

About 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

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 website, or during any of its educational programs or activities.

Thanks

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



Arthritis Research Centre of Canada
Arthrite-recherche Canada

Acknowledgements

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ACE thanks these private and public organizations and individuals.



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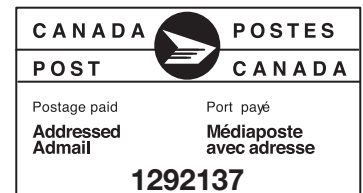
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Disclaimer

The material contained in this or any other ACE publication 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. If you have any healthcare related questions or concerns, you should contact your physician. Never disregard medical advice or delay in seeking it because of something you have read in any ACE publication.



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'net worth: getting the most out of social media



Desktop computers, laptops, tablets and mobile phones, in combination with the Internet, are the new file drawers, books, encyclopedias, libraries, marketing tools, community meeting places, healthcare tools, and more. Electronic devices can be adapted in countless ways. Some more useful than others. How can individuals and healthcare advocates get the most out of the technology? Find out in this issue of JointHealthTM monthly.

Whether you think social media is a valuable resource or a time-waster, it is transforming the way we communicate with people all over the world. People spend hours on their computers and smartphones, so from the point of view of organizations with a message to share, social media is a primary way to connect with audiences. Organizations that successfully use the Internet and social networking sites include the **American Red Cross** and the **Mayo Clinic**. Using innovative and widely different strategies, they built their profiles to drive people to take action to support their causes.

The American Red Cross has nearly 500,000 likes on their main Facebook page, and many more on pages created by its local chapters all over the United States. They also have just under 900,000 followers on Twitter and almost 12,000 subscribers on YouTube. And they can be found on LinkedIn, Pinterest, Flickr, and Google+. The organization's social media strategy is incredibly successful, yet simple. They ensured that every one of their local chapters was trained in social media. By providing all the guidelines the chapters needed to act independently, the organization was able to engage on a local level as well as nationally. Website: www.redcross.org

The Mayo Clinic's strategy was also simple. They published

press-ready videos that could be used in traditional TV news, for pitching stories to the media, and for providing information to patient communities quickly. They are also active on Twitter, Facebook, and several blogs. Their strategy was so successful, they developed the Mayo Clinic Center for Social Media to "improve health globally by accelerating effective application of social media tools throughout Mayo Clinic and spurring broader and deeper engagement in social media by hospitals, medical professionals and patients." For more information, visit www.socialmedia.mayoclinic.org

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.

eHealth: the way to a health e you

Have you heard of eHealth? It is short for electronic health, and it means using computers and other electronic devices to communicate and share health information. Its uses can range from administrative, such as entering medical notes into a database to track patients' health, to direct healthcare delivery through apps.

Electronic health allows patients to be more involved in their own healthcare and makes it easier for institutions and healthcare professionals to share information with each other. For example: on your healthcare team, you may have a physiotherapist, a rheumatologist, and a pharmacist, each working in different parts of your province at different institutions (a downtown office, a university hospital, and a pharmacy). Electronic health makes it far easier for information to be shared amongst all these aspects of your healthcare and, importantly, with you.

Basically, eHealth is making use of information technology for health-related services, education, and research.

Becoming increasingly important, eHealth allows:

- Patients to manage their own health information
 - Patients to look up their symptoms
 - Healthcare organizations to monitor and track diseases (like bird flu)
 - Governments to track statistics, such as the number of people who have a type of disease.
- The data can help determine how much funding

What is eHealth? Health Canada's definition is "an overarching term used today to describe the application of information and communications technologies in the health sector. It encompasses a whole range of purposes from purely administrative through to health care delivery."

is needed for diabetes or arthritis, for example, and to what extent services will be required for the disease.

- Physicians to keep abreast of guidelines on the latest information about medications and treatments
 - Patients who live in rural communities to have access to their doctor remotely
 - Patients the opportunity to communicate with other people who live with the same disease.
- Through social media, for example, they can learn each other's experiences and find out how others cope. This is a wonderful tool, especially for people who live with rarer diseases. You may not come across very many others with lupus, for example, in your community, but online you can connect with people from all over the

world. It can help people feel less isolated in their experience of their disease.

- Patients to be educated about their disease and learn about treatments
 - Electronic medical records can be mined for clinical information that could be used for research.
- An example of eHealth, recently introduced in British Columbia, is the Electronic Health Record (EHR). Its use will mean that healthcare records can be smoothly communicated between computer systems throughout the province. According to BC's Ministry of Health, eHealth will provide:
- Secure access to health records anywhere in the province (by an authorized person)
 - Physicians with better access to patient records
 - Patient test results filed together online for their caregivers when needed
 - Improved patient safety through an enhanced PharmaNet
 - X-rays, CT scans and MRIs available online for caregivers
 - Health services in rural and remote areas and for First Nations, through TeleHealth
 - Improved public health service delivery

For more information, please visit:

www.health.gov.bc.ca/ehealth
www.health.gov.bc.ca/ehealth/need.html
www.myehealth.ca
ehealth.med.ubc.ca/about/what-is-ehealth

Social media, advocacy, and you

Despite that over 4.5 million Canadians live with arthritis, it is not considered a 'status' disease. That is, arthritis is not as high profile as cancer or heart disease, even though it affects more people and certain types are life-threatening. Treatment continues to be unequal across Canada. The money that goes into arthritis research is a fraction of what goes into searching for a cure for cancer or HIV.

What worked for getting cancer well known and taken seriously by the general public? It affects people of all ages and just about everyone knows somebody with a type of cancer, so everyone is at least slightly afraid of it. And when people get sick from it, it shows. It feels close. Arthritis may not.

What does social media mean to you?

Is it a time waster or a valuable resource? Send us your views at feedback@jointhealth.org.

Part of the problem is that there are so many misconceptions about arthritis.

Largely dismissed as a disease of the elderly, generally, people do not realize that any one at any age can get arthritis. Though it is not always visible, arthritis is painful and often debilitating. Sometimes it is thought to be just aches and pains, that people who have it are somehow not tough enough, or that arthritis could easily be controlled by following a certain diet and exercise routine. Because it may not be taken very seriously or is simply not well known, people who have it are uncomfortable talking about it. Because they don't talk about it much, there's the illusion that it's not that prevalent or that it's not that serious. What can be done to end this cycle?

It is crucial that patients share their stories, 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.

Twitter, Facebook, YouTube, and blogs are among the many social media platforms that can be used as advocacy tools. They are ways to share personal

Health e apps:

Another form of eHealth is smartphone and tablet applications ('apps') that promote and help maintain health. This growing new technology is taking over the world of healthcare. From apps currently available that can track your calorie intake to those that can track moles for skin cancer, and upcoming apps that will help you take your blood pressure or monitor your heart rate and other vital signs, there is no limit to their potential.

Here are just a few free apps that are currently available that we tried and liked:

MyFitnessPal

This food diary and exercise tracker gives the calorie count for more than 2 million foods, including from Canadian companies. With its ability to read a food product's barcode, you can simply scan it and all the nutritional information about the product is automatically transferred to the diary. Another neat feature of the app is that you can do this with a friend, since it allows you to share your progress and motivate each other.

MapMyFitness

It tracks your workout routes as you walk, hike, run, cycle, and more using GPS on your phone. As you go it records duration, distance, pace, speed, and elevation. Indoor workouts can be tracked as well by directly entering information about your activities. It also records calories consumed and burned, but the options for the food diary are limited. There are a number of similar apps - some free and some not - that are specific to certain kinds of workouts, such as MapMyDogwalk, MapMyRide, and MapMyHike.

Fitness Buddy

There is a free version and a 99 cent (at time of printing) version. We have not tried the paid one, but the free app gives plenty of exercises and is more than useful. It provides numerous exercise routines that allow you to focus on certain muscle groups. If you want even more features like

stories, valuable information, and events. Through these media, people can learn about the issues and get involved.

Join a social networking website, create advocacy groups, follow and contribute to arthritis blogs or start your own blog. In short: share your arthritis story and help 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 allow for social interaction - and action - in real time. If you become involved, you can help change the political, social, and economic landscape for people living with arthritis.

... yes, you!

Please go to the JointHealth™ 'taking action' (www.jointhealth.org) tab to become an active participant in disease advocacy. Use the tools provided to

The NAAP APP

Developed to expand the conversation on arthritis with the public and healthcare professionals, **ArthritisID** and **ArthritisID PRO** are provided for free by the National Arthritis Awareness Program.

www.arthritisiscured.org



video demonstrations and the ability to track your heart rate, then the paid version may be better for you. None of the exercise routines are tailored for people with arthritis, though, so we advise checking with your doctor or physiotherapist before trying the exercises.

WebMD App

It allows you to check symptoms, identify pills, and look up information about conditions, medications, treatments, and first aid for medical emergencies. It also provides local health listings, but does not include Canadian hospitals, doctors, or pharmacies.

WebMD Pain Coach

An iPhone app designed for back pain, fibromyalgia, migraine, neck pain, nerve pain, osteoarthritis, rheumatoid arthritis, and diagnosed chronic pain management. It provides:

- A personal journal to help log pain levels on a scale of 1 to 10, triggers, moods, and treatments
- 588 tips, 379 articles, 25 videos, and 21 slideshows related to painful conditions
- Custom pdf reports that can be shared with your doctor

How popular are social networking sites?

Facebook: 1 billion users

YouTube: 800 million users

Twitter: 500 million users

This doesn't even include Flickr, Reddit, MySpace, Instagram, Pinterest, foursquare
... and the list goes on.

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.



ABN

We welcome contributors to the Arthritis Broadcast Network. Please send your blog posts to feedback@jointhealth.org. Or simply like, share, or comment on other posts at www.arthritisbroadcastnetwork.org.