

Your health, the internet and social media: making it work for you



Health websites, blogs, forums, YouTube, Facebook, Twitter, MySpace—what do they all mean, what are they for, and how do they work? More importantly, how can these different digital programs help you stay informed about cutting edge arthritis, osteoporosis, and other health information?

You may think of social media only as a way kids and “techie” chat and share photos, but in fact, they have much to offer as tools for education, information-sharing, and advocacy. Increasingly, people around the globe are turning to these various platforms for credible medical information. A recent report by the California HealthCare Foundation showed that people with chronic illness, such as arthritis, are using the internet and social media to access information and connect with other people who share their

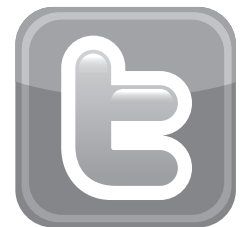
disease experience. Social networks have bridged the gaps created by geography, age, and socio-economic standing. It no longer matters that you live in a rural town and are the only person with a chronic disease – communities are being *built* through the internet and social media.

The internet and social media are changing how patients access information and advocate for better care for themselves. These various platforms have created an incredible information exchange from patient to patient, patient to healthcare worker, and patient to health organizations. People can share experiences, ask questions of one another, find events and support groups, and create advocacy communities.

Patients are no longer passive recipients of healthcare; they are taking control of their disease by showing up to their doctor’s appointment informed and armed with a better understanding of their disease and treatment options. Some doctors are concerned that patients are not finding neutral, scientifically sound information online. Ultimately, patients and their doctors must work together to come to mutual and well-informed treatment plan decisions.

The art is in knowing how and where to look

You Tube



for reliable information. The task can appear daunting. But, with a few tips you can get informed and become a better advocate for your health by becoming an active participant on your healthcare team. The important thing is to source information from reliable science-based organisations.



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Accessing information on the internet

There are some things to keep in mind when surfing the internet; consider using the following checklist to determine the quality and credibility of a given arthritis/health website.

- Look for established arthritis organizations that are patient focused.
- Determine whether there is full acknowledgement of funding sources to promote transparency.
- Look for pharmaceutical product advertising on the website – be wary of sites that are loaded with product logos.
- Beware of sites that do not list an author. It is not possible to investigate the writer's credentials without this information.
- Look at the URL (the website address). If it is an educational institution it will most likely end in **.edu**. If the site ends in **.gov**, then it is likely a government website with reasonably good statistics and basic medical information.
- Non-profit organizations usually end in **.org** or the country in which the organization is based such as:
 - **.ca** (Canada)
 - **.us** (United States)
 - **.uk** (United Kingdom)These can be an excellent source of information. www.jointhehealth.org is a good place to start for evidence-based scientific information.
- Look for the HONcode (<http://www.hon.ch/HONcode/Conduct.html>) certification. HON stands for the 'Health On the Net' Foundation, which has a strict code of conduct

for medical and health websites. If these sites, such as www.jointhehealth.org, have the HONcode approval you can be rest assured that the information is credible. Websites must indicate the qualifications of its authors, provide information that supports the patient/doctor relationship, respect the privacy of the visitor, cite its information sources, disclose its finances, and substantiate its claims.

- Look for the website's sources. A reputable publication will have a bibliography and you can follow the information directly to the source.
- Just because information comes from a clinical trial, does not mean it was an unbiased and un-sponsored trial. Here are some things to think about when looking at a clinical trial:
 - Consider how many participants were involved in the trial. If only a single trial studying 20 people had been conducted, the results cannot be generalized to an entire disease community, such as rheumatoid arthritis or osteoarthritis.
 - Look at the person running the trial (known as the 'principle investigator'). He/she should be well-respected in the arthritis research community. Check to see if they have published many research articles or books by searching their name on Google.
 - Look at the type of trial; one that includes a "control group" as a comparison to those people being studied is of higher quality. The same is true for trials that are "blinded", in other words, potential researcher bias is greatly reduced because they do not know which people in the trial are receiving the "intervention" (such as a medication or other type of treatment).
 - Look for a clearly defined trial "primary end point". In other words, determine whether what the researchers thought would be the main outcome of the trial, actually occurred. In the case of a drug clinical trial for rheumatoid arthritis, a common primary endpoint would be, "the drug significantly improves the signs and symptoms of rheumatoid arthritis".
 - For a glossary of research terminology, please visit the Arthritis Research Centre of Canada's Glossary of Research Terms. (<http://www.arthritisresearch.ca/research-glossary.html>).
- Here are some highly regarded arthritis organizations in Canada (all of which can

be accessed from the JointHealth™ website www.jointhehealth.org directly):







- **Arthritis Research Centre of Canada** www.arthritisresearch.ca
- **The BC Lupus Society** www.bclupus.org
- **Best Medicines Coalition** www.bestmedicines.ca
- **Better Pharmacare Coalition** www.betterpharmacare.com
- **Canadian Arthritis Patient Alliance** www.arthritis.ca/capa
- **Canadian Institutes of Health Research (CIHR), Institute of Musculoskeletal Health and Arthritis** www.cihr-irsc.gc.ca/e/13217.html
- **Canadian Rheumatology Association (CRA)** www.rheum.ca
- **Canadian Rheumatology Research Consortium** www.rheumtrials.ca
- **Canadian Spondylitis Association** www.spondylitis.ca
- **The Arthritis Society of Canada** www.arthritis.ca
- **The UBC Division of Rheumatology** www.ubcrheumatology.com
- **List of medical schools in Canada** <http://gradschool.about.com/cs/programdatabase/l/blmedcanada.htm>

Above all, it is crucial to think critically about what you are reading. Thinking critically means being mindful of the information that is provided and watching carefully for bias. In medical information you are looking for credibility, neutrality, accuracy and most of all that it is current.

Take action

Please go to the JointHealth™ 'taking action' (www.jointhehealth.org) tab to become an active participant in disease advocacy. Use the tools provided to write to your MLA and bombard the newspapers with letters to the editor. ACE has provided tips and templates to do just that. One letter represents thousands of people in your province. The power of the pen is not dead, and now it has expanded to include the power of online communities self-advocating via social media.

Definitions:

-  **Facebook profile:** a home page for a Facebook account
-  **Facebook wall:** part of a Facebook home page where friends can post messages
-  **MySpace:** similar to Facebook, but provides some different features
-  **Twitter tweet:** a 140 character post on your homepage
-  **Twitter retweet:** pasting someone else's tweet on your Twitter homepage
-  **YouTube channel:** a home page for a YouTube account

Your JointHealth™ guide to social media

facebook

On Facebook, you create a profile with as much or as little information as you would like. You can do everything from post pictures and videos, become 'friends' with people, write to other people on their 'walls', send private messages, create interest groups, and subscribe to various groups. In terms of arthritis you can connect with patients around the globe, find patient support groups, access national and international arthritis groups, chat and ask questions about arthritis from other patients, and find out about arthritis-based events. In short, there is a global community on Facebook with a bevy of information that could prove useful to you.

There are 49 pages on rheumatoid arthritis and over 500 groups available on Facebook. Osteoarthritis has over 200 pages and groups, osteoporosis, ankylosing spondylitis, and psoriatic arthritis each have about 100 pages and groups, and juvenile idiopathic arthritis has around 300. Please remember: it is important to be critical about the information you are accessing.

You can find several credible Canadian Facebook groups including www.facebook.com/JointHealth, www.facebook.com/ArthritisCured, www.facebook.com/WhereIsArthritis. Further examples are the **Consumer Advisory Board of the Arthritis Research Centre of Canada**, the **Canadian Arthritis Network**, and various chapters of the **Arthritis Society**. Unfortunately, the URLs are too long to include here, but you will easily find them by doing a search on facebook.com.

twitter

Twitter is a social networking and microblogging service. What exactly is microblogging? Users create a profile, and can then post messages, known as 'tweets', of no more than 140 characters. You post them on your profile and people (others in the Twitter community) can 'follow' your tweets. Subscribing to someone's tweets is called 'following' them. You can also share a message from another person's profile, which is called 'retweeting' and is one of many ways to put relevant information on your profile for your followers.

The premise is very easy, and it is not difficult to use. Twitterers can follow individual people such as celebrities, or subscribe to organizations such as news bodies. In the arthritis community, there are many individuals and organizations on Twitter. Here are some examples: JointHealth™, Health Canada, CBC Health, New York Times Health, etc. Twitter is an excellent platform to stay informed about breaking news in the arthritis world. You are also able to blog about your experiences in short, succinct phrases. You may find it useful to do some online research to learn techniques for communicating effectively and efficiently via Twitter

Arthritis Consumer Experts is on Twitter and can be reached at www.twitter.com/ACEjointhealth. Cheryl Koehn, President of ACE and a person living with RA, is also on Twitter at <http://twitter.com/CherylKoehn>.

You Tube

YouTube is a video sharing website where anyone can post video clips up to 15 minutes long. It is a global platform to upload, share, and view millions of videos. You do not need to have an account, like some other social media, to have access. However, if you wish to post an item then you must have an account.

How is YouTube useful for the arthritis community? There are over 5000 videos, from 142 'channels' related to arthritis, covering information about a variety of topics including exercises, pain relief, symptoms, and different treatment strategies.

The best way to access reliable information would be to search for a profile, known as a channel, relating to arthritis. You would type in your search, and specify that you only want to look at channels. Once you are convinced it is credible, you can subscribe to that channel. There is also a conversation aspect to YouTube, whereby viewers can comment on a given video and create discussion.

Arthritis Consumer Experts is on YouTube and has posted several interesting web workshops on arthritis. They can be found at <http://www.youtube.com/user/JointHealth>.

Advocacy via social media

These various social media are all excellent advocacy tools. They are a means to share personal stories, valuable information, and events. Through these media, people can learn about the issues and get involved.

Despite that more than 4.5 million Canadians suffer from arthritis, it is not considered a 'status' disease in Canada. That is to say, arthritis is not as high profile as cancer or heart disease, even though it affects more people and is life-threatening. There remains an inequity in treatment and discrimination in research funding.

It is thus crucial that patients use social media to create discussion, put information out there, and be heard. Using social media to do this will increase the profile of arthritis in Canada. The more powerful the arthritis community becomes, the better chance arthritis has of becoming a 'status' disease.

Join Facebook, Twitter, YouTube, MySpace, or any number of social networking websites. Create advocacy groups, share your story, attend arthritis

events and raise awareness. We have to build the advocacy community, using every tool we have. Nothing will change until the arthritis community advocates for the government to pay attention to the millions of Canadians suffering from this debilitating disease. Social media are, by definition, about people. They allow for social action in real time. If you become involved, you can help change the political, social, and economic landscape for people living with arthritis.

The brilliance of social media is that you can either be an active or passive participant. Anyone can watch arthritis videos on YouTube, read discussions on Facebook pages, and stay up-to-date on arthritis events via Twitter. Alternatively, if you have the time, prowess, and inclination you can be an active participant and become involved in whole new advocacy communities. With these new levels of accessibility and communication, becoming an advocate for arthritis now lies at your fingertips.

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.jointhehealth.org

Guiding principles and acknowledgement

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence

of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities, and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and healthcare providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

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Disclaimer

The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any healthcare related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.



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