

2013

# Making Treatment & Lifestyle Decisions: Thinking About Benefits & Risks

NORTH AMERICAN EDUCATION PROGRAM



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# Preface

Welcome to the 2013 North American Education Program, **Making Treatment & Lifestyle Decisions: Thinking About Benefits & Risks**, produced by the National MS Society in collaboration with the MS Society of Canada.

The advances in the care and treatment of people with multiple sclerosis since 1993 have been remarkable. Physicians have gone from being able to offer little more than a hug and a handshake to people diagnosed with MS to now helping them choose from a large slate of approved treatment options that can change the course of the disease.

People living with MS and their families have more tools available to them than ever before, including disease-modifying treatments, symptom-management strategies and lifestyle-related options that can improve quality of life.

Our program this year focuses on the factors that influence people with MS, as well as their physicians and family members, as they consider their treatment and lifestyle options. In the video portion of the program, you will hear from clinicians at the forefront of MS research and treatment discussing the issues that must be considered when looking at treatment and lifestyle decisions.

This program booklet provides an overview of the various factors that often complicate medical decision-making, as well as the variety of choices available for people living with MS to treat their disease so they can maintain their best quality of life.

While it's an exciting time in the field of MS research, we know there is still more work to be done developing treatment options for people with primary-progressive MS and developing treatments with better efficacy and less risk for all people living with MS.

We want to thank Bayer HealthCare; EMD Serono; Genentech; Genzyme, a Sanofi company; Novartis; Teva Neuroscience and Questcor Pharmaceuticals, Inc. for providing generous educational grants to make this program possible.

We hope you will find the program informative. For further information, visit [nationalMSsociety.org](http://nationalMSsociety.org) or [mssociety.ca](http://mssociety.ca), or call 1-800-344-4867 (U.S.) or 1-800-268-7582 (Canada).

Best Regards,

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# Program Overview & Goals

Until the early 1990s, no therapies were available to alter the course of MS. In the last 20 years, we've had a dramatic change, with 10 therapies now approved (eight in Canada) to change the course of the disease. MS has gone from a completely untreatable disease to a disease that now can be treated quite effectively for most people diagnosed today.

The expanded spectrum of treatment options—including disease-modifying therapies, symptom management, complementary and alternative treatments and lifestyle choices—has created a heightened sense of hope for people with MS and their families. People with MS are living fuller, more productive lives than ever before.

People with MS are also more engaged in discussions with their families and physicians, and playing a greater role in determining the course of their healthcare. Research has demonstrated that starting treatment with a disease-modifying therapy as soon as possible is the most effective way to slow disease progression and prevent future damage. Making those choices—whether and when to begin treatment, and then deciding which treatment is best for you—can be a very complicated and emotional process, and it's not the same for any two people.

This year's North American Education Program explores the factors people must consider when making treatment and lifestyle decisions, including when to begin treatment, the role information overload can play in decision-making, and how to weigh the benefits and risks of a treatment or lifestyle decision.

We hope this booklet helps guide discussions with your family members and treatment team so you can make the choices that are healthiest for you.

# Presenters

**Deborah M. Miller, PhD, LISW**  
Mellen Center for MS, Cleveland Clinic

**Amit Bar-Or, MD, CM, FRCPC**  
Professor, Neuro-immunology  
Director, Experimental Therapeutics Program  
Coordinator, Clinical Research Unit  
Montreal Neurological Institute, McGill University

**Robert Fox, MD**  
Mellen Center for MS, Cleveland Clinic

**Marie Namey, APRN**  
Mellen Center for MS, Cleveland Clinic

## **Deborah M. Miller, PhD LISW**

Deborah M. Miller, PhD, LISW, is a master's-prepared social worker, a member of the professional staff at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic, and an associate professor of medicine at the Cleveland Clinic Lerner College of Medicine of Case Western Reserve University. She also has a joint appointment in the Cleveland Clinic Department of Quantitative Health Sciences, Section of Clinical Outcomes. Her PhD is from the Case Western Reserve University School of Applied Social Sciences, with an emphasis in program development and evaluation. She has been a member of the Mellen Center's interdisciplinary care team since 1985.

Her practice interests focus on marital and family adjustment to the consequences of MS, and she has lectured nationally on these subjects.

## **Amit Bar-Or, MD, CM, FRCPC**

Dr. Amit Bar-Or is associate professor of neurology and associate in microbiology and immunology at McGill University/MUHC and serves as scientific director of the Clinical Research Unit at the Montreal Neurological Institute. He also founded and directs the Experimental Therapeutics Program at MNI.

He completed undergraduate studies in biopsychology at McMaster University and received his medical degree cum laude from McGill University. He then pursued an internship and neurology residency training at the Massachusetts General Hospital, Harvard University Medical School.

He subsequently pursued postdoctoral fellowship training in neuro-immunology at the Center for Neurologic Disease, Harvard, while also completing the prestigious Clinical Investigator Training Program in Translational Research at Harvard and MIT.

Dr. Amit Bar-Or, a neurologist and neuro-immunologist, conducts laboratory research directed at understanding principles of immune regulation including B cell, T cell and APC interactions, and how these might relate to inflammatory neurological diseases, primarily multiple sclerosis.

### **Robert Fox, MD**

Dr. Robert Fox is staff neurologist and medical director at the Mellen Center for Multiple Sclerosis Treatment and Research at the Cleveland Clinic. He received his medical degree from Johns Hopkins University, completed his neurology residency training at the University of Pennsylvania, MS fellowship training at Cleveland Clinic, and received a master's degree in clinical research from Case Western Reserve University.

He is an advisory committee member and principal site investigator for many clinical trials, including serving as coordinating global principal investigator for a phase 3 clinical trial of dimethyl fumarate in relapsing-remitting MS.

Dr. Fox's current research interests focus on innovative MRI techniques to evaluate MS treatments and tissue recovery after injury, where he is principal investigator and co-investigator on grants funded by the National Institutes of Health and the National MS Society. He serves as a member of various advisory and review committees for the National MS Society. He is also managing director of the NARCOMS MS Patient Registry, and a member of the General Advisory Council and Research Programs Committee for the Cleveland Clinic General Clinical Research Center.

### **Marie Namey, APRN**

Marie A. Namey is an advanced practice nurse and clinical nurse specialist at the Mellen Center for Multiple Sclerosis at the Cleveland Clinic. Namey received her Master of Science degree in nursing from Frances Payne Bolton School of Nursing at Case Western Reserve University. She received her Bachelor of Science degree in nursing from Villa Maria College, in Erie, Pa.

Namey has been part of the interdisciplinary team at the Mellen Center for Multiple Sclerosis Treatment and Research at the Cleveland Clinic Foundation since its inception in 1985. She is a member of the National MS Society's Ohio Buckeye Chapter Professional Advisory Committee and the Chapter Programs Committee.

She has been a member of the Consortium of Multiple Sclerosis Centers since 1986 and has served as secretary, vice president and president of this organization. She was chair of the Education Committee and participated on the Education Committee and Abstract Review Committee. She currently chairs the Advocacy Committee. She is a founding member and immediate past president of the International Organization of Multiple Sclerosis Nurses.



# KNOWLEDGE DRIVES DECISION-MAKING

People often feel most comfortable making important life decisions when they have an abundance of information to support them. We rely on data for everything from buying a car to deciding where to work, live or go to school.

When it comes to health management, knowledge becomes especially powerful. In the past 20 years, our understanding of multiple sclerosis has expanded tremendously—and so have our choices. As recently as the early 1990s, we had no effective treatments for MS. Now, thanks to ongoing research, we know more about the origins of the disease, its triggering factors, and the wide variations in symptom type, frequency and intensity. What's more, we now have many treatment options to modify disease activity for people with relapsing forms of MS **and** better address symptom management.

“There’s really been a dramatic change over the last two decades, from a completely untreatable disease to a disease that we can now treat quite effectively,” says Dr. Robert Fox, medical director at the Mellen Center for Multiple Sclerosis Treatment and Research at the Cleveland Clinic.

## TODAY’S TREATMENT LANDSCAPE

Medications that alter the course of the MS disease process by reducing the frequency and severity of MS relapses first became available with the approval of Betaseron® in the United States in 1993 (1995 in Canada). Two other disease-modifying therapies—Copaxone® and Avonex®—soon followed, with approval from the U.S. Food and Drug Administration (FDA) in 1996 (and from Health Canada in 1997 and 1998, respectively). Since those early days, the number of available disease-modifying therapies (DMTs) for relapsing-remitting MS has rapidly multiplied to 10 (eight in Canada), with more in the pipeline.

1981

MRI first used to examine a person with MS



1993

Betaseron® approved in US for people with RRMS



1996

Canadian researchers find gene linkage to MS susceptibility



1998

Rebif® and Avonex® approved in Canada for RRMS



2000

MSSRF funds study that aims to determine whether transplanting bone marrow stem cells can stop the disease



Betaseron® approved by Health Canada for treatment of people with relapsing-remitting MS

1995



Copaxone® and Avonex® approved in US for people with RRMS

1996



Copaxone® approved in Canada for people with RRMS; MSSRF funds Canadian Collaborative Project on Generic Susceptibility in MS

1997

Betaseron® approved by Health Canada as a treatment for Secondary-Progressive MS

1999



Novantrone® approved in US for worsening forms of MS; Rebif® approved in US for people with RRMS

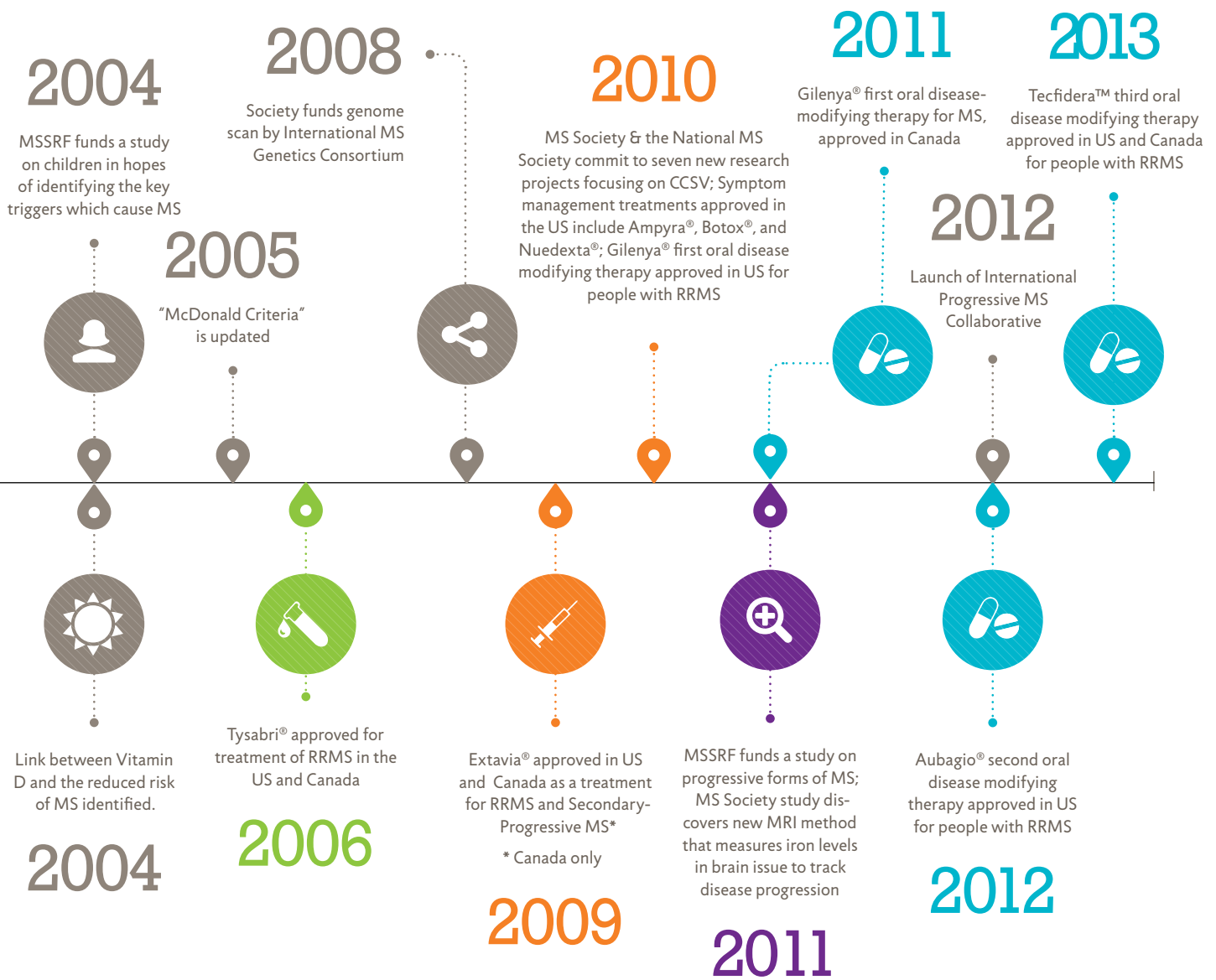
2002



Not only has the sheer number of DMTs expanded, but so has the variety of delivery options. Therapies are now available as injections, infusions and oral medications, giving people new options for how, when and where to take their medications. People who use injectable medications give themselves shots on a schedule that ranges from daily to weekly. Medications administered by intravenous infusion require a visit to a medical facility but the frequency of treatment is reduced to only monthly or

quarterly. In 2010, the FDA approved the first oral medication in the U.S., and two other pills have become available since then. Two of the oral medications are taken once a day and one is taken twice daily. (Only two oral treatments currently are available in Canada.)

“When we developed injectable therapies, they were a great asset because finally we had treatment for this disease,” says Dr. Fox. “One of the drawbacks of injectables is that they are



only partially effective. They only reduce the annualized relapse rate, or the frequency of episodes of MS, by about 30 percent, which leaves about two-thirds of the relapses still happening. There are also flu-like side effects and skin reactions, and patients don't like poking themselves for their MS therapy.

"So now in the last 10 years, we have many new therapies," Dr. Fox continues. "We have infusion therapies that are highly effective and

given infrequently. We also have oral therapies that appear, as best as we can tell, to be more effective than the older injectable therapies. But injectable therapies are extraordinarily safe. So this is an exciting time."

We've also come a long way in our ability to manage the **symptoms** of MS. Medications can help improve walking and ease fatigue, pain, spasticity, and bladder and bowel dysfunction, as well as other common symptoms.

We've learned a lot, too, about the effects that lifestyle choices have on MS symptoms. For example, experts used to caution people with MS not to exercise, thinking it would worsen fatigue; we now know that moderate physical activity actually can improve energy levels, balance, strength and more. Likewise, we have more information about the role smoking, nutrition, stress management and other factors play in determining how well people live with MS.

## MOVING FORWARD

We're not done yet, though. Researchers are accelerating their efforts to stop disease progression, restore function and end MS forever. They're looking at innovative therapies to repair myelin, the insulating sheath around nerves that is damaged in MS. They're studying whether such factors as vitamin D, hormones or probiotics can reduce MS immune attacks. They're working collaboratively to find treatments that can stop progressive forms of MS.

But that's just the beginning: The National MS Society and the MS Society of Canada have committed to increasing their funding of research activities to move closer to a world free of MS.

# YOUR MS, YOUR DECISIONS

Sometimes, arriving at the diagnosis of MS after numerous doctors visits and tests almost feels like a relief. Even though it brings a lot of uncertainty about the future, at least there's an explanation for all the mysterious symptoms. As such, it's tempting to put medical issues on the back burner for a while, and resume other activities.

But once the diagnosis of relapsing-remitting MS is made, it's imperative to start thinking about treatment choices right away. Early and ongoing treatment with an approved therapy can make a significant difference for most people with MS. (For treatment recommendations for progressive MS, please see page 28.)

If you feel well more often than not, you may think that you have time before you need to begin a disease-modifying therapy. However, even when you don't have active symptoms, MS can be operating in the background, causing irreversible damage (lesions) to the brain and spinal cord. This is true for people with relapsing-remitting forms of MS as well as those who have progressive forms. In fact, lesions occur 10 to 20 times more often than symptoms are felt by a person with MS.

“Early in MS, there's active inflammation in the brain and the spinal cord that causes acute injury. It damages the myelin sheath that covers the nerves, and also cuts the nerves at that very early stage. Although patients typically recover quite well from their early relapses, we do know

from MRI studies that there is a lot of injury left behind. There's scarring and shrinkage of the brain, or atrophy, which is left after that acute inflammation,” says Dr. Fox. So the earlier you begin a disease-modifying therapy, the more you can limit long-term disability.

**Taking medication before you feel like you need it is an investment in your future.**

Still, some people may be reluctant to start a therapy, citing factors such as fear of needles or the costs involved. If you delay treatment, however, you risk experiencing a major exacerbation of the disease. People who don't start treatment after their first MS attack typically have a second attack within two years, and additional relapses every six to 12 months. These relapses can result in changes in vision, balance, walking ability, sensation, cognitive function and many other symptoms—as well as new lesions. DMTs can cut relapse rates by approximately one-third to one-half, depending on the medication.

## THE LEARNING CURVE

Once you've made the decision to begin a DMT, you're faced with another choice: **which** medication to take. Having so many therapies available now can complicate the process.

There was a time when we simply relied on doctors to make such decisions for us. They told us what the best treatment was for our condition, and we accepted that verdict. Now, many of us expect to take a greater role in our healthcare decisions, partnering with our medical team and advocating for our needs. That's a positive development, says Deborah Miller, PhD, LISW, a social worker on Dr. Fox's team at the Cleveland Clinic. "It makes people aware and gets them thinking aloud about what it is they do and do not want out of their care. And it really leads to greater adherence to treatment decisions."

In some regards, that awareness is easier to achieve because of the vast amount of information now available to us. But that can quickly turn to information overload. Consider some of the sources where we now get medical information:

**Scientific data.** Many of us now conduct online searches for information about our health concerns. In doing so, we may read about clinical studies that examine the effects of certain treatments on large groups of people, and try to make decisions based on that. It's not unusual to find that studies often contradict one another, especially in the early stages of research—and that can add to our confusion. And for the majority of us who aren't savvy regarding research study design and interpretation, reading through scientific papers can be overwhelming.

**The media.** Mainstream media often report on studies that seem to show that a treatment is either a breakthrough cure or a devastating failure. However, they typically report only the headlines, not the variables that affected results.

In recent years, we've also become increasingly exposed to direct advertising from pharmaceutical companies—on TV, in print and online. Their marketing campaigns are designed to promote the benefits of their products, but may not give us all the information we need to make an informed decision. Social media goes even further, allowing for the rapid exchange of ideas and personal anecdotes.

"With popular media, the Web and so on, there is a huge amount of information—some of it terrific, and other information that is not as good and can give people ideas that are not substantiated," says Dr. Amit Bar-Or, a neurologist and neuro-immunologist who is coordinator of the Clinical Research Unit at Montreal Neurological Institute at McGill University, and director of the Experimental Therapeutics Program there.

**Friends and family.** Our social networks also influence us; it's not uncommon to know someone who has taken a DMT, and his or her personal story can color our perception of a particular therapy, either positively or negatively. Again, it's important to remember that these are single examples, and each individual responds to an intervention differently. And, adds Dr. Fox, "MS is highly variable, and patients can get better or not get better in very unpredictable ways," making it difficult to discern whether any specific approach really led to a person's improvement. Dr. Fox encourages people to more strongly

consider scientifically valid data, such as results from clinical trials and consensus statements from groups of experts.

**Healthcare professionals.** Even when we meet with our healthcare team, we may discover that a “successful” therapy means something very different to clinicians than it does to us.

“When we talk about the benefit of the disease-modifying therapies, it’s usually in terms of the number of exacerbations, the number of lesions and the changes in the Expanded Disability Status Scale (a scale that many neurologists use to measure function and level of disability). That really has very little to do with how people experience joy or happiness in their daily life,” says Miller.

“I look at it from a perspective of relapses and lesions on the MRI. Patients look at it from, ‘Can I do what I want to do in life? Can I go to the soccer game? Can I go to work? Can I do what I want to do at home?’” says Dr. Fox. “Which view is right? They’re both right. They’re just different perspectives of the same disease.”

**“It’s important for me to recognize that the patient wants to function, and important that the patient recognizes that I want to keep the lesions off the MRI at the beginning because that’s what’s going to keep them functioning in the long term.”**

## THE TREATMENT DECISION MATRIX

People are often understandably confused by the differences between disease-modifying therapies (which alter the course of MS by limiting new disease activity) and symptom management medications, which reduce the severity of some of the changes—physical, cognitive and emotional—brought on by MS.

“I review with patients three facets of treating their MS. One is treating active inflammation during a relapse. We typically do that with intravenous steroids. The second is disease-modifying therapies—the preventive therapies, which are trying to prevent relapses, prevent lesions on the MRI, prevent progressive disability over time. And the third—and it’s important to keep them separate—is treating symptoms. What symptoms have been left over from previous injury that need to be addressed? This can be pain or stiffness, or bladder, bowel or sexual dysfunction,” among others, Dr. Fox says.

In the last few years, we have seen the approval of Ampyra® (Fampyra® in Canada) to improve walking; Nuedexta® for pseudobulbar affect symptoms such as excessive or uncontrollable crying or laughing; and Botox® for upper-limb spasticity and urinary incontinence. These medications, while they may provide significant relief from symptoms, do not alter the course of MS disease activity.

Likewise, says Dr. Fox, it’s important to clarify the goal of disease-modifying therapy. “It’s not restorative. People are not going to feel better. It’s not something that they are going to notice. It’s meant to be preventive.”



As the number of approved therapies grows, the decision can become more complex. The truth is, there's no single perfect choice. "A perfect treatment would be one that would be very easy to take, would be absolutely

safe, would have no problems of tolerability and would be 100 percent effective," says Dr. Bar-Or. Each medication currently available, particularly when it comes to DMTs, comes with risks and benefits.

**\*Content was removed from this section of the original program book because the information it contained was out of date. For the most current information please refer to:**

- The Use of Disease Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence (A Consensus Paper by the Multiple Sclerosis Coalition)  
[www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT\\_Consensus\\_MS\\_Coalition\\_color](http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color)
- The MS Disease-Modifying Medications  
[nationalMSSociety.org/brochures](http://nationalMSSociety.org/brochures)
- Emerging Therapies Collaborative  
[ms-coalition.org/emergingtherapies](http://ms-coalition.org/emergingtherapies)
- MS Society of Canada Disease-Modifying Medications  
[beta.mssociety.ca/about-ms/treatments/disease-modifying-therapies-dmts](http://beta.mssociety.ca/about-ms/treatments/disease-modifying-therapies-dmts)
- MS Society of Canada emerging therapies  
[beta.mssociety.ca/research-news/treatments-in-development](http://beta.mssociety.ca/research-news/treatments-in-development)



## RISKY BUSINESS

As we now know, disease-modifying medications that offer greater benefit often come with increased—or unknown—risks. Because of this, people considering a specific therapy must decide how much risk they feel comfortable with. In addition, they must weigh numerous other factors, such as: their willingness to participate in careful screening and ongoing monitoring of their health, their ability to tolerate different kinds of side effects, and the convenience of one treatment method over another.

People vary widely in their tolerance for risk. “Unless we really talk to a patient in depth about their risks, and their thoughts about risk, we can’t really assume what they’re feeling because each individual brings to the table their whole constellation of life experience. So what’s risky for me may not be risky at all for a person with MS, or what I don’t see as a risk may be a huge risk for a person with MS,” says Marie Namey, an advanced practice nurse at the Cleveland Clinic.

The risk levels that people bear in their daily life—in sports, the stock market or anything else—may have little in common with the risk they are willing to take with regard to their health. “Patients who have experienced active MS that causes problems often will gravitate toward a treatment that packs a bigger punch up front. They may be more willing to take certain risks associated with that treatment—whether those are side effects or tolerability issues,” because they now understand the importance of limiting new relapses, says Dr. Bar-Or. “If a person is doing very well with their MS overall, and we’re suggesting a

treatment that might limit relapses—as a kind of an investment in their future because they are very, very functional—they may be less willing to take risks to decrease new injury.”

Research backs up those observations, showing that for most people, their risk aversion fluctuates over time. In general, the longer a person has had a disease, and the worse they believe their health condition to be, the more risk they are willing to bear from a treatment that offers relief. Given the variability of MS symptoms, a person’s tolerance for risk is likely to shift.

Naturally, you’ll want to involve your family and your healthcare team in your treatment decisions. “It’s important to keep in mind that MS is a family disease,” says Miller, the Cleveland Clinic social worker. She encourages family members to openly discuss their hopes and their fears about different medications. What feels like a safe bet for one person may feel reckless to another. Even though the choice is ultimately up to the person with MS, family members may also bring up considerations or pressures that might not be top-of-mind for the patient. By discussing these concerns, family members can often agree on a plan that feels comfortable to everyone.

Jennifer Whelan, 41, of Peninsula, Ohio, said that became apparent after her diagnosis in 2002. “When I decided what disease-modifying medication I was going to take, I looked at it not just for me and my professional circumstances—I traveled all the time, so I needed to make sure that I factored that in—but what this would mean for my home life. What part would my husband play or not play? What would he need to know about? What would he need to do to help me

continue that treatment moving forward? It's really important that the people closest to you are involved enough to understand what's happening with you and help support your decisions."

"It's always a question of figuring out the balance between impacting their MS, but also living with that treatment choice on a daily basis," says Dr. Bar-Or. "This contributes importantly to a treatment decision that is more likely to stand the test of time," he adds.

Namey suggests that it shouldn't be a one-time discussion. "I think because the decision-making process is more complex now, because there are more medications that we can use to treat MS, and there are certainly concerns about the risk-benefit ratio, there should be more communication between patients and their healthcare providers. There needs to be more dialogue."

Your healthcare team can also help you build the skills necessary to wade through the vast amounts of information, and make confident decisions. They can help you assess the likelihood of various risks given your individual characteristics, and can also help you put some risks in perspective. For example, the risk of an adverse effect like PML or ITP may feel ominous, but when you compare it to other daily risks, it loses some of its magnitude. Consider the following:

- Risk of developing MS: 1 in 750
- Risk of developing PML: Up to 11 in 1,000\*
- Lifetime risk of dying from heart disease: 1 in 5
- Lifetime risk of dying from a car crash: 1 in 368
- Lifetime risk of dying from crossing the street: 1 in 701

\* Risk varies depending on individual factors.

Even figures like these can be misleading. Statistics are based on the aggregate data from a group, not on individuals. "Phase 3 trials are the pivotal ones that we tend to hang our hats on in terms of understanding, in the experience of several thousand people with MS over a few years, what the balance might be between efficacy on one hand and safety on the other," says Dr. Bar-Or. "This discussion is based on averages. That doesn't necessarily tell us what is relevant to the person sitting in front of us."

**Individual genetic, environmental and behavioral factors can play a role in how a person responds to a certain drug— both in terms of benefit and in developing side effects.**

"Sometimes, patients get very focused on the potential risk and lose track of the purpose of the medicine—to prevent relapses, progressive disability, scars and injury to the brain and spinal cord—and they get very focused on, well, 'I don't want to have diarrhea. I don't want to have flu-like side effects. I don't want to have skin reactions.' Sometimes they lose track of the bigger picture of trying to prevent this disease from causing progressive disability," says Dr. Fox. A person's healthcare team can guide a discussion around that.

But remember that just as people living with MS have different definitions of treatment success than do physicians and researchers, they will also have different degrees of tolerance for risk. While a person with MS may be eager to try the newest medication, a doctor

may want to wait for more long-term data, or vice versa, and just like family members, both patient and doctor will need to openly discuss expectations.

“It definitely is a little bit overwhelming because there are so many different options,” says Alexander Normandin, 30, of Montreal, QC, who has been living with MS since 2007. “But I think speaking with my neurologist and other physicians was really helpful for me. They really laid out the treatment options and explained the risks and benefits of each one. I wanted to really try to get the disease under control so I went with the most aggressive form of therapy that was available to me at the time.” Normandin says his neurologist also made sure he was aware that no treatment was 100 percent effective, “just to make sure that I didn’t have unrealistic expectations.”

In contrast, Aaron Hawkins, 40, of Stow, Ohio, diagnosed in 2003, made a different choice. “I opted for the one that had the least dramatic side effects because I need to be around—as a wage earner for my family, as a husband to my wife and as a dad to my kids.”

Government regulators have yet another perspective on risk. It’s not uncommon to hear about treatments available in another country and wonder why we can’t access it here. Some agencies are more conservative than others, and want an abundance of proof that a medication is both safe and effective before approving it. An example is when cladribine, a medication that went through phase 2 and 3 trials, was approved in Russia and Australia for treating relapsing forms of MS. However the FDA and European regulators rejected it, citing concerns

about cancer cases correlated with its use. A few months later, its manufacturer decided not to pursue approval, and also pulled the product from the markets where it had gained approval.

There’s no single “right” amount of risk, and no “right” medication, but it **is** important to be comfortable with your decision so that you stick with the treatment and get the best possible result. Consider your job, family, social life, hobbies and anything else that’s important to you—and think through the impact that each risk or benefit would have in each of these realms— now and into the future.

As Whelan says, “You have a long life ahead of you, and I think your job as a patient is to figure out what’s going to help you to live your life the best that you can, the way you want to live it. And we’re lucky enough to have a lot of different options out there to support that future.”

## STOPPING OR SWITCHING MEDICATIONS

Dr. Bar-Or emphasizes that while deciding on the best course of treatment is important, it’s even more important not to get stuck in analysis paralysis. “When I initiate the first treatment discussion, I make the point that this is not a lifelong marriage to this particular treatment.”

It **is** important to commit to your choice for a period of time— at least six months—to properly assess how it affects you, both in terms of limiting your disease activity and in terms of side effects.

## COMPARING YOUR TREATMENT OPTIONS

Questions	Answers	My thoughts
Which medication do you think would best control my MS?		
Are there any reasons why I shouldn't take a specific drug?		
What are the advantages and disadvantages of injecting/infusing my medication?		
What are the advantages and disadvantages of an oral treatment?		
How will the different medications affect my lifestyle?		
What problems have other people had on a specific medication?		
What tests and procedures will be needed?		
What is involved with these tests and procedures?		
What side effects am I most likely to have?		
What side effects are the hardest to cope with?		
Are there any factors that might make it difficult for me to stay on the medication?		
What are my options if the treatment doesn't work or I can no longer take it?		

Remember that even though you might still have symptoms, such as fatigue, pain or spasticity, the medication may still be working well, meaning that it is preventing the disease from progressing—a fact that usually can be corroborated with MRIs and assessments of disability.

If you continue to have relapses on your current medication, or don't tolerate it well, then you and your family and healthcare team may wish to review other options, perhaps returning to the worksheet on page 24. In such cases, Dr. Fox reminds his patients “Just because the clinical trials may have suggested that it's more effective, in you it may not be.” Patients may also want to discuss switching to a new therapy if they find they dislike injecting themselves or visiting the infusion center once a month. (Guidelines for changing medications differ in Canada, so you should consult with your physician to find out what is appropriate in your circumstances.)

If you decide to become pregnant, you may need to change or stop your disease-modifying therapy. None of the DMTs are approved for use during pregnancy or breast-feeding. All DMTs except Gilenya and Aubagio have a “C” rating, with the evidence suggesting the chance of fetal harm. Gilenya has a “B” rating, meaning there's no evidence yet of any harm to a fetus but it remains a possibility. As noted on pg. 19, Aubagio is unique in having an X rating for men and women. Any woman or man who wants to have a baby should discuss it with his or her physician so they can develop a plan for coming off the DMT, and for managing MS symptoms while trying to conceive, carrying the baby and breast-feeding, if desired.

However, people shouldn't change therapies just because a new DMT becomes available, Dr. Fox emphasizes. In certain cases, switching therapies can carry additional risks. In some instances, physicians will recommend a “washout” period to ensure that the first medication is out of your system before the new treatment is started; this prevents complications that could occur from two therapies being active at the same time.

For example, if you have been taking Tysabri or Novantrone, which have profound effects on the immune system, your physician will want to monitor you closely before switching you to Gilenya, which can result in lower white blood cell count and decreased ability to fight infections. For this reason, these medications may require a washout period of at least six months. Because a washout essentially is a period of time with no active disease-modifying therapy, it introduces the possibility of a relapse. For that same reason, a person should never abruptly stop taking a DMT without consulting a physician.

In fact, Dr. Fox says that the trend of late is to keep most washout periods as short as possible to prevent relapses between the therapies, though Dr. Bar-Or notes that for a patient who is switching for tolerability reasons and not because of high levels of MS activity, a longer washout period might be preferred.

## FINANCIAL FACTORS

If only health considerations and convenience were the sole factors in determining which DMT to take. In all areas of medicine, however, the high cost of medications and the differences between insurance plans have a significant effect on individuals' access to medications and the choices they may have.

A number of recent studies have examined the costs of living with MS, including the costs of DMTs and other direct medical costs, the costs associated with relapses, the impact of disease severity or disability, and indirect costs such as diminished productivity at work. Because MS is usually diagnosed at a relatively young age, and because of the costs associated with it, the total economic impact of MS exceeds that of other debilitating diseases that usually occur later in life, such as stroke or Alzheimer's disease.

Many but not all private insurance plans in the U.S. and Canada cover prescription medications; furthermore, plans may cover certain medications but not others, or may cover only part of the cost. It's always best to inquire about your out-of-pocket costs for specific medications with your insurance carrier before making a decision. Insurance plans that don't cover medications may still cover intravenous infusions because they are medical procedures carried out in an approved facility.

In the U.S., Medicare Part B does cover Novantrone and Tysabri because they must be infused. Similarly, because Avonex is injected into a muscle (as opposed to under the skin), it can be covered under Medicare Part B as well, if it is administered in a physician's office or clinic. Medicare Part D covers prescription drugs through private plans approved through

Medicare. Medicaid also covers certain prescription drugs, though these may vary from state to state. For more information on Medicare and Medicaid programs, call the National MS Society at 1-800-344-4867.

Individual insurance carriers also will vary in their coverage of symptom-management medications. If the drug your doctor recommends for bowel or bladder function, spasticity, pain or other symptom control is not covered, you may be able to find a lower-cost medication, such as a generic alternative.

Even for U.S. patients who have insurance, annual out-of-pocket expenses for MS are high. A recent study found that starting DMTs earlier in the disease course results in greater cost-effectiveness.

Each of the pharmaceutical companies that distributes DMTs offers a program to assist people in applying for and using federal and state assistance programs. They also provide their own assistance programs to some people who are uninsured or underinsured. A discount program, **needymeds.org**, can help offset some of the cost of medications. It can't be combined with insurance, however. For a list of patient assistance programs, please see the Additional Resources section at the back of this book, beginning on page 44.

Veterans and their dependents may qualify for assistance in paying for medications. Contact the Department of Veterans Affairs at **va.gov/health** or Tricare at **tricare.osd.mil** and 1-800-273-8255.

In Canada, treatment costs for DMTs vary among provinces and private insurance companies. For more information on specific provincial drug programs, call the MS Society of Canada at 1-800-268-7582.



## Progress On Progressive MS

For people who live with progressive MS, the treatment options are much more limited. Virtually every DMT approved for relapsing-remitting MS has been tried (or is currently undergoing clinical trial) for progressive MS, but most haven't proved effective in people who are not experiencing relapses.

While Novantrone has been approved for use in secondary-progressive MS, it isn't prescribed often in the U.S. because of the risks outlined on pg. 17. We're still learning what's different about progressive MS and how to treat it. "The anti-inflammatory therapies of early MS don't seem to work at all in progressive MS, so that points us toward the conclusion that whatever is going on is very different," says Dr. Fox. In addition, says Dr. Bar-Or, "Our experience has taught us that the treatments that are effective at limiting relapses are not particularly effective at changing the trajectory of progression or the rate of progression that patients experience."

People with progressive MS may question why they can't at least try one of the medications approved for relapsing-remitting MS, particularly if they hear of a therapy that is marketed as being able to limit progression. "There are two different ways by which patients can develop worsening neurological problems. One has to do with relapses that don't get completely better ... and this would be a progression of their disability. This is not the same as saying that this treatment is effective

for the progressive forms of MS," says Dr. Bar-Or. "If a treatment is not effective, there's no real point in exposing the person to either the tolerability issues of the potential risks of a treatment," he adds.

Clinical trials of experimental therapies for progressive MS, too, have met with limited success. Trials in relapsing-remitting MS often rely on counting relapses or using MRI scans to detect immune activity. Because there are no relapses to count, these strategies do not work for progressive MS. Instead, researchers need to study very large groups of people over very long periods of time to identify when progression occurs (or when an experimental therapy halts progression). "These are very, very difficult studies to do," Dr. Bar-Or says. The fact that there is no easy way to identify progression quickly (or to tell when an experimental therapy halts progression) is one reason why drug development for progressive MS is lagging. Researchers believe one way to measure progression is through brain atrophy; worsening of physical disability is another possible sign. But we need more definitive answers.

Through the International Committee on Clinical Trials in MS (supported by the National MS Society and the European Committee on Treatment and Research in Multiple Sclerosis), researchers are studying the underlying biology to create better definitions of MS and progression, better clinical trials and, ultimately, to improve MS diagnosis and treatment.

To spur innovation, the National MS Society and the MS Society of Canada have joined forces with the MS societies from Italy, the Netherlands, the United Kingdom and the MS International Federation to create the International Progressive MS Collaborative. The Collaborative is focused on several key challenges:

- Finding ways to replicate progressive MS in the lab in order to determine what factors contribute to the disease, and develop potential solutions.
- Finding new tools to identify potential drug treatments for progressive MS.
- Finding new ways to test potential treatments for progressive MS faster and with fewer patients.
- Finding useful treatments for symptoms associated with progressive MS and developing rehabilitation strategies to improve quality of life.

To this end, several large clinical trials are underway, with up to \$85 million being invested around the world to understand progressive MS. Some of the newer medications approved (or submitted for approval) for relapsing-remitting MS are being studied for their effects on progressive MS. Tysabri is currently in phase 3 trials, and these

should be completed by December 2014. Researchers are also looking at using Gilenya and ocrelizumab to modify the course of progressive MS, and results are expected by fall 2014 and July 2019, respectively.

Other potential therapies under study for progressive MS include rituximab, a medication used to treat rheumatoid arthritis and some forms of cancer, for secondary-progressive MS; and idebenone, an oral therapy structurally similar to the naturally occurring antioxidant coenzyme Q-10, a common dietary supplement sometimes simply called CoQ10.

In the United Kingdom, researchers have begun testing four potential therapies for secondary-progressive MS. Each of the four—ibudilast, amiloride, pirfenidone and riluzole—targets a different key pathway implicated in MS-related nerve damage. If any of these therapies shows a clear effect in the first stage, it will undergo further testing.

Other studies are focusing on whether MS progression can be limited by protecting the nervous system from further damage. Trials taking this approach are testing lipoic acid, an antioxidant; and phenytoin and oxcarbazepine, therapies used for epilepsy.

In 2012, researchers also completed the first human trial of an experimental therapy targeting myelin repair. In mice, an antibody that inhibits a molecule called LINGO-1 increased myelin repair. That finding led to a study of 64 healthy adults and 42 people with either secondary-progressive or relapsing-remitting MS. There were no serious adverse events—headache was the most common side effect—so further clinical trials are expected.



Another robust avenue of research today explores the potential use of stem cells to slow MS disease activity or repair existing damage to the nervous system. One type of procedure being studied, called “autologous hematopoietic stem cell transplantation,” involves taking stem cells taken from an adult and later transplanting them in the same person.

This procedure has been used in attempts to “reboot” the immune system. These stem cells (derived from the bone marrow or blood) are stored, and the rest of the individual’s immune cells are destroyed by chemotherapy, radiation or both. Then the stored stem cells are reintroduced by injection. Eventually they grow and repopulate the body with immune cells. While this procedure is still experimental, the hope is that the new immune cells will no longer attack myelin or other brain tissue, and the person will essentially have a completely new immune system. This approach is being investigated in Canada, the United States, Europe and elsewhere. In addition, Fast Forward (the National MS Society’s initiative to accelerate drug development) is funding MultiStem, a promising new stem cell product being developed by Athersys to treat all forms of MS.

Investigators also recognize the importance of being able to determine when progression occurs or doesn’t occur. The National MS Society has joined forces with the Critical Path Institute to launch the Multiple Sclerosis Outcome Assessments Consortium, which has attracted the involvement of industry, academia, patient representatives, and regulatory and other government agencies. This coalition will collect, standardize and analyze data from MS studies with the goal

of developing a meaningful way to measure disability that can be used in future MS trials. The new clinical outcome measure will spur the development of therapies for all forms of MS, but perhaps especially for progressive MS.

In the meantime, physicians focus on providing therapies that can improve the symptoms and day-to-day functioning of people with progressive MS. “We can help with weakness, we can help with spasticity, with walking, bladder, bowel, sexual function, pain, mood. There are very few symptoms of progressive MS that we don’t have some treatment or some modality that we can use to help improve the quality of life for patients,” says Dr. Fox.

## TREATMENTS IN THE PIPELINE

- Amiloride
- Cannabis extract
- Erythropoietin
- Fingolimod
- GNBAC1
- Green tea extract
- Hydroxyurea
- Idebenone
- Ibudilast
- Lipoic acid
- Lithium
- Masitinib
- Mesenchymal stem cells
- MIS416
- Natalizumab
- Ocrelizumab
- Oxcarbazepine
- Pirfenidone
- Riluzole
- Rituximab
- Siponimod
- Tcelna

# Taking Charge of Your Health

The act of researching therapies, discussing their risks and benefits with your family and healthcare team, and deciding on the best option for your circumstances can be empowering. You're taking active steps to remain as healthy as possible for as long as possible.

Those choices also confer a lot of personal responsibility to ensure treatment is as successful as possible. That can mean setting alarms to remind you to take your pills, arranging for a ride to the infusion center, or making sure you have all the supplies you need for self-injections.

As important as disease-modifying therapies are, they can't work in a vacuum. It's essential that people with MS take positive actions to care for their bodies in other ways, too. Part of that involves being aware of symptoms, and the ways that they can be most effectively managed.

“When I introduce the treatment landscape to a person with MS, I often describe the different categories of treatments that are available,” says Dr. Bar-Or. He begins by describing steroid medications used to limit the duration of an acute exacerbation, and then discusses DMTs to alter the course of the disease. “The final category can be called symptomatic treatment,” he says. “These types of treatments may substantially limit or take away certain symptoms but they do not change the MS process. Nonetheless, they can

be critical for a person who experiences such symptoms on a daily basis as fatigue, problems with bladder control, numbness, tingling or a variety of other symptoms. For these people, symptomatic treatment can be quite effective.”

In fact, says Namey, the Cleveland Clinic advanced practice nurse, “symptom management is the hallmark of care for people because symptoms are what really affect quality of life over time.”

## SYMPTOM MANAGEMENT

Sometimes it's difficult to tease out MS-related symptoms from other aches and pains and feelings of fatigue, but people who've lived with the disease for some time begin to recognize how various activities affect them.

As Normandin says, “I have to make sure that I'm going to be able to sit if I go somewhere for a long time. And getting the right amount of sleep has been really important for me. I've had to be a lot more deliberate about all the choices I've made. Before, I was maybe a little more breezy. Now I have to plan everything.”

To arrive at that level of understanding, it can be helpful to understand the spectrum of symptoms.

The most common symptoms include:

- Fatigue
- Numbness
- Walking, balance and coordination problems
- Bladder or bowel dysfunction
- Vision problems
- Dizziness and vertigo
- Sexual dysfunction
- Pain
- Cognitive dysfunction
- Emotional changes
- Depression
- Spasticity

This list is not exhaustive, however. Less common symptoms include speech or swallowing problems, headaches, hearing loss, seizures, tremors, breathing difficulty and itching. For more information on medications for specific symptoms, please go to [nationalMSSociety.org/meds](https://nationalMSSociety.org/meds) or [mssociety.ca/en/information/symptoms.htm](https://mssociety.ca/en/information/symptoms.htm). You can also call the National MS Society at 1-800-344-4867 or the MS Society of Canada at 1-800-268-7582.

What's important to know is that nearly every symptom of MS can be treated with medication or rehabilitation. People experiencing one or more of these symptoms should discuss them with their healthcare providers and determine which treatment options are best for them.

“People become homebound because of bladder incontinence, and that’s just not necessary,” says Miller. “If they let us know that they’re afraid to leave the house because they don’t know where the next bathroom is, we can help them with that.” Or, people may have difficulty with cognitive changes. Because cognitive changes can be subtle or go unnoticed by those around them – including physicians, who often don’t get to spend as much time as they’d like with patients – it’s important for people to let their healthcare team know if they think their memory, reasoning or other cognitive skills have been affected. “We are really good at teaching people how to compensate for those changes. It’s very important for people to be aware of and use compensatory strategies to manage the memory problems associated with MS. It can make a huge impact in how they feel about themselves and how they interact with their family and friends,” she says.

While physical changes (and to a certain degree, cognitive changes) are expected when people receive a life-altering diagnosis, they’re often surprised to learn that MS may have profound emotional consequences, too.

**Depression.** Depression, perhaps the most common mood change, can occur as part of the disease process, or as a reaction to it. It can also be a side effect of some of the disease-modifying therapies, most notably the interferons. Corticosteroids, often used to manage an acute exacerbation, can also have this effect. Depression is biologically based, and is not something that a person can control or prevent by willpower or determination, and it does not indicate a weak character. But depression IS treatable.

The first step, as with any other symptom or illness, is to become aware of it. “Sometimes people need to have family members or friends point it out,” says Miller. Depression is different than the normal grief a person will feel adjusting to the new reality of living with MS. It is usually diagnosed after a person has gone two weeks or longer without showing interest in the things that normally bring them pleasure, or has changes in sleep or appetite (either more or less than usual), feelings of worthlessness or guilt, or thoughts of suicide.

If you’re experiencing these symptoms, it’s important to call your healthcare provider right away. That can be the nurse in your MS clinic who provides most of your care, your primary care physician or your neurologist. They’ll all be experienced in dealing with depression, and there’s no need to have any more anxiety about discussing these symptoms than about, say, high blood pressure.

“Treating depression can improve every aspect of a person’s functioning,” says Miller. “Being depressed clouds every aspect of how you view life. It can influence how you feel your symptoms are. It can influence your assessment of how you’re physically functioning.”

But left untreated, depression can disrupt sleep, worsen fatigue, memory and concentration, and can also significantly raise your risk for self-harm. Your healthcare provider can help you determine the best course of treatment—perhaps medication, “talk therapy,” or both.

Other emotional changes can also occur as a result of MS. These include:

- **Anxiety.** Worry, agitation and muscle tension are common reactions to the unpredictability of MS. Other symptoms of anxiety may include insomnia or restlessness, and panic attacks. Like depression, it can be treated with medications and talk therapy.
- **Moodiness and irritability.** Some people with MS notice that they have more difficulty controlling their feelings of anger or irritability, and that these mood swings can occur quickly and without warning. This is distressing not only to the person experiencing the mood change but also to family, friends and others around them. This type of mood swing can often be successfully treated with mood-stabilizing medications and with family counseling.
- **Uncontrolled emotions.** Inappropriate and uncontrollable bouts of laughing or crying—called pseudobulbar affect—can occur if the part of the brain that controls emotion is affected by MS. People with this symptom often report that they don’t feel the emotion that corresponds to the behavior. This symptom is often treated with a medication called Nuedexta.

## LIFESTYLE STRATEGIES

“Wellness” is a popular concept these days, and it’s an important one. It incorporates physical, emotional, mental and spiritual health. As Namey points out, it’s not just freedom from disease or symptoms. “It means making the most of the health and well-being that a person has,” she says.

One of the most important ways to do that is to remember that you’re much more than a person with MS. You’ll face the same primary healthcare concerns as everyone else, and will need routine exams such as mammograms, colonoscopies and prostate screenings. That means that in addition to your MS team, a primary care physician should also be involved in your healthcare, and you should schedule regular appointments with him or her. Make sure your primary care physician knows about any changes in your MS treatment, and vice versa: Your MS team needs to know about any new medical conditions and treatments you’re taking for them.

People with MS have many additional lifestyle choices they can make, which are equally empowering and can go a long way toward overall wellness. Here are some ways you can take control.

**Stress.** Nearly everyone feels stressed these days. A 2012 study by the American Psychological Association found that 72 percent of participants reported their stress levels had stayed the same or increased in the past five years. They cited factors ranging from financial and work concerns to family responsibilities and relationships. Add something like MS into that mix, and it would be hard **not** to feel strained.

The unpredictability of the disease itself can take a toll; so too can concerns about your future, the need to adjust to ever-changing levels of ability, others’ responses to your symptoms, and more.

It’s well documented that stress can affect various aspects of our well-being, such as heart health and digestion. Some people feel that stress makes their MS symptoms worse, too. While there’s no consistent scientific evidence confirming that, it’s clearly beneficial to manage stress in any healthy way possible.

One of the most time-honored ways of handling stress is to talk to someone about the factors creating the stress. That could be a trusted friend, a spouse or partner, or a professional counselor. You can also find support through National MS Society programs like MSFriends (1-866-673-7436) or **MSconnection.org**.

Other people find that getting away from the source of the stress—either mentally or physically—can help. Many people find relief through creative outlets, such as writing, painting or playing a musical instrument. Others are partial to meditation, visualization, relaxation and breathing practices that help refocus attention. Some find gentle forms of exercise, such as yoga or tai chi, help relieve stress. Others turn to more rigorous exercise such as running or biking to escape their tense mindsets for a while.

**Sleep.** MS can affect sleep in a number of ways. If a person has an untreated bladder problem, for example, middle-of-the-night trips to the bathroom can interfere with sleep. So too can pain, spastic limb movements and mood changes such as depression or anxiety. And lack

of sleep, in turn, worsens MS-related fatigue and overall quality of life. If MS symptoms are keeping you from a restful night's sleep, talk to your doctor to determine the best way of addressing it.

“I think that most people with MS live with some order of sleep deprivation,” says Miller. She says that while some of that is likely due to MS symptoms, it's often because of poor sleep habits as well. “And sleep hygiene is very simple.”

Experts recommend going to bed at the same time every night, and limiting screen time for two hours before bedtime, as the lights from TVs, computers and cellphones can interrupt our sleep/wake cycles. It's also wise to avoid caffeine and exercise for several hours before bed. Large meals and alcohol consumed too close to bedtime can also prevent you from staying asleep through the night. Sleep environment is critical too: The bedroom should be dark (cover up those glowing lights from clocks and other electronic devices if necessary) and cool. Practicing stress-management techniques will also make it easier to fall asleep at the end of the day.

**Nutrition.** A healthy diet is important for everyone. We now know that good dietary habits can prevent heart disease, stroke, diabetes and perhaps some types of cancer. Just like everyone else, people with MS can be at risk for these other conditions, and should eat well to minimize these risks.

But a healthy diet is important for people with MS for other reasons, too. Just as a steady regimen of fast food and snacks can sap energy, a healthy diet can boost energy and lessen fatigue; it can support good bone health and keep your bladder and bowel functioning

optimally. Getting the right **amount** of food for your level of activity can be as important as eating the right types of food; if you become overweight, you may experience reduced mobility, and if you don't eat enough, your energy may lag.

There's no “MS diet” that's been proven to reduce symptoms. “It's very, very difficult to carry out an organized trial that relates to people's diet,” says Dr. Bar-Or. So healthcare professionals generally recommend a Mediterranean-style diet, with an abundance of lean protein—found in poultry, fish, beans and soy products—as well as healthy, unsaturated fats like those in olive oil, and lots of fruits and vegetables. The fiber in the fruits and vegetables can be especially helpful in managing constipation, which often occurs with MS.

In addition to these general recommendations, research is showing that certain nutrients may play a role in the development or prevention of MS. Three studies conducted in 2012 suggested that excessive salt in the diet may spur autoimmune activity, although the research is not conclusive. “At this point I am not recommending to my patients that they modify their salt intake, other than following a general low-salt diet, which is a general medical recommendation,” says Dr. Fox.

Significantly more research supports the idea that vitamin D may influence the development of MS. In 2010, researchers in France noted that low levels of vitamin D seem to trigger a similar disease in mice; and that numerous studies have shown a direct association between how near to the equator people live and their exposure to the sun. That in turn affects their vitamin D levels, which seems to



correlate to their risk of developing MS. Those with the lowest levels appear more likely to develop the disease.

Additional studies continue to examine the role of vitamin D in MS. Swedish investigators found that high levels of vitamin D in the blood of pregnant women were associated with reducing the women's risk of developing MS later on. And a new study sponsored by the National MS Society is looking at whether Copaxone plus high doses of vitamin D can reduce the frequency of MS relapses.

While these studies are promising, they are not conclusive. And there's no consensus yet on whether, or how, this data should inform treatment decisions. People who are interested in vitamin D supplementation may wish to ask their healthcare provider for a blood test to find out if their levels are indeed low. The test typically costs between \$50 and \$200, and insurers may or may not pay for it. A person can take supplements without taking a blood test. However, without a test, it's difficult to know the proper dosage, especially considering that sunlight exposure and diet affect vitamin D metabolism and absorption. Many experts recommend that if you do take vitamin D supplements, that you look for it as D-3, the form most available to the body, and consult your physician for help in determining the best dosage for you.

Recent research is exploring the role that the "gut microbiome" may play in immune activity, including that involved in MS. The idea is that the large numbers of microorganisms that live in the body, such as in saliva and the intestines, may be involved in turning on or off immune attacks. Although this research holds promise,

there is currently insufficient evidence to support any specific diet or probiotic regimen that can turn off MS disease activity.

**Exercise.** We know that regular exercise contributes to heart health and to maintaining a healthy weight. For decades, many doctors cautioned people with MS against exercising, with the concern that it could worsen fatigue and potentially raise the core body temperature in people who already had a difficult time managing heat.

Now we understand that MS isn't a reason to sit on the sidelines; in fact, studies show that exercise is quite beneficial for people with MS. Rather than worsen fatigue, it may improve energy levels. In addition, it can help maintain bone health and help manage bowel dysfunction. Exercise also has physiological benefits for the brain, improving both sleep and mood. Preliminary research also suggests that exercise may be good for cognitive function. The overall effect: Exercise helps people with MS function better.

A recent study showed that people with MS who exercised twice a week for six months showed improvement in strength and endurance—regardless of their degree of physical disability. Those gains in strength and endurance translated into better balance and walking, and decreased fatigue. Exercise routines included using common resistance training equipment, such as weight machines and free weights, as well as performing balance exercises.

Another study demonstrated that people who worked out on an elliptical trainer showed significant improvements in fatigue levels as well as overall quality of life. Elliptical trainers—cardio equipment commonly found



at gyms—simulate a natural walking pattern, and are favored by many people for their low impact on joints. People can control both the speed and the resistance, or difficulty, of the exercise on these machines.

People who have heat sensitivity issues may wish to focus primarily on strength training, which does not raise core body temperature as much as cardio exercises do. Cardio training is not out of the question; water-based exercises can help cool your body as you work out. Cooling vests can also help, as can exercising in a cool room or in front of a fan.

Dr. Fox says that even people who use wheelchairs, canes or walkers can exercise. “You can still sit on an exercise bicycle, or if patients aren’t able to use their legs, they can use a table bicycle wheel,” which is propelled by arm movements.

The MS Society of Canada partnered with the Canadian Society for Exercise Physiology and ParticipACTION Canada to develop physical activity guidelines for adults with MS. In the U.S., the National MS Society encourages people to work with their healthcare team, who can provide individualized recommendations and can often help people find appropriate exercise options in their communities.

If you’re not accustomed to exercising, you may need to start off slowly and gradually work up. Namey says, “I often tell my patients to start at 5 minutes a day. Even if they feel they could do 10 or 20, start at 5.” Then increase that amount by 5 minutes each week until you can exercise comfortably for 30 minutes.

It’s a good idea to get cleared first by your physician, who can address any possible factors that might affect your ability to exercise

safely. If spasticity or other symptoms are preventing you from exercising, treatments are available. Your physician may also want you to see a physical therapist, who can evaluate your strength, balance and visual abilities, and recommend an appropriate exercise program based on these assessments.

**Smoking.** By now, everyone knows that smoking has grave effects on health. It contributes to cancer, obstructive respiratory diseases like emphysema and bronchitis, and to stroke and heart disease. Smoking is responsible for nearly one in five deaths in the U.S.

What’s lesser known is that smoking appears to contribute to the risk of developing MS, and to its progression. Research suggests that people who have smoked at any time in their lives have a nearly 30 percent higher risk of developing MS than people who have never smoked. In addition, those who smoked and developed relapsing-remitting MS had more than three times the risk of it converting to secondary-progressive MS than those who had relapsing-remitting MS but never smoked. Smokers with MS develop more lesions and brain atrophy, and a greater degree of disability in a shorter period. They are also more likely to die at a younger age.

While so much of the course of MS is unpredictable, “Smoking is something that patients can change themselves,” notes Dr. Fox.

“I had a tobacco habit when I was first diagnosed,” Hawkins admits. “Shortly thereafter, I decided that I’d already heard enough bad news from people in white lab coats. I quit cold turkey and haven’t looked back.”

### Complementary and alternative medicine.

A desire to assert control over the disease often drives interest in exploring complementary and alternative medicine (CAM) to help manage MS symptoms. In the United States today, approximately 75 percent of people with MS use some form of CAM, generally in combination with their prescribed MS treatments. “With a disease where we don’t have a cause and we don’t have a cure, people with MS want to try some other options, and feel empowered,” says Namey.

CAM encompasses a range of treatments: massage, acupuncture, chiropractic, meditation, yoga, dietary supplements and more. Vitamin D supplementation is perhaps the most widely accepted CAM treatment, and many physicians are now testing their patients’ vitamin D levels and recommending supplementation when appropriate, as described earlier on page 36.

Most healthcare providers will not discourage patients from pursuing other forms of CAM—as long as they are not damaging to a patient’s health or causing financial hardship—but do want to know about all treatments a person is pursuing, so they can help to balance them with medications. “Some CAM treatments may influence the way that your disease-modifying therapies or other prescriptions affect you. And it’s important for your clinician to know what steps you’re taking to really manage your illness yourself—what sense of self-efficacy you have, and how confident and knowledgeable you are about these different therapies,” says Miller.

It’s also important not to rely on CAM as a replacement for medication. Many CAM treatments can feel nourishing and healthful, but they don’t undergo the same rigorous study of efficacy and safety as approved medications. “The data about complementary and alternative treatments is not as robust,” says Namey, “so we don’t have that exact knowledge about the risks and benefits of some of these interventions.”

Adds Dr. Bar-Or, “Certainly there will be people who might say, ‘This has been the best thing for me, and I absolutely advocate this for other people living with MS.’ This is something that is best discussed broadly in the context of the variety of treatment choices out there. What has worked for one person is an anecdote, and is not necessarily something that will be broadly applicable across the board.”

For more information about CAM, visit [nationalMSSociety.org/CAM](http://nationalMSSociety.org/CAM).

# Deciding What's Right For You

Living with MS is challenging. But a trusted healthcare team can make navigating the complexities a bit easier. The team comprises many people: a neurologist, an MS nurse, a social worker and perhaps other specialists, such as an ophthalmologist or an occupational, physical or speech therapist, depending on your symptoms and needs. Each brings a different expertise and can help you make decisions about disease-modifying therapies, symptom management, complementary and alternative treatments, and lifestyle—and help you balance each in your overall plan of care—now and into the future.

You'll also want to find a primary care physician who can help you navigate all the other realms of healthcare you need to pay attention to that **aren't** related to MS—from regular gynecological or prostate exams to cholesterol screenings and winter colds.

Your healthcare team can help you to be an educated consumer, and use the wealth of information now available to your advantage. “One of the things that we try, as a team, to do is to make sure patients can distinguish between information that is high quality and that has been somehow vetted, and information that may be out there but shouldn't necessarily carry the same weight,” says Dr. Bar-Or.

Learn what the data from clinical trials can and cannot tell you. Understand what the different kinds of studies are, and how factors like the number of people studied and the

length of time a treatment was given affect the outcome. And realize that whatever the statistics show may or may not be true for a given individual. Your genetics, your environment and your behaviors all affect your outcome. Your team can help you use all of that information to arrive at the best decision for you.

It's great to be open to different opinions and new information. The field of MS research is continually evolving, and we're learning more every day. But as you weigh different pieces of information, remember to consider the source. How much knowledge or experience does the person expressing a viewpoint have? How important is their viewpoint to you? Is what they're saying “too good to be true”?

As you discover anecdotal stories online and in the broader media, keep your perspective. Remember that the media uses headlines to

attract attention, and they don't always report the subtleties or nuances of a study or finding. You're likely to hear the very best and the very worst stories, but the experience of most people falls somewhere in the middle.

As you think through the pros and cons of each potential treatment and lifestyle choice, it can be helpful to view your decision with the benefit of hindsight. For each option you consider, ask yourself how you might feel about this decision several years from now.

But remember, making decisions about disease and symptom management is a process. New information may come to light—either in the form of scientific developments or in understanding how well something is or is not working for you. And you have the right to change your mind. There's no crystal ball in MS management, but you can use all the tools at your disposal to make the best possible decisions today.

# APPENDIX

## WORKSHEETS

The following worksheets may help you as you sift through your options.

### WORKSHEET A

The MS Society of Canada adapted the following worksheet from the Ottawa Hospital Research Institute to help weight the benefits and risks of MS treatments, and to learn where you need more information or support to make a decision.

### QUESTIONS TO ASK YOUR MS TEAM

The following are some questions that you may want to discuss with your MS clinic team.

#### MULTIPLE SCLEROSIS

1. How will MS affect my life?
2. What are the physical and cognitive symptoms I could develop?
3. How will I know if my MS is getting worse?
4. What is the likelihood that I'll end up with physical and/or mental disabilities?
5. Will MS affect my ability to have children, or to raise a family?

#### TREATMENT

1. Will treatment be effective for my type of MS?
2. What are the possible benefits of treatment?
3. How will different treatments affect my lifestyle?
4. What side effects may occur? What is the likelihood that I'll experience these side effects?
5. What can I do if these side effects occur?

6. Is special monitoring needed once I start the medication? How often? Who pays for these tests?
7. How will I know if the medication is working? If it isn't working, should I continue with my current treatment or switch to something that may be better?
8. What do I do if I forget to take a dose?
9. What if the medication doesn't work? How will that affect my treatment options later on?
10. Whom do I contact if I run into problems with my medication?

**ADDITIONAL QUESTIONS:**

## WORKSHEET B

The Multiple Sclerosis Association of America has developed an easy-to-remember list of factors to consider when evaluating treatments and lifestyle choices. The word **SEARCH** can remind you to consider:

**S:** Safety

**E:** Effectiveness

**A:** Affordability

**R:** Risks

**C:** Convenience

**H:** Health outcomes (overall wellness/quality of life)

Downloadable workbooks and other tools and information are available at **[MSAAssociation.org/programs/Search](https://www.msaa.org/programs/Search)**.

## ADDITIONAL RESOURCES

### IN THE UNITED STATES

The National MS Society has an extensive library of resources about MS, including publications about treatment options, symptom management and living well with MS.

The Society's MS Navigators also offer assistance in answering questions about living with MS. These highly skilled professionals can help you connect to resources in your community, access optimal healthcare, meet workplace challenges, understand health insurance, plan for the future and much more. Whether you are a person living with MS, a family member or someone who cares about a person with MS, you can call an MS Navigator at 1-800-344-4867 during standard business hours, Monday through Friday. You can also email us at [contactusnmss@nmss.org](mailto:contactusnmss@nmss.org) or find us on Facebook at [facebook.com/NavigatorMS](https://www.facebook.com/NavigatorMS).

### PUBLICATIONS

The publications listed below are available at [nationalMSSociety.org/brochures](https://www.nationalMSSociety.org/brochures) or by calling 1-800-344-4867. In addition, the National MS Society's flagship publication, **Momentum**, offers many articles on treatment and lifestyle choices. Visit [MomentumMagazineOnline.com](https://www.MomentumMagazineOnline.com) to explore.

### GENERAL INFORMATION

#### **The MS Disease-Modifying Medications**

Information on the disease-modifying medications. Includes how each is taken, potential side effects and benefits. Also includes information on assistance to alleviate financial difficulties.

#### **Making Comfortable Treatment Decisions: Tips for Thinking Clearly About Benefits and Risks**

Factors that complicate medical decision-making.

### STAYING WELL

#### **Clear Thinking about Alternative Therapies**

Facts and common misconceptions, plus practical ways to evaluate benefits and risks of alternative and complementary therapies.

#### **Exercise as Part of Everyday Life**

Describes ways to make physical activity a regular part of staying healthy. Includes tips on handling MS symptoms.

#### **Food for Thought: MS & Nutrition**

A guide to healthy eating, which includes managing symptoms, changing eating habits, and the effects of diet on MS.

#### **Managing MS through Rehabilitation**

An overview of what rehabilitation can do for mobility, fatigue, driving, speech, memory, bowel or bladder problems, sexuality and more.

#### **Stretching for People with MS**

An illustrated manual showing range of motion, stretching and balance exercises for a basic at-home program.

#### **Stretching with a Helper for People with MS**

An illustrated manual showing most of the same exercises, but designed for individuals who need a helper.

#### **Multiple Sclerosis & Your Emotions**

How to handle some of the emotional challenges created by MS.



## **Preventive Care Recommendations for Adults with MS**

A colorful chart detailing the medical tests, vaccinations, and general health and safety rules recommended for all adults with MS.

## **Vitamins, Minerals & Herbs in MS: An Introduction**

A practical guide to dietary supplements for people with MS. Outlines what is and is not known, with references for further study.

## **MANAGING SPECIFIC ISSUES**

### **Depression and Multiple Sclerosis**

Discusses the symptoms of depression, the relationship between MS and depression, available therapies, and where to find help.

### **Review of Regular Medications & Supplements**

A form to help people keep track of their prescription drugs, over-the-counter remedies, herbals, vitamins or other dietary supplements.

### **Sleep Disorders & MS: The Basic Facts**

Reviews common sleep problems and what can be done about them.

## **MANAGING MAJOR CHANGES**

### **Managing Progressive MS**

An overview of symptom management and coping strategies when progressive MS makes the road rougher.

### **So You Have Progressive MS?**

An MS veteran of more than a decade writes frankly about life, family, work, dating and pursuing your dreams when the diagnosis is progressive MS.

## **ONLINE**

The National MS Society also offers helpful information online about making treatment and lifestyle choices in the context of MS.

### **Live Fully, Live Well**

**[nationalMSsociety.org/LiveFullyLiveWell](http://nationalMSsociety.org/LiveFullyLiveWell)**

A comprehensive wellness program from the National MS Society and Can Do MS, designed for people living with MS and their support partners. Live Fully, Live Well covers topics affecting the whole family living with MS in order to strengthen relationships, increase understanding and promote improved health and quality of life.

### **MS Learn Online**

**[nationalMSsociety.org/MSLearnOnline](http://nationalMSsociety.org/MSLearnOnline)**

The Society offers a variety of online educational programs on MS, including MS basics, symptom management, relationships, employment and research. Transcripts and podcasts are available for most programs.

### **Multimedia Library: DVDs**

**[nationalMSsociety.org/DVDs](http://nationalMSsociety.org/DVDs)**

These videos can help you on your personal journey of living with MS. Learn more about health and wellness, research, employment, mobility and accessibility, parenting and more.

### **Primary-Progressive Multiple Sclerosis: Perspectives on Moving Forward**

**[nationalMSsociety.org/PPMSmovingforward](http://nationalMSsociety.org/PPMSmovingforward)**

A companion DVD to the book **Primary Progressive Multiple Sclerosis: What You Need to Know**, this program profiles five people living with primary-progressive MS, who offer their strategies for managing the disease and moving forward with their lives.

## Online Classes

[nationalMSSociety.org/onlineclasses](http://nationalMSSociety.org/onlineclasses)

Online courses provide in-depth information that can be accessed at your convenience.

Course topics are wide-ranging, from intimacy to financial matters. Of particular note is a four-hour course on “Navigating the Medication Maze,” which helps learners analyze risks and benefits, and use a decision map to objectively review information.

## IN CANADA

The Multiple Sclerosis Society of Canada offers vast numbers of resources, in print, online and in person. To get started finding the information you need, visit [mssociety.ca](http://mssociety.ca) or call 1-800-268-7582.

## RECOMMENDED READING

**Multiple Sclerosis: The Facts You Need**, 5<sup>th</sup> ed., by Dr. Paul O’Connor (Elsevier Canada, 2013)

## BROCHURES

### **Exploring Your Options: Considering Risks and Benefits of MS Medications**

Choosing the best treatment option will be a very personal decision that will be influenced by many factors. This booklet discusses the risks and benefits of MS medications.

### **Everybody Stretch: A Physical Activity Booklet for People with MS**

This illustrated workbook outlines a flexible, individualized stretching program that can be adapted to changing physical abilities.

### **Healthy Eating: A Guide for People with MS**

Based on Canada’s **Food Guide**, this booklet discusses the importance of a well-balanced diet and offers practical tips on meal selection and preparation.

### **Living with Progressive Multiple Sclerosis**

A straightforward and supportive guide that recognizes the special concerns of people with progressive MS. Looking at the issues of treatment and symptom management, this booklet also explores non-pharmacological ways of improving quality of life.

### **MS Get Fit Toolkit:**

A resource to help adults living with MS meet the Canadian Physical Activity Guidelines.

### **Multiple Sclerosis: Its Effects on You and Those You Love**

A comprehensive guide about MS, including answers to some of the most frequently asked questions about the disease.

### **You and MS: Considering Your Treatment Choices**

This booklet explains what may happen to you during the course of the disease, why you have symptoms, and the medications that are available to treat your MS. Only available in PDF format.

## PRESCRIPTION ASSISTANCE PROGRAMS

### IN THE UNITED STATES

#### **Acthar®**

888-435-2284

[actharmsrelapse.com/acthar-support-services/get-reimbursement-support-and-more.html](http://actharmsrelapse.com/acthar-support-services/get-reimbursement-support-and-more.html)

#### **Aubagio®**

855-676-6326

[MSOnetoOne.com](http://MSOnetoOne.com)

#### **Avonex®**

800-456-2255

[avonex.com](http://avonex.com)

#### **Betaseron®**

800-788-1467

[betaseron.com/betaplus/affordability](http://betaseron.com/betaplus/affordability)

#### **Copaxone®**

800-887-8100

[copaxone.com/AboutSharedSolutions.aspx](http://copaxone.com/AboutSharedSolutions.aspx)

#### **Extavia®**

866-925-2333

[extavia.com](http://extavia.com)

#### **Gilenya®**

877-408-4974

[gilenya.com/c/paying-for-gilenya](http://gilenya.com/c/paying-for-gilenya)

#### **NeedyMeds**

[needymeds.org](http://needymeds.org)

#### **Rebif®**

877-44-REBIF (877-447-3243)

[mslifelines.com](http://mslifelines.com)

#### **Tecfidera™**

800-456-2255

[tecfidera.com](http://tecfidera.com)

#### **Tysabri®**

800-456-2255

[tysabri.com](http://tysabri.com)

### IN CANADA

#### **Avonex®**

888-456-2263

[msalliance.com](http://msalliance.com)

#### **Betaseron®**

800-977-2770

[betaplus.ca](http://betaplus.ca)

#### **Copaxone®**

800-283-0034

[mswatch.ca](http://mswatch.ca)

#### **Extavia®**

888-557-5050

[extavia.ca](http://extavia.ca)

#### **Gilenya®**

855-PILL-4MS (855-745-5467)

[gilenya.ca](http://gilenya.ca)

#### **Rebif®**

877-677-3243

[msprogram.ca](http://msprogram.ca)

#### **Tecfidera™**

855-MSONE-00 (1-855-676-6300)

#### **Tysabri®**

888-827-2827

[tysabri.ca](http://tysabri.ca)

## OTHER ORGANIZATIONS

The following organizations can provide additional information about research, medications and living with MS.

### **The Multiple Sclerosis Coalition**

A partnership of eight organizations, including the National MS Society, striving to educate, advocate, collaborate and improve the efficiency of services for individuals with MS.

800-532-7667 x 112

[ms-coalition.org/cms/index.php](http://ms-coalition.org/cms/index.php)

### **The Emerging Therapies Collaborative**

A partnership of the Multiple Sclerosis Coalition, the American Academy of Neurology, the Multiple Sclerosis VA Centers of Excellence East and West, and the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS). The partnership is focused on promoting optimal, individualized treatment through effective communication and medical decision-making. The collaborative offers downloadable, evidence-based information.

[ms-coalition.org/emergingtherapies](http://ms-coalition.org/emergingtherapies)

### **Multiple Sclerosis International Federation (MSIF)**

This international organization links the activities of MS societies worldwide, and promotes research and awareness.

+4 420 7620 1911

[msif.org](http://msif.org)

### **The Canadian Society for Exercise Physiology (CSEP)**

CSEP is the resource and voice for exercise physiology and health and fitness, providing leadership in research, education and practice to improve health outcomes for Canadians.

1-877-651-3755

[csep.ca](http://csep.ca)

## GLOSSARY

**Atrophy.** A decrease in size, or shrinking, of an organ or tissue.

**Autoimmune activity.** When the immune system reacts against normally occurring substances in the body.

**Blood-brain barrier.** A membrane between circulating blood and the brain, which prevents damaging substances from reaching brain tissue.

**Clinical trials.** Studies that test whether a particular treatment is safe and effective in humans. Studies are typically divided into **phases**:

**Phase 1.** To determine whether a treatment is safe, investigators administer it to a small number of healthy volunteers, and observe how the human body reacts.

**Phase 2.** If the therapy proves to be safe, investigators administer it to large numbers of people with MS, and compare its effectiveness against an existing treatment or a placebo.

**Phase 3.** If the therapy appears effective, researchers administer it to even larger groups of people, usually in multiple centers in several countries.

**Cognition.** A broad term that encompasses a person's ability to pay attention, remember, plan, organize and reason, among other high-level brain skills. Cognitive dysfunction, a common symptom of MS, refers to any degree of impairment of those skills.

**Disease-modifying therapy.** A medication that reduces the frequency and severity of MS attacks by altering the immune response.

**Electrocardiogram.** A test that monitors the electrical activity of the heart. Useful in detecting certain heart abnormalities.

**Food and Drug Administration.** An agency of the U.S. government, the FDA oversees drugs, medical devices, dietary supplements, food and cosmetics. It has strict regulations about how each of these product categories must be tested for safety and efficacy before and/or after they become available to consumers.

**Health Canada.** An agency of the Canadian government that oversees the country's healthcare system. Similar to the FDA, it oversees testing and safety of foods, drugs, cosmetics and other household products.

**Infusion therapy.** One way of administering certain medications that involves injecting a liquid medication directly into the bloodstream via a tube inserted into a vein.

**Interferon beta.** Interferons are a group of natural proteins that are produced by human cells in response to viral infection and other conditions. They were named for their ability to interfere with viruses. Interferon beta is produced mainly by white blood cells and certain connective tissue cells. Several of the approved disease-modifying therapies use interferon beta to reduce the immune attack in MS.

**Lesions.** Plaques, scarring or other damage that occur in the central nervous system as the result of MS disease activity.

**MRI.** Short for **magnetic resonance imaging**, an MRI is a test that uses a magnetic field to produce an image of the brain, spinal cord or other parts of the body. It's currently the most reliable means of detecting MS lesions.

**Myelin.** A protective sheath around nerve fibers that acts as insulation. MS immune activity damages the myelin, resulting in lesions along the nerve, which in turn produces many of the symptoms of MS.

**PML.** Short for progressive multifocal leukoencephalopathy, PML is a rare brain infection that can occur in certain people who take Tysabri. It is fatal in about 20 percent of cases. See pg. 17 for more discussion.

**Pregnancy rating.** A classification system used to denote the risks a medication may pose to a developing fetus. The Food and Drug Administration's ratings run from A (safest) through D (positive evidence of fetal harm, but the benefits to the mother may outweigh the risks), plus an X rating for therapies in which the risks clearly outweigh any benefit.

**Progressive MS.** In very general terms, refers to MS that gets progressively worse over time, without relapses and remissions.

**Relapsing-remitting MS.** the most common type of MS, in which a person experiences attacks (also called relapses or exacerbations) of worsening neurologic functioning and symptoms, followed by periods of remission, in which partial or complete recovery occurs.

**Spasticity.** Stiffness, tightness or involuntary spasms that occur in limb muscles, but most commonly in the legs in MS.

**Stem cell.** A cell without a specialized function that can be grown into a more differentiated cell, such as a skin, muscle or nerve cell. They represent an exciting avenue of research for MS investigators.

**Wash-out period.** A period of time in which no medication is taken. This ensures that one medication is out of the body before a new treatment begins, preventing possible complications.







**National  
Multiple Sclerosis  
Society**

The National Multiple Sclerosis Society is a collective of passionate individuals, moving together to create a world free of MS.

*[nationalMSsociety.org](http://nationalMSsociety.org)*  
1-800-344-4867

**PUBLISHED IN PARTNERSHIP WITH:**



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

*[mssociety.ca](http://mssociety.ca)*  
1-800-268-7582