

Education

arthritis **101** Implementing national standards for arthritis prevention and care

According to Health Canada's Arthritis in Canada report (2003), arthritis is the third most commonly reported health concern in Canada. It affects 4 million Canadians –one in five adults – yet, based on discussions with Canada's federal and provincial elected officials, government awareness about the best, evidence-based strategies to prevent and treat arthritis is not what it should be.

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This issue of JointHealth Monthly is provided in print and online in English and français.



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Because arthritis impacts so many, government officials must be aware of arthritis and its effects in order to develop and implement health policy to appropriately meet the needs of Canadians and their families living with the disease.

To address the arthritis awareness "gap" at government, the Alliance for the Canadian Arthritis Program (ACAP) has developed a national initiative called "Arthritis 101". From October through December 2006, ACAP member organizations will host Arthritis 101 events across Canada. The events will target Canada's elected officials, and will be comprised of two parts: an information session containing the latest on arthritis prevention and care strategies followed by an arthritis screening clinic.

During Arthritis 101 events, ACAP member organizations will focus on providing the scientific evidence that supports the three priority standards from the Standards for Arthritis Prevention and Care Strategy (see **JointHealth™ monthly – April 2006**):

- 1) Every Canadian must be aware of arthritis.
- 2) All relevant health professionals must be able to perform a valid, standardized, age-appropriate musculoskeletal screening assessment.
- 3) Every Canadian with arthritis must have timely and equal access to appropriate medications.

Working together, the ACAP and government can make a real difference in the lives of Canadians with arthritis.

Representatives from the ACAP member organizations will provide elected officials with recommendations on what specific health policies are needed to meet the three priority standards.

The impact of arthritis

Arthritis can have a devastating impact on

the lives and families of people living with the disease. As well, undiagnosed and advanced arthritis puts a great burden on the medical system, as the cost of treating arthritis and its symptoms increases if the disease is left to progress unchecked. Some straightforward changes would make a huge difference in the lives of people living with arthritis, and provide a significant cost-savings to the medical system.

For example, one out of every five Canadians has some form of arthritis, yet the typical healthcare provider receives approximately 17 hours of arthritis specific training. If elected officials put into place a requirement for medical schools and other health care accreditation bodies to include an appropriate arthritis screening exam as part of the curriculum, the healthcare system would deliver significantly improved access to

"Working together, the ACAP and government can make a real difference in the lives of Canadians with arthritis"

care and relieve the cost burden associated with undiagnosed and advanced arthritis.

Support ACAP by exercising your voice

To make Arthritis 101 a success in your province and in Ottawa, ACE urges you to contact your MLA (Member of the Legislative Assembly), MPP (Member of the Provincial Parliament), and MP (Member of Parliament) to tell them about the event and courage their attendance. Their awareness of arthritis and its devastating effects is critical in the development of provincial and federal health policy to meet the needs of one out of every five of their constituents.

To contact your MP, visit www.canada.gc.ca, or call **1 800 622-6232**. To contact your provincial MLA or MPP, visit your provincial government web site or phone the general information number listed in your telephone service providers' book.

Make sure your voice is heard. With one out of every five Canadians living with arthritis, it is the responsibility of our elected officials to make arthritis prevention and care in Canada the best it can possibly be.

In September, arthritis awareness month in Canada, ACE launched its new JointHealth™ podcast program. This innovative program is designed to allow

members of the arthritis community to listen in on informative conversations between leading arthritis patient advocates and medical experts in the fields of arthritis research, prevention, treatment, and advocacy.

Each program provides clear evidence-based arthritis information from the featured rheumatologist (arthritis specialist) or arthritis health care provider, and expert advice from people living with arthritis and active in the community.

JointHealth™ podcasts can be accessed by visiting the ACE website at www.arthritisconsumerexperts.org and clicking on the podcast button. In moments, you will be able to hear in-depth interviews with leaders in the field—the kind of conversations many of us would love to be able to have with our doctors or peers.

You can listen to podcasts online, or download them to your computer or personal MP3 player, just as you would with a piece of music. JointHealth™ podcasts are then portable and totally convenient—you can listen to them whenever it works for you.

Below are brief outlines of podcasts currently available live on the ACE website. We look forward to bringing you 12 more JointHealth™ podcast programs beginning in January 2007. Upcoming podcasts will include conversations with leading rheumatologists on the latest treatment advances, leading patient advocates on how to get what you need from today's health care system and dieticians, among others.



Advancements in Arthritis Research, with Dr. John Esdaile

This fascinating 38 minute podcast provides a “behind the scenes” look at some of the latest, most groundbreaking work currently being done in arthritis research.

Dr Esdaile, scientific director of the Arthritis Research Centre of Canada and professor and head of the Division of Rheumatology, Department of Medicine at the University of British Columbia, speaks with patient advocate Cheryl Koehn about a number of topics of interest to the arthritis community, including:

- An overview of the types of research currently



being conducted in Canada

- The urgent need for more funding for arthritis research, and better training for healthcare professionals, as well as the staggering shortage of rheumatologists available in Canada
- Exciting research advances in the areas of early diagnosis, genetic components of the disease, treatment of inflammation, and links between inflammatory arthritis and other diseases
- Examples of consumer groups helping to set the agenda for research priorities in Canada.

The future of arthritis prevention and treatment depends on research, and Dr. Esdaile gives the listener a clear idea of where we are and where we are headed in the world of research.



Treatment Advances for Inflammatory Arthritis, with Dr. Kam Shojania

In this informative 36 minute podcast, you will be provided with some of the most up-to-date information available regarding treatments for inflammatory arthritis.

Dr Kam Shojania, clinical associate professor in the Division of Rheumatology, Department of Medicine at the University of British Columbia and a clinical leader in the field of rheumatology, speaks with patient advocate Cheryl Koehn about advancements in a number of different areas, including:

- The importance of a well rounded treatment plan in inflammatory arthritis
- An overview of types of medications and therapies, including combination therapies and the latest on biologic response modifiers
- The early and aggressive treatment approach in inflammatory arthritis
- Talking with your rheumatologist about medication decision-making.

This informative conversation is just the type that many people living with inflammatory arthritis want to have with a rheumatologist.



Exercise and Arthritis, with Dr. Linda Li

The latest research strongly suggests that exercise is an integral component of a

successful, holistic treatment plan for many forms of arthritis.

In this enlightening 40 minute podcast Dr. Li, an assistant professor at the UBC School of Rehabilitation and

Harold Robinson / Arthritis Society Chair in Arthritic Diseases and an expert on the role of exercise in the treatment of arthritis, speaks with arthritis advocate Cheryl Koehn and provides us with information on:

- Safe types of exercise for people living with different types of arthritis
- Strategies for preparing for exercise, and what to do to prevent injury, joint pain, and stiffness
- The specific benefits of exercise for people living with inflammatory arthritis and osteoarthritis
- Striking a positive balance between physical activity and rest
- Finding the right type of healthcare professional to help create an exercise program that is tailored to age, gender, and type of disease.

If you have ever wondered about fitting exercise into your treatment plan, this podcast will answer many of your questions.



Arthritis and Work, with Dr. Diane Lacaille

Diseases affecting bones and joints, like arthritis, prevent people from holding down steady employment more than any other type of disease. In this fascinating 36 minute podcast, Dr Lacaille, assistant professor, Division of Rheumatology, Department of Medicine at the University of

British Columbia and Canada's leading expert on issues of arthritis and employment, speaks to arthritis advocate Cheryl Koehn and provides an overview of the challenges people with arthritis face in the workplace, including:

- Common work-related challenges brought on by inflammatory arthritis
- Simple strategies for minimizing physical discomfort at work
- How to talk to your employer about your arthritis
- How to talk to your healthcare provider about your employment.
- Self-employment for people with arthritis as an alternative to full-time work

Work is often a critical part of our lives, and this podcast provides sensible ideas and advice for people living, and working, with arthritis. ☺

Results from the Survey to Help Implement the Alliance for the Canadian Arthritis Program's Standards for Arthritis Prevention and Care

At ACE, we believe that arthritis healthcare reform should be driven by people with arthritis. In August, we asked you to do just that. We asked you to tell us how best to implement two of the Alliance for the Canadian Arthritis Program's priority standards:

- 1) Every Canadian must be aware of arthritis.
- 2) Every Canadian with arthritis must have timely and equal access to appropriate medications.

HERE ARE YOUR RESPONSES:

Arthritis awareness

You told us that public awareness of arthritis is not at the level it needs to be to encourage early diagnosis and treatment. At the time of diagnosis, while 76% of you knew what arthritis was, 87% had no idea that there were over 100 types of arthritis, and 70% did not know what to do when you thought you had arthritis.

We asked you to brainstorm with us about how to increase awareness of arthritis among the public. You came up with some excellent suggestions, and emphasized many of the reasons that you believe awareness needs to be improved.

Many of you suggested that Public Service Announcements featuring real people with various types of arthritis on television and radio should be a focus in the drive to improve awareness. Some of you also made the suggestion that elementary and secondary school students should be educated about prevention, symptoms, and treatment in public health or physical education classes. Here are some more of your responses:

- Run TV ads that explain that arthritis is not just "a sign of old age"
- Arthritis awareness posters for hospitals and doctor's offices
- Choose a ribbon colour to symbolize the fight against arthritis, like pink ribbons do for breast cancer
- Provide young people with articles written at their reading level on juvenile forms of arthritis
- Raise awareness that children get arthritis, too. More parents need to be aware of the warning signs so that they can be more insistent with doctors that the early pain and stiffness of juvenile arthritis may be more than just "growing pains"
- Arthritis organizations should provide

pamphlets and information to groups interacting with people with disabilities

- A "checklist" of symptoms could be sent out in the mail so that people are aware of the signs and symptoms of arthritis
- Articles in popular magazines, and stories on local news "healthwatch" segments
- GPs should have more info pamphlets on hand at their offices
- People with arthritis must meet with their elected officials and make them aware
- More should be done to let people know that arthritis is not a catch-all for every ache and pain you may have.

Access to arthritis medications

We wanted to know how effectively your arthritis has been treated within our medical system, and your answers were staggering. Only half of you were diagnosed by the first medical doctor you saw about your arthritis symptoms, and 61% of you were not prescribed medication that helped your arthritis symptoms by the first medical doctor you saw. Only slightly more than half of

"Finally, fully 90% of you said you needed more information than the diagnosing doctor provided."

you felt you were diagnosed within a reasonable length of time after first speaking with a family doctor. Finally, fully 90% of you said you needed more information than the diagnosing doctor provided.

Regarding access to medications, more than half of you have to pay out of pocket for some or all prescription arthritis medications prescribed by your doctor. On average, you pay about \$820 per year, but medication costs for some of you go up to \$6000 per year—and more.

We asked you to tell us how to improve arthritis treatment, and what impact access to medications has on your health. You told us that access to medications under private/public insurance plans is critical to your well-being. You said that timely access to a rheumatologist is urgently needed, and in many cases is simply not available. You also told us you would like to see a more generous availability of complementary therapies including massage, chiropractic, and acupuncture.

Here are some of your comments:

- Medical care is minimal. Doctors don't have time to "chit chat". They only want to prescribe drugs and have you leave. They treat you like you are a product on an assembly line.
- I pay for extended health care benefits out of pocket at a cost of \$112 per month so that I am able to get my medications. I live on two disability pensions and this, along with paying for syringes, puts a bit of a burden on my finances
- My daughter is being treated at a children's facility and the doctor is totally overextended... we have to wait 6 months for her to see her new rheumatologist.

Many of you also provided some concrete suggestions regarding improvements you would like to see in arthritis care:

- Easier access to a rheumatologist
- Access to drugs that will help battle both pain and chronic fatigue
- Access to a warm water pool to exercise in
- Less restrictive BC PharmaCare coverage, and coverage for physiotherapy and massage therapy
- Affordable access to more alternative treatments like acupuncture, massage, chiropractic care
- Access to publicly funded physiotherapy
- The ability to access a specialist, and affordable medications and/or treatment options
- New hips
- Provincial approval of newest treatments.

Thank you to all of you who took the time to fill out the Survey to Help Implement the Alliance for the Canadian Arthritis Program's Standards for Arthritis Prevention and Care. Your voices have been heard, and will continue to be heard; we will be providing a report, including your answers and comments, to the research community and to Canada's federal and provincial elected officials.

Listening to you

We hope you find this information of use. Please tell us what you think by writing to us or emailing us at info@arthritisconsumerexperts.org. Through your ongoing and active participation, ACE can make its work more relevant to all Canadians living with arthritis. ☺

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 health care 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.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, 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 health care 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

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



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ACE thanks these private and public organizations.

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 health care related questions or concerns, you should contact your physician. You never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter. <


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