is believed to be higher, with some estimates of prevalence exceeding 30%. Whether MS is part of the cause of insomnia, or if it exists as a separate condition in people with MS, remains unclear. Treatment strategies for insomnia can include a combination of discussing lifestyle changes to improve sleep hygiene and, if necessary, pharmacological intervention.

Obstructive sleep apnea hypopnea (OASH) syndrome: A sleep-related breathing disorder, OASH syndrome is characterized by interruptions in breathing that occur during the night as a result of a collapse of the upper airway. Each interruption can persist for up to 30 seconds, until the brain detects reduced oxygen levels in the blood and triggers a brief awakening to restore normal breathing. Although someone with OASH can experience hundreds of these breathing interruptions and arousals in a night, they often don’t realize their sleep has been fragmented, despite feeling sleepy and fatigued during the day. In addition to causing poor sleep quality, OASH has been linked with other serious illnesses, such as heart disease and diabetes. OASH affects an estimated 3% of Canadians, and recent data reveals that an estimated 58% of people with MS are affected with this condition. Dr. Daria Trojan and colleagues at the Montreal Neurological Institute demonstrated in an MS Society-funded study that OASH is the most frequent sleep disorder found in people with MS, and went on to show that treating OASH in those people may lead to improved fatigue. I talk about this in more detail further along in this article.

Restless legs syndrome (RLS): People with RLS report uncomfortable and unpleasant sensations in the legs that occur primarily at night, resulting in an uncontrollable urge to move their legs in order to relieve the discomfort. RLS is often accompanied by a condition called periodic limb movements of sleep (PLMS), in which people experience severe and involuntary jerking of the limbs during sleep, causing sleep fragmentation and daytime sleepiness. Like many other sleep disorders, RLS appears to be significantly more common in people living with MS compared to the general population, and the (continued on page 5)
associated sensory and motor impairments—including involuntary limb movements during sleep and feelings of “insects crawling up the legs” during waking—can seriously aggravate other MS symptoms.

**Narcolepsy:** Narcolepsy is a disorder distinguished by instability in the sleep-wake cycle. The symptoms of narcolepsy are several-fold, the most common of which is excessive daytime sleepiness. However, one of the most striking features is a symptom called cataplexy, in which positive emotions, such as laughter, can bring about a sudden bout of muscle weakness and loss of voluntary muscle control. You may have heard the expression that laughter can make you feel “weak in the knees”; now imagine that weakness magnified to the point of physical collapse! Narcolepsy is believed to be caused by the loss of a certain molecule which promotes waking—called hypocretin—in the brain. Considerable evidence suggests that an autoimmune response may be the culprit for this loss of hypocretin (although this issue is still a matter of debate). Thus since MS, and to a lesser extent narcolepsy, are considered autoimmune disorders, understanding the disease mechanisms that underline narcolepsy may shed light on potential therapies for MS.

**Sleep disorders: at the root of fatigue in MS?**
There is an increasing awareness among the scientific community that sleep disorders may be a vital contributing factor to the debilitating fatigue experienced by individuals with MS. This is important because many tried-and-tested strategies for managing sleep disorders in the clinician's toolkit can potentially allow people with MS to feel less tired and more refreshed and alert, leading to improved daily functioning. We’ll take a look at a few studies that have offered crucial insights into the links between MS, fatigue and sleep disorders.

A landmark study by a team at McGill University, published in *Multiple Sclerosis Journal* in 2012 and funded in part by the MS Society, demonstrated for the first time that measures of fatigue were significantly improved in people with MS whose sleep disorders were successfully treated, compared to those whose sleep disorders went untreated or who did not present with any sleep disorders. The most remarkable improvement was seen in patients with OSAH, presumably because OSAH was the most common sleep disorder among the participants and had one of the strongest associations with severe fatigue. These findings were confirmed by a German research group, whose article published last year in *Clinical Neurology and Neurosurgery* also showed that clinical treatment of such sleep disturbances as insomnia, OSAH and RLS may improve fatigue in MS.

A more recent study that came out of the University of California Davis and was published in the *Journal of Clinical Sleep Medicine* last month was perhaps the largest single investigation of sleep disorders in people with MS. This survey-based population study of 2,375 individuals diagnosed with MS revealed that a high proportion of respondents screened positive for one or more sleep disorders—including insomnia, OASH or RLS—yet a vast majority were undiagnosed by their clinicians. This discovery points to an important gap in our recognition of the presence and impact of sleep disorders in people living with MS. It is encouraging to see that important studies such as these have unlocked promising avenues for understanding what factors cause fatigue alongside other MS symptoms, and offer hope to people with MS that there are ways to finally put their fatigue to bed.

**What can you do?**
I have heard from many people living with MS that fatigue is a common part of their daily lives, which imposes on them serious challenges such as those I mentioned at the beginning of this article. Fortunately, there is no hope for managing fatigue in people with MS by tackling potential underlying sleep disorders. If you have MS and feel tired and poorly rested throughout the day, your family doctor can help to find the right treatment.
From the Fundraising Desk.....
Brietta Gerrard – Event & Volunteer Engagement Coordinator

Brietta graduated with a Bachelor of Science (B.Sc.) degree in Psychology from the University of Lethbridge in 2011. Following her B.Sc., Brietta completed a Master of Science degree in Neuroscience at the University of Lethbridge in 2014. Brietta’s Master’s research had a specific focus on MS. Beyond school, Brietta has been an active volunteer for the Lethbridge MS Society by being involved with Bingo, the Carnation Campaign, Hit a Ball, and the MS Walk. Currently, Brietta is planning a number of new fundraising activities and looks forward to expanding her role as Event & Volunteer Engagement Coordinator!

We are excited to announce that the MS Walk presented by Mr. Lube will be held at Indian Battle Park beginning at Fort Whoop Up on Saturday, May 2, 2015.
Our Walk Website is scheduled to launch on Monday, November 17, 2014. Register and start your fundraising early by visiting www.mswalks.ca.
In 2014, you helped us raise over $175,000!
Start building your team today!

February 7, 2015
10:00 -11:30 am
Gymnasium 2, The Lethbridge Senior Citizen’s Association (LSCO), 500 11 St S
$20 in advance
$25 at the door
Pledge forms and tickets available at the MS Society Lethbridge Office and through PayPal at tine403.zumba.com. For more information call 403-328-7002.
All Proceeds Benefit The MS Society, Lethbridge & District Chapter

With ZUMBA® Jammer Candidate Tine Gulbrandsen and all of your favourite Lethbridge and area Zumba® instructors!

@mssocietyleth  MS Society - Lethbridge & District Chapter
**CALENDAR OF EVENTS**

**Thursday, November 6** . . . . . . . . . . . . . Primary Progressive MS Research Update presented by: Dr. M. Koch, Faculty of Medicine, University of Calgary

**Tuesday, November 11** . . . . . . . . . . . . . Remembrance Day Holiday, MS Society Office

**Wednesday, November 12** . . . . . . . . . . . . . Bingo, 5 pm at Winner’s Bingo Hall

**Friday, November 14** . . . . . . . . . . . . . Crowsnest Pass Support Group in Blairmore

**Thursday, November 20** . . . . . . . . . . . . Brown Bag Lunch, Noon, MS Society Office

**Tuesday, November 25** . . . . . . . . . . . . . Board Meeting, 5:15 pm, MS Society Office

**Thursday, November 27** . . . . . . . . . . . Annual Christmas Supper, 6pm, Lethbridge Lodge Hotel, Aspen Ballroom. **RSVP** to the office by November 20.

**Wednesday, December 10** . . . . . . . . . . . Bingo, 5 pm at Winner’s Bingo Hall

**Wednesday, December 24 at noon to January 2, 2015** . . . . . . MS Society Office will be Closed for the Holidays.

**Tuesday, January 6, 2015** . . . . . . . . . . . Board Meeting, 5:15 pm, MS Society Office

**Wednesday, January 14** . . . . . . . . . . . . . Bingo, 5 pm at Winner’s Bingo Hall

**Saturday, February 7** . . . . . . . . . . . . . **ZUMBATHON** Charity Event for MS. See page 6.

**Wednesday, February 11** . . . . . . . . . . . Bingo, 5 pm at Winner’s Bingo Hall

**Monday, February 23** . . . . . . . . . . . . . **Neuroimmunology 101** presented by Dr. Wee Yong, Calgary MS Clinic, Details TBA

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**Brown Bag Lunches—**

Join us from Noon—1pm on:

**Thursday, November 21,**

*No meeting in December*

**Thursday, January 16, 2015**

**Thursday, February 26**

For more information: call 403-328-7002 or email: Allan.Kristianson@mssociety.ca
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(Continued from page 5) . . .

plan for you. He or she may refer you to a sleep clinic, where you can participate in a sleep consult and have the opportunity to talk to a specialist about issues you’ve encountered with sleep.

One potential approach is participation in a sleep study, which involves spending the night in the clinic while your brain activity, heart rate, breathing, eye movements and muscle activity are monitored using a technique called polysomnography. This painless completely unaware of (after all, it’s difficult to notice symptoms when you’re asleep and, hence, unconscious!). In contrast, a variety of daytime tests are used to gauge levels of sleepiness and alertness during the day. These and other tools will provide your sleep specialist(s) with important information for diagnosing and treating any underlying sleep disorders.

Researchers note that identifying the symptoms associated with sleep disorders as soon as possible will increase the likelihood of overcoming fatigue and improving quality of life, while decreasing the risk of developing other potentially serious illnesses that are linked to sleep disorders. As more evidence on this topic surfaces, the research and medical communities will be able to uncover the role sleep disorders plays in the onset and severity of fatigue among people with MS, as well as determine if MS is directly linked to the development of sleep disorders. This insight can potentially lead to new treatments that reduce fatigue and enable people living with MS to undertake daily activities and participate fully within the community.

by Dr. Karen Lee, Vice-President Research, MS Society of Canada, National office, October 2014

Please take note . . .

We want to reiterate that you are receiving this email because you are a member, or have expressed an interest in receiving our quarterly newsletter—at any time, should you wish to be removed from our mailing/emailing list simply contact the office.

Due to rising postage costs we would really prefer to have our newsletter emailed straight to your inbox. Please call the office or email alisa.laturnus@mssociety.ca and we will add you to our emailing list.