



Multiple
Sclerosis
Society of
Canada

Accessing Reliable Health Information

We are exposed to thousands of messages every day—from the radio, television, social media, the internet, and word of mouth. These messages can influence our thinking about which ideas we should believe in.

While MS research has advanced significantly, much is still unknown about the disease. This makes it susceptible to all sorts of speculation, theories, and false claims. Unfounded claims and unreliable information are common, especially in the age of social media. We need to be able to critically assess new facts carefully to separate the information from misinformation.

The Five “Ws”

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

Who is telling me this?

Information comes from a variety of sources.

- **Medical journals** are the most credible information source about MS. These publications are written and edited by health professionals and researchers. This source of information is often very technical and not always easily understood.
- **Medical or science magazines** provide well-informed easily digestible articles that summarize the technical information in medical journals.
- **Online health articles** such as online blogs/social media platforms or in newspapers/lifestyle magazines. Unless they are written by health professionals or researchers, there could be a lot of room for misunderstanding or a misrepresentation of the facts.
- **Books** often have the appearance of being more credible than other types of publications, but here again the buyer should beware. Books might be written by someone who is trying to promote a certain point of view or might be trying to sell you something.
- **People in your life** are no doubt trustworthy, but they may unwittingly give you the wrong information. People might say they have “heard something about MS” but stories we hear from people might be anecdotal information. If you find information intriguing, ask someone who should know: your healthcare team or the MS Society.

What is the information about?

Research 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 research are often conditional—waiting for someone to prove them wrong.

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

When learning about MS, ask yourself: What is the information about? What is the evidence to support it? Did the study involve people? How many people? (more people typically means the information is more reliable). Were the people like me? Were they the same age and sex? What type of MS did they have? How many years have they had MS compared to me?

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 MS information, try to identify where the information is coming from. You need to trust the source.

The Internet:

It’s 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’ or click-bait. You may not know who is posting the information, or why. The internet is generally 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?

When was this information published or posted?

It is important to determine when the information was first published or posted on a website or in a book. Information can change quickly and may become outdated.

Why is this information important?

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 disease, 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 you of your research, identify new information, and help you decide if the new information is valid.

A second important point is relevance: why is it important to me? The amount of information about MS is inexhaustible, so you will have to sift through to find what information is relevant to you.

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.

How do I research MS?

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

1. **Learn about MS.** Educating yourself can give you a sense of control over your life and disease—you'll understand how to better manage your life with MS.
2. **Be selective in your research.** You can't read everything that has been written about MS. Focus on a topic and investigate it.
3. **Collect information from different sources.** For example: your healthcare team, medical journals, scientific magazines, MS Society of Canada's Knowledge Network.
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 about what you already know.** Is this information surprising? Is it related to what you knew before?
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 that you can trust.
7. **Verify the facts.** Mention some of the things you have learned to your healthcare team and have them verify the facts.
8. **Ensure the information is relevant to you and your life.** You know what is important to you, trust yourself.
9. **Piece together 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 have learned enough about a topic—stop. Give yourself a break.

The MS Knowledge Network

The MS Knowledge Network is the MS Society of Canada's hub of knowledge, lead by a team of MS Navigators, who provide trusted, consistent, quality MS information and support. MS Navigators are available to assist anyone in Canada, from 8am to 8pm ET, Monday to Friday. Connect with an MS Navigator by:

Phone: 1-844-859-6789

Email: msnavigators@mssociety.ca

Live Web Chat: visit the MS Information or Support & Services sections of our website

Other Resources

- Multiple Sclerosis Society of Canada: www.mssociety.ca
- MS Society Research Canada: <https://msresearch.ca/>
- Dr. Karen Lee MS Research blog: <https://blog.mssociety.ca/category/research/>
- National Multiple Sclerosis Society (U.S.): www.nmss.org (note that some of the information is only relevant to the U.S.)
- Multiple Sclerosis International Federation: www.msif.org
- Consortium of MS Centres: www.mscares.org
- MSology: <http://msology.ca/>