

EXPLORING
YOUR OPTIONS:
Considering Risks
and Benefits of
MS Medications



Living with MS

Multiple sclerosis is believed to be an immune-mediated disease, in which cells of a person's immune system attack the protective covering (called *myelin*) around nerve fibres in the central nervous system (the brain and spinal cord). In the short term, periodic flare-ups (called *relapses*) of inflammation result in a variety of symptoms relating to sensation (e.g. nerve tingling or “buzzing”, “pins and needles”) and muscle function (e.g. weakness, walking ability). In the longer term, progressive nerve damage (called *neurodegeneration*) can result in permanent disability.

Most people with MS are diagnosed when they are 20-40 years old and have *relapsing-remitting* MS. This means that they have occasional relapses when symptoms are worse, followed by periods of remission, when symptoms typically improve. Over the course of time, there is a slow accumulation of nerve damage and many will progress to a *secondary-progressive* phase of the disease. Relapses are often less frequent during this phase, but there is a steady worsening of function.

Unlike relapsing-remitting MS, in which symptoms subside and you often return to your previous level of functioning, the setbacks you experience during the secondary-progressive phase may become the “new normal”. If you were accustomed to walking 2 blocks without difficulty, the new limit may be 1 block or less. If you develop a new symptom, such as an area of numbness, this change may not improve.

MS is an illness of uncertainty. The disease is highly variable and affects everyone differently. Relapses may strike every few months, or may occur years apart. Attacks are usually fairly mild (numbness, blurred vision), but can occasionally be severe. Some people will find that they get much worse from year to year. Others may live with MS for decades with relatively little impact on their day-to-day functioning. Living with uncertainty is one of the greatest challenges of MS. It is very difficult not knowing when a relapse will strike, how well you will feel on a given day, or what you will be like in a few years from now.

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The Importance of Treatment

Left unchecked, MS can do permanent damage to the brain and spinal cord. That is why treating MS is so important. Medications can provide some measure of control over the inflammation that injures nerve fibres, improve the inflammation seen on MRI, and generally reduce the frequency and severity of MS relapses. Slowing the accumulation of nerve damage may also prevent some of the disability seen during the lifetime course of MS. That is why your doctor has probably advised you to start treatment as soon as possible. The best course of action is to prevent tissue damage early on before any problems occur and become irreversible.

For most of the long history of MS, there were no effective medications to treat the disease. That changed in the 1990s with the arrival of the first disease-modifying therapies for MS. Current MS medications are the beta-interferons (Avonex[®], Betaseron[®], Extavia[®] and Rebif[®]), glatiramer acetate (Copaxone[®]), and natalizumab (Tysabri[®]). All of these medications are intended for people with relapsing-remitting disease, although some (Betaseron[®], Extavia[®], Rebif[®] as well as other drugs) can also be taken for secondary-progressive MS. More information on these medications is available online at www.msociety.ca.

What these disease-modifying therapies have in common is that all are taken by injection. Different ways of combating MS are now being researched and several new MS medications – some in pill form – are currently in development. The way that these medications work may be more effective. But different mechanisms of action mean that there may be different side effects, and different risks to be considered.

As the number of MS treatments increases, there will be more options available to you. With more choices will come more challenging decisions when choosing the therapy that is best for you.

Weighing the Benefits and Risks

MS will affect each person differently, so perhaps it is not surprising that treatment is very individualized. Choosing the best treatment option will be a very personal decision that will be influenced by many factors. Some of these factors will be medical and these should be discussed with your doctor. For example, a change in your condition may mean that you would benefit from another medication. Other factors will depend on your personal preferences, your lifestyle, and who you are as a person. When assessing your options, it's important to think about how important the benefits of treatment are to you, and how much the potential risks of therapy will influence your choice.

All medications – even nonprescription pain relievers or supplements – have the potential to cause unwanted effects. A more potent medication may be more effective in controlling a disease, but that same potency will have a greater potential to produce serious side effects.

So there is often a trade-off in choosing a medication: more potency and a greater risk of serious side effects, or less effectiveness and less risk of serious side effects. The key word in both of these scenarios is risk. How much risk are you prepared to accept?

In part this will be determined by how much there is to gain, and the type and degree of risk. For example, if you were investing money, would you prefer a 1% return and zero risk? A 5% return, with a 10% chance of losing 20% of your money? A 25% return, but a 15% chance of losing 50% of your money? There is no right or wrong answer for everyone. The right answer is the one that you are most comfortable living with.

What Are the Possible Benefits of Treatment?

Over the past two decades of MS treatment, the benefits of therapy have become well established. Current MS treatments reduce the frequency of relapses by about one-third (the exception is natalizumab, a riskier medication that reduces relapses by two-thirds). This means that a person having three relapses a year will probably experience no more than two relapses a year. These treatments reduce inflammation so there is less damage to the delicate nerve fibres of the central nervous system (the brain and spinal cord). Since treatment trials are only two or three years' duration, it cannot be stated definitively that these benefits will mean a significant reduction in disability over the 20 or 30 years that a person lives with MS (and effective treatments haven't been available for 30 years). However, it is hoped that by starting treatment as soon as possible, and continuing with regular treatment, the potentially disabling long-term consequences of the disease will be reduced.

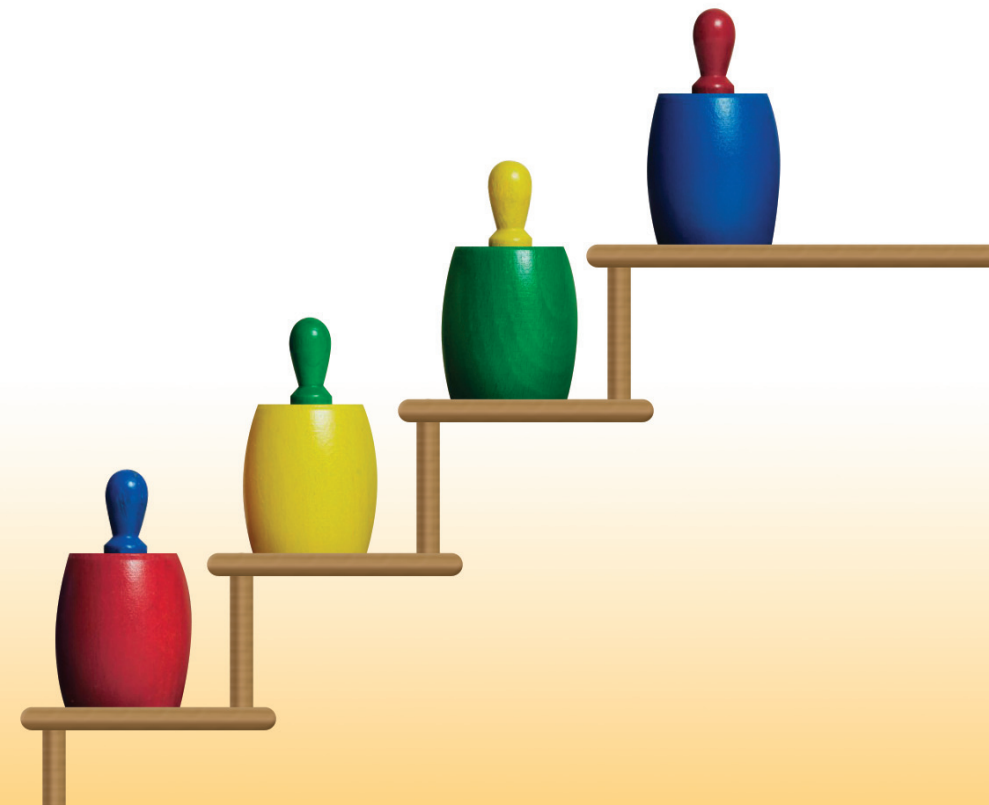
Generally speaking, the newer MS medications – some of which will be available as pills – may be more potent than the older therapies. A common perception is that a pill is not as strong as an injectable medication, but this is incorrect. The potency of a drug is determined by its effects on the body, not on the way it is taken. So it should not be assumed that a new MS medication will cause fewer side effects just because it is a pill. In your assessment of the benefits of treatment, it is important to note:

- The most important benefit of treatment for many people will be the prevention of disability during the lifetime course of MS. At present, the long-term impact of treatments on disability is largely

unknown. Prevention of disability can only be established once enough people have been on therapy for a long enough time. The hope is that treatment will be effective in this regard, and that more potent medications will result in greater reductions in disability.

- Greater potency often means greater risk. It's important to understand the nature of the risks involved and if you can minimize them.

So let's look at how to assess the risk of therapies.



What Are the Possible Risks of Treatment?

There is some degree of risk in putting any medication (including nonprescription and alternative medicines) into our bodies. All drugs can produce unwanted side effects. Some are less severe (e.g. dry mouth), while others can be very serious even if you're not aware of them (e.g. liver damage).

In assessing the risks of a medication, there are several things to consider:

What is the nature of the risk?

Before prescribing any drug, your doctor will tell you about the possible side effects of the medication and how serious they may be. It is also important to know if the side effects will go away if the medication is stopped.

What are the chances that I will be affected?

While your doctor cannot predict if you will develop specific side effects with a medication, he/she can tell you which side effects are more likely.

Can the risks be minimized?

Doctors have many ways to minimize the risk of developing side effects, or to minimize the consequences if a side effect does develop. One important strategy is to monitor you closely, especially in the first few months of starting a treatment. Monitoring may include

such things as periodic blood tests. Your doctor and nurse will let you know which tests are needed. Having these tests is important since they will enable your doctor to respond quickly if a problem does develop.

Is a drug with greater potency the best option for me?

Some people do very well on treatments that provide modest benefits and have less serious side effects.

Is there anything I can do?

Once a treatment decision has been made, it is important to be well informed about your medication and to follow the advice of your doctors and your MS nurse. This includes taking your medication as directed by your doctor, and showing up for your scheduled appointments (clinic visits and tests). It is also essential that you report any side effects that you think you are experiencing so effective steps can be taken to minimize them. Health Canada will also keep track of medication side effects through its pharmacovigilance program.

Deciding on the Best Course of Action

Regularly taking a treatment for a life-long disease such as MS requires a commitment – but it is your best course of action to gain some control over the disease process.

With so many treatment choices available, how does someone decide which one will be the best option? Decisions about treatment are best arrived at in consultation with your MS team. They can answer your questions and advise you of the benefits and risks of treatments to help you make an informed decision. It's important to realize that while your MS team has your best interests in mind, they cannot make the final decision for you. How they assess the risks and benefits of a treatment may differ from how you assess these things. Here are some points to consider as you make your choice:

What is important to me?

As part of the coping process, people learn to accept MS and accommodate some degree of impact on their daily life. How acceptable is that to you? Is your goal to be free of symptoms? To keep working? To raise your family? To avoid sleepless nights worrying about the future? To avoid worrying about side effects? Only you know what your life means to you, what MS means in your life, and how you want to handle things.

What are my hopes and concerns?

What do you hope to achieve (or avoid) with treatment, and what are your key concerns? Are you worried about what MS may do to your body and your life? Are you concerned about what people will think

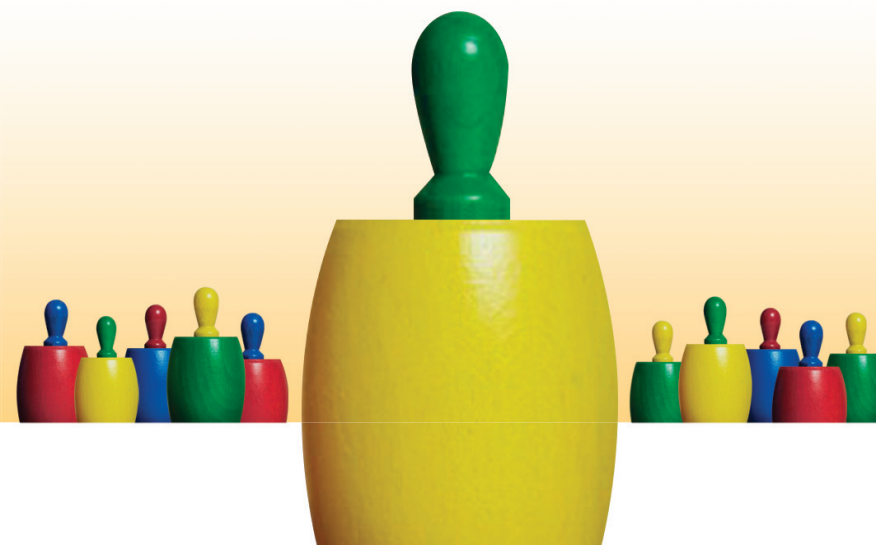
if you don't do something about your MS? Discussing your concerns with others may help you feel more in control of the situation.

How will my decision affect my life?

Ask your doctor and MS nurse if you won't be able to do certain things because of starting a particular treatment. Will side effects or monitoring requirements cause you to miss work or school? If you start on a treatment, will that mean you won't be able to try another one? What if you decide not to start treatment?

How will my decision affect the people in my life?

It can be helpful to discuss your situation with family and friends as you think through your decision. You are an important part of their lives, and your MS affects them as well. Some people will urge you to do everything you can. Others will advise caution. Try to understand their concerns and address them if you can. Ultimately it is your body, and your health and well-being. The final decisions about managing your MS will be up to you.



Deciding on an MS Treatment

The following decision aid may help you consider your treatment options and decide on the best course of action for your situation. *Adapted from the Ottawa Hospital Research Institute (www.ohri.ca/DecisionAid/).*

1. In thinking through your decision, write down three possible options in the table below.
2. List the benefits for each of the options.
3. List the possible risks for each of the options.
4. Now underline the benefits and risks that you think are most likely to happen.
5. Put a check mark (✓) beside each benefit and risk to indicate how much it means to you. Five check marks means “a lot”, while no check marks means “not at all”.
6. Circle the option with the benefits that matter most to you and which are most likely to happen.

	BENEFITS		RISKS		
	Reasons to choose this option	How much does each benefit matter to me? (insert check marks)	Reasons to avoid this option	How much does each risk matter to me? (insert check marks)	
OPTION 1					<i>Which option did you prefer?</i>
OPTION 2					
OPTION 3					

OPTION 1
 OPTION 2
 OPTION 3
 Unsure

Your Decision-Making Needs

Knowledge:

Do you know the benefits and risks of each option?

Yes No

Values:

Are you clear about which benefits and risks matter most to you?

Yes No

Support:

Do you have enough support and advice from others to make a choice?

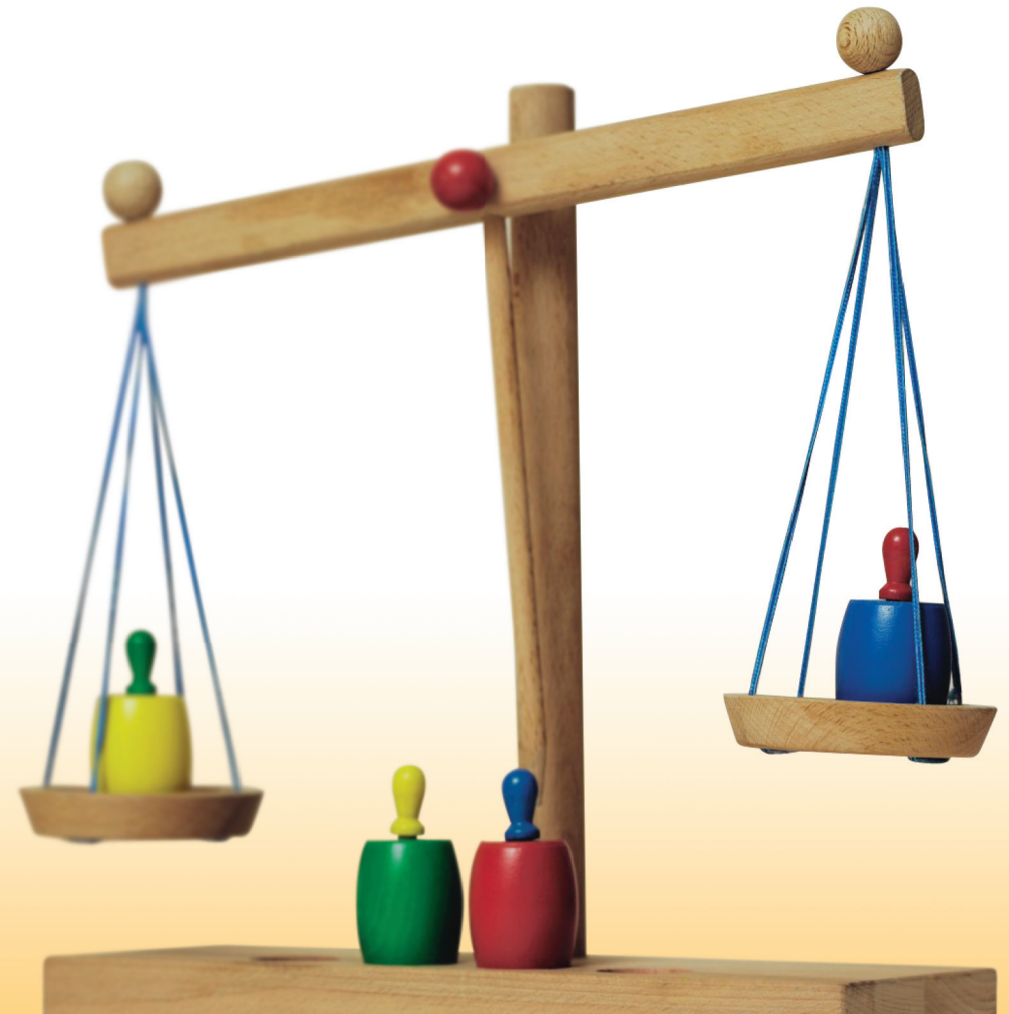
Yes No

Certainty:

Do you feel sure about the best choice?

Yes No

People who answer “No” to one or more of these questions have decision-making needs. They are more likely to delay their decision, change their mind, feel regret about their choice, or blame others for bad outcomes.



Questions to Ask Your MS Team



The following are some questions that you may want to discuss with your MS clinic team. Jot down additional questions in the space provided or on a separate page.

Multiple sclerosis

1. How will MS affect my life?
2. What are the physical and mental 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 is 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:



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