

10 myths and misconceptions about multiple sclerosis



MS is fatal.

Most people with MS will have a normal or near-normal life expectancy.

MS is contagious.

Multiple sclerosis is not a contagious or infectious disease; it cannot be caught from contact with another person.

Everyone with MS will end up in a wheelchair, and that's an awful fate

Many people with MS will never require a wheelchair. But the use of mobility devices has positive aspects. For a person with MS, wheelchairs and scooters and other equipment can provide independence and relief from fatigue and other symptoms.

You should stop working because of the stress.

A lot of people with MS have long careers. There is no evidence that work stress directly influences the disease course, but workplace accommodations may be necessary to help manage symptoms at work.

Having children will be too difficult for you and make your MS worse.

Many people with MS choose to have families. Some women report that their MS goes into remission in pregnancy, though they are at increased risk of an attack after giving birth. Despite these short-term effects, there seems to be no long-term

consequence on one's MS.

MS doesn't cause pain.

The presence of pain in MS has just come to be understood in the last couple of decades. It used to be thought that MS did not cause pain; now it is known that different types of pain can be present in MS. Physicians are often able to recommend pain management strategies for people with MS pain.

If a person with MS has a child, that child is likely to get MS.

While people with relatives who have MS have a slightly higher chance of being diagnosed with MS, there is never a genetic certainty of diagnosis with MS as there is with other diseases. In identical twin studies where one twin has MS, the other is

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Living with MS

Looking for understanding when MS is invisible



Joan O'Gorman

Joan O'Gorman, a former flight attendant, became pregnant with her son shortly after her diagnosis with multiple sclerosis. When she returned to work after her maternity leave, she went on

two flights and then decided she had to stop, despite how much she loved her job.

"It was something I always wanted to do. You really lose your identity when you can't work."

The fatigue and symptoms from her MS made working on the planes too difficult.

For the 10 years she was a flight attendant, Joan had been traveling to Europe, the Caribbean and Hawaii. England was a second home for her, she says, and it's where she woke up one day with pins and needles on the left side of her body. Two years later, she was diagnosed with MS.

But Joan's MS is the relapsing-remitting type, and when she is not having an attack, people often can't empathize with the fact she has a chronic disease.

When she left her position as a flight attendant, the company wanted to give her an office job as a trainer and recruiter, but changed their minds when she couldn't answer the question, "Can you tell us when you'll be sick again?" So she went on long-

term disability instead.

After Joan left work, she says she felt the loss of a good life of travelling and friends. She says she tried to occupy herself with other projects but often felt too much fatigue.

Joan says a misconception people have often made about her MS is if it's not visible, such as with the use of a walker or a cane, there is nothing wrong with her.

"I've often felt judged," she says. "People have asked me, "Why don't you work?" She says that people have suggested she's scamming so that she can stay on long-term disability or making excuses. Other people have told her that they know someone with MS who works, so she should as well.

These comments have come from many people: friends, family, former co-workers and the general public.

While she says she is overall grateful for the course her MS has taken, she says that people with her type of MS can have a different battle – the battle of trying to convince others that she is really sick.

"You look too good for my sympathy," people have said to me. I tell them "I don't want your sympathy, I want your understanding." ♦

Would you like to contribute to MSToronto?
Please contact Julie at 416-967-3046 or
julie.crljen@mssociety.ca.

A round of applause please...

for Toronto Chapter volunteers!

Call Julie to ask about current opportunities 416-967-3046



Chapter Events

The Toronto Chapter Presents...

Parenting with MS



Featuring Helen Baker,

Parent Education Network

Helen has been a facilitator with the Parent Education Network since 2004. She recently returned to school, became a registered nurse, and is working in the field of pediatric cardiology.

Saturday, October 24, 2009

Willowdale Ave./Cummer Ave.

Registration 2 p.m.

Presentation 2:30 p.m. to 4 p.m.

Light refreshments

Wheel-Trans can be arranged if requested

Employment Education Series



Six-week program co-hosted by the MS Society of Canada, Toronto Chapter, and Canadian Paraplegic Association Ontario, Employment Services. This workshop is intended for those who are working.

6 p.m. to 8 p.m.

Bloor St./Church St.

\$10 registration fee

September 21 & October 5- Personality Dimensions

October 19 - Legal and Human Resources Issues

November 2 - Disclosure/Duty to Accommodation

November 16 - Fatigue/Stress/Bladder Management

November 30- Closing with presentations from CPA and MS Society of Canada

Wheel-Trans can be arranged if requested

Event
Registration

If you would like to register for an event, please contact the chapter by telephone, e-mail or by using our online form.

 Telephone

416-922-6600 x.2501

 E-mail

torontoevents@mssociety.ca

 Online

www.mssociety.ca/toronto
(Click on "Events")

Support Groups

12 Step MS Support Group

The CHAT ROOM: For Women with MS

Family Support Group

East End Women's Wellness Group

Etobicoke MS Group:

VIVA (*Persons with MS and family members*)

Start-up Support Groups

GLAMS (*Gay and lesbian*)

Iranian Support Group

Downtown Group

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◀ *Story continued from page 1*

Ten myths of MS...

diagnosed around 30 per cent of the time. This means two people with the exact same genes are not necessarily both going to be diagnosed, likely because of an unknown environmental trigger.

There are no treatments for MS

The last decade or so has seen the development of disease modifying therapies (DMTs) that have been shown to affect the underlying disease process in relapsing-remitting MS. A physician will determine the best DMT course for his or her patients. As well, there are many medicinal and alternative therapies that can help manage symptoms. Researchers are in the process of developing new treatments for both relapsing-remitting and progressive types of MS.

If a person with MS looks fine, they obviously are fine.

MS can be an invisible disease, meaning that symptoms can have no outward manifestation, but the individual could still be struggling with fatigue, optic neuritis, pain, numbness, incontinence and many other symptoms.

Treatments for MS make people sicker than they would be with the disease.

Disease Modifying Therapies (DMTs) often have short-term side effects, but it's important to remember that the objective of the DMT is to modify the long-term effects of the disease. ♦

Special Report

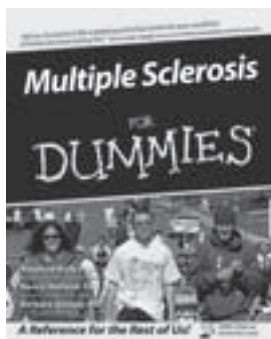
Save the date for AGM 2009

The Toronto Chapter's Annual General Meeting 2009 will be held on Saturday, November 21, 2009. The event will take place at the Columbus Centre and will feature a presentation by neurologist Dr. Liesly Lee. Invitations will be mailed approximately one month before the event.

We thank Biogen Idec Canada Inc. for providing an unrestricted educational grant. ♦

Book Review

Multiple Sclerosis for Dummies



By Rosalind Kalb, PhD; Nancy Holland, EdD, RN, MSCN; and Barbara Giesser, MD. ISBN# 978-0-470-05592-2.

Multiple Sclerosis for Dummies is an essential beginner's guide for realistic, practical and objective information about MS. This all-encompassing guide covers topics ranging from the physiology of MS to lifestyle management to wellness strategies.

As is typical of books in the "Dummies" series, this book is written to be accessible and readable, with touches of humour and straightforward language.

The excellent quality of information in this book is due to the credibility of the three authors, each with long-standing careers in different facets of care for people with MS.

While some information may not translate for a Canadian audience – the authors are American – it is still a worthy read for everyone who lives with MS. ♦



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A Budget for
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Toronto Chapter
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416-703-0571

Special Report

East York Book Club

Every third Tuesday of each month
Starts September 15, 2009
11:00 a.m. to 12:30 p.m.
S. Walter Stewart Library
170 Memorial Park Ave.

Contact Angela for details
416-967-3034
angela.rodriquez@mssociety.ca

The first the book to be discussed will be *Late Nights on Air* by Elizabeth Hay. If you have difficulty finding the book at your library, you can contact Linda Falconer at 416-396-8752 or lfalconer@torontopubliclibrary.ca.

Resources

Multiple Sclerosis Society of Canada,
Toronto Chapter
416-967-6065
www.mssociety.ca/toronto
toronto@mssociety.ca

National MS Society
www.nationalmssociety.org

UK Multiple Sclerosis Society
www.mssociety.org.uk

The Multiple Sclerosis Resource Network
www.msresourcenetwork.org

Donations

June 16-09 to Aug-15-09

Memberships

\$2,590

Donations, General

\$3,870

Commemorative Giving

\$14,993

Gifts in Kind

\$9,985

United Way Toronto,

Donor's Choice

\$3,636

Thank you donors!

Your contributions help to provide services to individuals and families, including educational, social and financial programs.

A reminder

If you would like to donate to Toronto Chapter programs & services, please make your cheque payable to:

Toronto Chapter, MS Society

and address it to the attention of Patricia Cole. Thank you!

Special Report

Equipment available from the Toronto Chapter

The Toronto Chapter has the following equipment available for long-term loan:

Rollators/walkers

Manual/power wheelchairs

Scooters

Hospital beds

Bath equipment

To find out how to access any of these items, please contact Nancy by telephone at 416-967-3033 or by e-mail at nancy.torrance@mssociety.ca. ♦

Special Report

Holiday cards available to order



Snowy Firs by
Patricia
MacCulloch

Packages

10 cards.....\$12

25 cards.....\$30

50 cards.....\$55

100 cards.....\$100

Support the chapter while spreading holiday cheer. Contact Patricia at 416-967-3036 or patricia.cole@mssociety.ca. ♦

Commemorative Giving

The gift that helps to improve the quality of life for people with MS

Birthdays ♦ Anniversaries

♦ Memoriams ♦ Bar

mitzvahs & bat mitzvahs ♦

Wedding favours...and more

Contact Patricia Cole at 416-967-3036 or patricia.cole@mssociety.ca, or visit www.mssociety.ca/toronto/help.htm

Want to go green?

Get the MS Toronto newsletter and Toronto Chapter flyers by e-mail instead of regular mail by contacting Julie at 416-967-3046 or julie.crljen@mssociety.ca.

Chapter Update

Equipment donation program

One of the most frequent inquiries we get at the chapter is about our equipment donation program, and what equipment we will accept for our chapter loan pool.

The chapter considers each piece of mobility and bath safety equipment and air conditioner that is offered to us.

While we appreciate the generosity of every potential donation, the space we have for storing the equipment is limited. In addition, the chapter funds the repairs and maintenance of the pieces that come in, so we are careful to accept newer pieces in great condition so that those costs will be less extensive.

In general, we take pieces that are

- * Up to three years old;
- * Currently needed in our inventory; and
- * In excellent condition.

Tax receipts may be issued for some equipment at a fair market value (determined by a valid third party vendor). The Toronto Chapter will arrange for the pick-up of the donated equipment.

Please contact Nancy Torrance if you have any questions or concerns about the program, 416-967-3033 or nancy.torrance@mssociety.ca.

Programs and Services

The MS Society, Toronto Chapter offers the following services:

Education, Information & Referral

- Bimonthly newsletter, literature, resource room and a website
- Education workshops and specialized courses including MS 101

Equipment Loans & Equipment Funding

Subsidies for Home Help & Incontinence Supplies

Supportive Counselling & Support Groups

Recreation Programs

Volunteer Services

Social Action & Advocacy

www.mssociety.ca/toronto

Art Therapy in the historic Distillery District

55 Mill St.
Case Goods Warehouse

Please e-mail Alison for details
alisonbaldock@yahoo.com

Wheelchair accessible
Wednesdays

Morning or evening sessions

Material fee—\$20/session; \$250/15 sessions



Members Helping Members

Balancing the demands of parenting

by **Rena Bone**

Dear Rena,

My partner and I want to have children, but I am concerned about getting pregnant because friends and family and even my doctor have implied I will have trouble keeping up with the demands of a baby. Currently, I have relapsing-remitting MS and experience a lot of fatigue. Is it too difficult and how does a person with MS manage parenthood?

Signed

Biological Clock



Rena Bone

Dear B.C.,

I was diagnosed with relapsing-remitting MS in 1992. After having several attacks, I was apprehensive about having children. Now having an eight and almost-six year old, I wouldn't change any decision I made.

I felt my best during the pregnancies but would encourage having extra help after the baby is born. You need to get as much sleep as you can, so sleep whenever the baby sleeps.

If you can, get your partner or a night nurse to help with the evening feeds. Take as much help as you can get.

I hope they will one day mimic the hormones of pregnancy for patients with MS as I never felt better. But there is a possibility of an attack six to eight weeks after the baby is born. I had an attack after each pregnancy. If you need to go on any drug therapy, try and get your infant to take a supplement bottle for those feeding times. The more help you have, the better – it will allow you to rest when needed.

As the infant grows you can get into a routine of taking naps when they nap – even in the middle of the day. I found if I was rested I was better able to cope. Remember to eat for yourself as you can get tired and forget. Snack when you are feeding your infant. Get your exercise by taking the baby for a walk or doing yoga with your baby.

Remember, if a friend or family member offers their help – take it! ♦

MS Toronto

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Lynn Laccohee

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MS Toronto is published bimonthly by the Multiple Sclerosis Society of Canada, Toronto Chapter. The contents may be reprinted with customary credit. Your submissions are welcomed. Please note that we do not publish information about alternative treatments, therapies and natural remedies

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MS Society of Canada Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

Toronto Chapter Vision

To maximize the quality of life for persons with MS and their support network living in Toronto Chapter's geographic boundaries.

The opinions expressed in the articles are those of the authors and do not necessarily reflect those of MS Toronto and of the Multiple Sclerosis Society of Canada. Articles on products and services are for information only and are not meant to be seen as endorsements.



The Toronto Chapter, Multiple Sclerosis Society of Canada is a United Way member agency.