

Red Flags & Green Lights

Accessing Reliable Health Information



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1-800-268-7582
www.mssociety.ca

Introduction

All of us are exposed to thousands of messages every day — from television and radio, books, newspapers and magazines, the Internet and word-of-mouth. The information can be brash and intrusive, or more subtle and persuasive. These messages can influence our thinking about which movie to see, which clothes to buy, which ideas we should believe in.

Often we don't question these messages or who is communicating them. We don't ask ourselves: why are they telling me this?

Seeing the wrong movie (*"You'll love it!"*) or buying the wrong clothes (*"You'll look wonderful!"*) is one thing. It's another thing if you have an illness and you are misled — about the nature of your disease and how to treat it. That kind of misinformation can be dangerous and damaging — to your health, your wealth and your well-being.

Multiple sclerosis (MS) is an illness about which much is still unknown. This makes it susceptible to all sorts of speculation, pet theories and false claims. Unreliable or unsound information is all too common. Sometimes this information comes from people with the best of intentions. But intentions are not facts.

We need more facts about MS. And we need to be able to critically assess new facts very carefully to separate the information from the misinformation.

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This booklet, **Red Flags & Green Lights: Accessing Reliable Health Information**, is a guide for people with MS to help them weigh information about their illness to empower them in making decisions in their daily lives. A *red flag* is a warning — the information may not be credible and you should view it with some skepticism. A *green light* means you can go forward with the assurance that the information is probably correct.

The publication is part of the *Red Flags & Green Lights* educational series provided by the Multiple Sclerosis Society of Canada, and has been prepared with the assistance of an unrestricted educational grant from Teva Neuroscience. The information is based in part on the information presented by the series speakers: neurologists, pharmacists, nurses and members of the MS Society. We hope you find it helpful in your search for the truth about MS.

IDENTIFYING RED FLAGS & GREEN LIGHTS:

The Five Ws

When critically assessing information, it's a good idea to ask yourself the journalist's five Ws: Who, What, Where, When, Why. They are a good starting point when researching MS and will help you feel reassured if you're planning to incorporate any of the ideas you come across into your daily life.

WHO is telling me this?

Not all sources of information are alike. The most credible information source about MS is a **medical journal**. These publications, written and edited by health professionals, are intended for other professionals to educate them about recent developments in research and clinical medicine. This means that the information is often very technical and may not be well understood by the average person.

Medical or **science magazines** try to correct this problem by offering people generally well-informed articles that summarize the information in medical journals. These publications can provide the all-important context — the history of where an idea has come from and what it means in daily life. It's usually stated if a point-of-view is controversial. The people writing and editing the articles are often health professionals (such as a doctor, nurse or pharmacist), or medical journalists who specialize in the field.

Health articles or columns in **newspapers** or **lifestyle magazines** are generally not written by health professionals, nor do the editors have much experience in reporting medical news. While the information may have originally come from a credible source — a medical journal or an interview with a doctor — there is a lot of room for a misunderstanding or a misrepresentation of the facts. An interesting new development may become the headline: New Cure for MS.



If it says 'cure' or 'breakthrough' — don't believe it. Ask a health professional to explain what the information really means.

Books often have the appearance of being more credible than other types of publications, but here again the buyer should beware. Not all authors and publishers are the same. Books may be written by someone who is trying to promote a certain point of view or pet theory (e.g. that MS is caused by a type of diet), or they may be trying to sell you something (e.g. a medicine or device that is supposed to ease symptoms or cure MS). Some of these people are con artists or zealots. Some are well-meaning individuals, often people with MS, who honestly believe that making a change in their lifestyle has helped their illness. Unfortunately, while they may believe something has worked for them, it is unlikely it will work for you. Therapies need to be tested properly to ensure that they will work for everyone.



Watch for information sources that are trying to sell you something. DO NOT send money or provide a credit card number. Be cautious about giving anyone your address, telephone number or email address.

People in your life are no doubt trustworthy, but they may unwittingly give you the wrong information. We all have well-meaning relatives or friends who have “heard something about MS.” You can thank them for the information, but exercise a little healthy skepticism when it comes to hearsay. Beware of what doctors call ‘anecdotal information’ — stories you hear from people about new treatments or alternative medicines that have helped them or someone they know if this information is not backed up by credible scientific studies. If you do find the information intriguing, ask someone who should know: your doctor, nurse, MS clinic or the MS Society.



*If it sounds too good to be true
— it probably is.*



*Healthcare professionals — doctors, nurses, pharmacists
— can be counted on to provide you with unbiased
information about your health.*

TABLE 1. Common sources of information about MS.

SOURCE	COMMENTS
Doctor	<ul style="list-style-type: none"> • Accurate • Ask specific (not vague) questions • Can address MS and non-MS health concerns
MS clinic	<ul style="list-style-type: none"> • Accurate • Has good understanding of your overall situation • Can tell you how new research is relevant to you
MS Society 1-800-268-7582 www.mssociety.ca	<ul style="list-style-type: none"> • Accurate • Provides updates on new research and its importance • Publishes information booklets (print or online) • Can connect you with support groups
MS clinic/ hospital website	<ul style="list-style-type: none"> • Accurate • May provide booklets on various topics (e.g. diet, exercise)
Government health services	<ul style="list-style-type: none"> • Useful information on benefits, coverage, disability, etc. • Websites useful to fine-tune search before telephoning
Medical books	<ul style="list-style-type: none"> • Accurate but may not reflect current developments • Information may be difficult to understand
Medical journals	<ul style="list-style-type: none"> • Accurate and most current • Information may be difficult to understand • New studies/research need to be taken in context (no “breakthroughs”)
Consumer books*	<ul style="list-style-type: none"> • May not be accurate • May be out-of-date • Author may be promoting a product or point-of-view that distorts the information • May not give you answers to your specific questions
Consumer magazines	<ul style="list-style-type: none"> • Information may be biased or sensationalized by writer/publication • Writer may be promoting an “angle” or point-of-view that may not be accurate • Stories tend to focus on “human interest” (hearsay) rather than medical facts
Television, radio	<ul style="list-style-type: none"> • Information often too brief to be useful • Information may be biased or sensationalized by reporter/news organization • Information may be edited/becomes meaningless
MS websites	<ul style="list-style-type: none"> • Information may not be accurate or well informed (hearsay) • Information may be out-of-date — check when story was posted • Web host may be promoting a point-of-view that distorts the information • Site may be promoting a product — “miracle cure” or “new breakthrough” with untested claims
Pharmaceutical company telephone help lines	<ul style="list-style-type: none"> • Useful information on company’s product • May offer advice on drug reimbursement programs

* See page 15 of this booklet for some recent, accurate books on MS.

WHAT is the information about?

Medical science is a slow accumulation of facts. Each fact is like a colour dot which, eventually, forms a picture of something real. This doesn't mean that there aren't inspired insights or that great leaps aren't made. But these are rare. Most of medicine is about observing some small truth, then testing that truth until it seems like a certainty. Unfortunately, it is easier to prove definitively if something is untrue than if it is true. So even "certainties" in science are often conditional — waiting for someone to prove them wrong. Ancient Egyptian astronomers proved that the sun revolves around the earth. Their facts withstood the test of time for two millennia, until they were proved wrong.

Medicine follows a process — from laboratory experiments, to studies on animals, to studies on a small number of people. Only a treatment that has survived all of these tests will become available to the general public.

A problem can arise, however, if one of these interim steps is misinterpreted as the final step. Sometimes a report will state that there's a new theory about the causes or progression of MS, but that theory has only been tested in a test tube with nerve cells. Other reports will imply a new treatment has been developed — but it has only been tested in rats. Rats are not human beings. And there are many cases where a medication that works in them doesn't work in us.

So when learning about MS, ask yourself: What is the information about? How 'proven' is it? Did the study involve people? How many people? (More people means the information is more reliable.) Were they people like me? Were they the same age and sex? Did they have relapsing-remitting MS? Progressive MS? How many years have they had their illness compared to me?

These things are important because otherwise you may be comparing apples and oranges. A medication in a healthy person may not behave the same way as one in a person with MS. A person who is newly-diagnosed with MS may be at a different stage than someone who was diagnosed twenty years ago.



Watch for descriptions of studies. “Laboratory research” usually means the study was done in vitro (meaning “in glass”, i.e. a test tube or Petri dish) and not in vivo (in a living person). A ‘preliminary’ study means that all of the facts aren’t know yet. If it says “a small study”, ask yourself: How small?



The most scientifically reliable study is a randomized, double-blind, controlled trial (RCT). ‘Randomized’ means that people in the study were randomly assigned to different treatment groups (which eliminates any bias there might be in the selection, e.g. putting sicker people in one group). ‘Double-blind’ means that neither the doctor nor the patient knows which treatment the person is getting (also to eliminate bias). ‘Controlled’ means placebo-controlled — comparing a therapy with placebo (no treatment) to see if there is any difference. Often people in studies, because of the extra care they are receiving, will feel better even though they aren’t receiving any medication. It’s important to factor out this ‘placebo effect’ to determine just how good a new therapy is.

WHERE is the information coming from?

Research is usually conducted in hospitals, universities, MS clinics, or some other reputable centre. Credible research is not usually done in private ‘institutes’, unidentified ‘laboratories’, or in private homes.

When you hear or read a report about some new information on MS, try to identify where the information is coming from. You need to trust the source.

The Internet

It’s also important to ask: *Where is the information being reported from?*

This is one of the challenges posed by the Internet. It is often ‘news from nowhere’. You are never sure who is posting the information, and why. The Internet is often the first place people turn to when they need information. However, many websites are misleading, unreliable or untrustworthy. Remember to ask yourself:

- Who is creating this website? What are their credentials? Are they affiliated with any group or association? Is there a contact name, address or telephone number?
- Is there a message, product or claim that is being promoted?



Watch out for websites that seem to promote a product or opinion, or which present claims or facts that you have never heard from other sources.

Logging onto a chat room can be entertaining and it can be helpful to share your story with others. But don’t accept medical advice from members. You are never sure of the identity of anyone in a chat group, so you can never be sure if the person’s opinions are well-informed. The MS Society of Canada has a list of chat rooms that are affiliated with reputable MS societies from across North America and the United Kingdom.

The MS Society also has a coordinator of the National Information Resource Centre, whose job it is to locate the best websites offering the most reliable information. Talk to the MS Society, and be sure to visit the site at www.mssociety.ca. Other useful websites screened by the MS Society are listed in the back of this booklet.



Look for the MS Society logo on websites or publications. This information has been reviewed by experts and found to be factual and unbiased.

WHEN was this information published or posted?

Every week there are new developments in MS research. So it's important to determine when the information was first published or posted on a website. Information can change quickly and may become outdated. A newspaper may not view medical news as time-sensitive, so it can sit in the editor's In Box for weeks.

Magazines often have a three- to six-month publication schedule, so any MS 'news' will be stale by the time it is printed. Books have an even longer production schedule, and their information can easily become dated.

The Internet gives the appearance of posting timely information. But if you search the page or site for a posting date, you will often find that the information is old. Some sites aren't updated for years. More general information about MS won't necessarily be affected, but any 'news' will have to be viewed skeptically. You may also ask yourself why no one has recently updated the site. It may be a sign of a non-professional, who may have a non-professional attitude toward the information.

WHY is this information important (to me)?

Just as you may well ask why someone is telling you something about MS, you should also ask yourself why it is important. And why is it important to you?

As you research MS, you develop an overall idea of the illness, its symptoms and course, and how to manage it on a day-to-day basis. In this context, information is important if it tells you something you didn't know before, clarifies an issue, or tells you of a new development. The key is context. The knowledge you already have will inform your research, identify new information, and help you to decide if the new information is valid.



Question any new information if it doesn't seem to 'fit' with what you already know about MS.

A second important point is relevance: why is this important to me? The amount of information about MS is inexhaustible so you will have to sift through it to find the nuggets. These nuggets may not be a gold mine. You might learn a few tips on managing fatigue, or you might discover a new exercise that helps reduce spasms. You will decide. Only you can say what information is relevant — it doesn't matter that it isn't relevant to someone else (such as someone without fatigue or spasms).

When accessing information, to avoid getting overwhelmed it can be helpful to set a research question for yourself. This will enable you to focus on your immediate concern without getting sidetracked. Know what is important to you — and pursue it.



Your MS clinic is the best source for information that is directly relevant to you. They know your medical history, the stage of your illness and your specific circumstances. So they are the best people to advise you about the specifics of your health. They can also provide reliable advice about any medications, therapies or devices that you may have read about.

HOW do I research MS?

Here are 10 tips to help you get the information you need.

- 1. Decide to learn about MS.** Educating yourself can give you back a sense of control over your life and illness — you'll understand better what you're dealing with. You need the facts to keep the fears at bay.
- 2. Be selective in your research.** You can't read everything that has been written about MS. So focus on a topic (e.g. who gets MS, what causes MS, or how to relieve symptoms) and investigate it.
- 3. Collect information from different sources.** Physicians, nurses, hospital libraries, the Internet, medical journals, magazines, etc.
- 4. Sift through the facts to make sure they're accurate.** Assess the facts based on who is reporting them, where they were published, broadcast or posted, how timely they are, etc.
- 5. Compare new information with what you already know.** Is the new information surprising? Does it seem to come out of nowhere and isn't really related to what you knew before? If the shoe doesn't fit, the problem is usually the shoemaker, not the foot.
- 6. Screen out unreliable information sources.** If three sources say one thing and another source says something entirely different — there is probably something wrong with that fourth source. Find another source you can trust.
- 7. Verify the facts.** Mention some of the things you've learned to a healthcare professional. Have them verify that the facts are correct or that you've understood them properly.
- 8. Ensure the information is relevant to you and your life.** You know what is important to you. Trust yourself.
- 9. Piece together all of the puzzle.** As you gain more knowledge about MS, you will know what to expect. Solving the puzzle means being better able to make important life decisions based on the facts.
- 10. Know when to stop.** Once you've learned enough about a topic — stop. Give yourself a break. The point of your research is to inform your life, not become your life.

ALTERNATIVE INFORMATION:

Getting the Facts about Herbal Remedies & Naturopathic Medicines

A lot of the information about MS, most often available on the Internet, involves claims for nonprescription treatments or purportedly “natural” remedies. Many websites make these products available over the web if you provide a credit card number.

Buyer beware.

Drugs vs. “Natural” Products

Health Canada, the government department that regulates products under the Food and Drug Act, defines a *drug* as any treatment that makes a claim about health — from relieving pain to curing baldness. Drugs are available by prescription from a medical doctor, or may be distributed over-the-counter at a pharmacy.

So-called “natural” products are often herbal or ‘alternative’ products that are available not just in pharmacies but in department stores, supermarkets, or your corner store.

The idea that something is ‘natural’ is misleading. ‘Natural’ doesn’t mean ‘healthy’. Marijuana, belladonna, tobacco and alcohol are all natural products. But most of us think of them as drugs. When you consume them, they act on the body to produce effects. And they can all affect your health and well-being.

So often a ‘natural’ or alternative medicine is simply a drug that causes effects that have not been properly studied. So the manufacturer can’t make a claim about its effectiveness. However, they will suggest, in a variety of ways, that their product is beneficial. Some products, once they’ve been investigated, may be found to cause harm — as in the case of the recent banning in Canada of kava-kava. Due to concerns about the widespread use of often untested remedies, Health Canada created the Office of Natural Products, which plans to start regulating the alternative medicine market beginning in December 2002.

Complementary medicines

Alternative therapies are often called ‘complementary’ — they are meant to complement the prescription and nonprescription medications that you take. This can be very dangerous. When we take any substance into our bodies, it is broken down by the liver and distributed throughout the tissues in complicated ways. That is why a pharmacist may tell you not to drink alcohol if you are taking a certain medication. Even a substance as benign as grapefruit juice will interact with some medications, such as certain antidepressants.

Complementary medicines can also interact with food, alcohol, and prescription or nonprescription drugs and the effects of these combinations have generally not been studied. Taking a substance such as St. John’s wort can cause severe reactions in people who are already taking a prescription medicine for depression.

Be careful when you take any kind of therapy. Tell your doctor or pharmacist about any type of medicine you are taking. They can offer you guidance about any side effects you may experience.



Some Questions to Ask Yourself:

- **What is supporting the product’s claims?** A medicine may claim to be beneficial. Find out what studies are supporting the claim. It isn’t enough to say, “People in China have been taking this medicine for thousands of years.” People in China have also been dying for thousands of years.
- **What is in this pill or capsule?** What are the active ingredients? One concern about alternative remedies is that there is no distinction between different plant species. For example, ginseng may be Korean ginseng (*Panax ginseng*), or American ginseng (*Panax quinquefolius*, a different member of the family), or Russian ginseng (*Eleutherococcus senticosus*, an entirely different family of plant). Any studies on one plant may not apply to another.

In addition, different pills will come in different strengths. But you can’t always tell what the true strength is because different parts of the plant may be used, and there may be added ingredients, etc.

- **Who is producing this product?** Different companies offer different products, which are made in different manufacturing facilities. Unfortunately, the quality and purity standards will be different among companies.
- **What are the effects and side effects?** Natural products will produce effects and side effects. For example, echinacea stimulates the immune system, which may cause relapse symptoms in people with MS. Echinacea can also cause side effects, such as allergic reactions in some people. Unfortunately, there is currently no law that requires manufacturers to report the side effects caused by natural products.
- **Will this interact with the medications I'm already taking?** As noted above, some alternative remedies can cause severe, sometimes life-threatening, reactions when they are mixed with prescription or nonprescription medications. Ask your doctor or pharmacist about the medicines you are taking.



Your doctor or pharmacist can help you select remedies that may be helpful.

- **Who is offering me this product?** Be very cautious if the person recommending a medicine (in person, in stores or over the Internet) is also the person selling the medication. They may be concerned about your wealth — not your health.
- **Can I afford this?** Many alternative therapies are expensive. Do not bankrupt yourself. Make sure you are seeking treatment for the right reason — to enhance your health or relieve symptoms, not to discover a cure for MS.



Let your body guide you. If you want to try an alternative medication, begin slowly and see how well you tolerate it. Don't take high doses or multiple medications before you know how your body is going to respond.

For More Information on MS

Books

- ***Multiple Sclerosis: The Facts You Need***
by Dr. Paul O'Connor.
- ***Alternative Medicine and Multiple Sclerosis***
by Dr. Allen C. Bowling.
- ***Multiple Sclerosis: the questions you have, the answers you need***, (2nd Edition) by Rosalind C. Kalb, Ph.D. (editor).
- ***Symptom Management in Multiple Sclerosis***, 3rd Edition,
by Dr. Randall T. Schapiro.
- ***Multiple Sclerosis: The Guide to Treatment and Management***, 5th Edition, by Drs. Chris H. Polman, Alan J. Thompson, T. Jock Murray, and W. Ian McDonald.
(This book is downloadable free, online at www.msif.org)

Publishers

- Cambridge University Press
- Demos Medical Publishing
- HarperCollins
- John Wiley & Sons
- Lippincott Williams & Wilkins
- Marcel Dekker Inc.
- Martin Dunitz
- Oxford University Press
- University of Toronto Press

Medical journals

- Multiple Sclerosis
- International Journal of MS Care
- The Canadian Journal of Neurological Sciences
- Annals of Neurology
- Archives of Neurology
- Neurology

Websites

ASSOCIATIONS

- **MS Society of Canada:** www.mssociety.ca
- **U.S. National MS Society:** www.nmss.org. Note that some of the information is only relevant to the U.S.
- **International MS societies:** www.msif.org
- **Consortium of MS Centres:** www.msicare.org

GENERAL HEALTH INFORMATION

Canadian Health Network: www.canadian-health-network.ca

PHARMACEUTICAL COMPANIES

The following companies manufacture disease-modifying therapies for MS:

- Berlex: www.mspathways.ca
- Biogen: www.msactivesource.com
- Serono Canada: www.ms-network.com
- Teva Neuroscience: www.mswatch.ca

MS Society of Canada Division Offices

Atlantic Division

71 Ilsley Avenue, Unit 12
Dartmouth, Nova Scotia
B3B 1L5
(902) 468-8230

Quebec Division

666 Sherbrooke Street West
Suite 1500
Montréal, Québec
H3A 1E7
(514) 849-7591

Ontario Division

250 Bloor Street East
Suite 1000
Toronto, Ontario
M4W 3P9
(416) 922-6065

Manitoba Division

141 Bannatyne Avenue
Suite 400
Winnipeg, Manitoba
R3B 0R3
(204) 943-9595

Saskatchewan Division

150 Albert Street
Regina, Saskatchewan
S4R 2N2
(306) 522-5600

Alberta Division

10104-79th Street
Edmonton, Alberta
T6A 3G3
(780) 463-1190

British Columbia Division

1130 West Pender Street
16th Floor
Vancouver, British Columbia
V6E 4A4
(604) 689-3144

National Office

250 Bloor Street East
Suite 1000
Toronto, Ontario
M4W 3P9
(416) 922-6065



Call toll-free in Canada: 1-800-268-7582
Email: info@mssociety.ca
Web site: www.mssociety.ca

The Multiple Sclerosis Society of Canada is an independent, voluntary health agency and does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.

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