

Education

Getting a referral from a family physician to a rheumatologist (arthritis specialist)

One of the most common comments made by participants at ACE workshops is how difficult it was for them to get a referral to a rheumatologist (a medical doctor specializing in the care of arthritis) for their inflammatory arthritis. If one of out of five Canadians lives with some form of arthritis, why is it so difficult to get a referral?

When it comes to inflammatory arthritis, like rheumatoid arthritis (RA) and ankylosing spondylitis (AS), the answer comes in three parts:

September is arthritis month in Canada, and it seemed fitting to make this special eight page issue of JointHealth™ monthly about a broad range of topics, from getting a referral to a rheumatologist, to making the most informed decisions about arthritis medications.

Education

- Getting a referral from a family physician to a rheumatologist (arthritis specialist)
- Prevention and treatment of osteoarthritis
- The effects of rheumatoid arthritis on relationships
- Arthritis medications

Advocacy

- Summit on Standards for Arthritis Prevention and Care, Nov 1-3, 2005
- How to find out who your MLA, MPP & MP is

Arthritis Consumer Experts (ACE)

- Who we are
- Guiding principles and acknowledgement
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1. Diseases like RA and AS occur in the adult population at a frequency of about 1 percent and 0.5 percent, respectively. So in the case of RA, only one out of 100 people will show signs and experience the symptoms of the disease. In other words, on an individual basis, family physicians may not see many people with signs and symptoms of RA and AS out of the thousands they care for on a regular basis.

2. Out of four years of medical school training, a family physician receives only about 17 hours of training on the over 100 different types of arthritis and related diseases. They simply do not receive enough education and training on RA and AS to recognize the signs.

3. Other disease symptoms can look like those of RA and AS and send the family physician down the wrong path of investigation and diagnosis. As well, because the public has very low awareness of diseases like RA and AS, people who experience the early symptoms do not recognize them as being related to arthritis.

For these reasons and others, it can be very difficult getting a referral from a family physician to a rheumatologist. That is why the medical school curricula in Canada on arthritis and related conditions are in urgent need of expansion and updating. This becomes increasingly important in that the peak age of diagnosis for RA is between the ages of 50 and 60. With the aging population of Canada, family physicians will be seeing more and more people in their offices with signs of this and other inflammatory diseases.

In addition, broad public awareness on inflammatory arthritis is needed around the

hallmark symptoms of this group of diseases: **joint pain and swelling, morning stiffness for more than an hour, and loss of ability to do daily living and work activities.** Currently, no community, provincial, territorial or federal government web sites or health publications highlight arthritis as a major health concern affecting four million Canadians. Until they do, members of the public who go on to develop inflammatory arthritis will not have access to the information and education they and their health care professionals will need to deal with the problem within the six week time period recommended by arthritis experts.

The bottom line is this: Getting a referral from a family physician to a rheumatologist continues to be difficult and it is having a significant negative effect on people experiencing the symptoms of diseases like RA and AS. So first and foremost, if a person is experiencing joint pain and swelling, morning stiffness for more than an hour after arising, and losing their ability to do daily living and work activities, they need to tell their family physician these things, and ask for a referral to a rheumatologist. The family physician's referral letter needs to include these important points:

- The suspected diagnosis of inflammatory arthritis
- A brief history and clinical findings including a description of the patient's changes such as morning stiffness and how long it lasts, record of weight changes, fever and the number of joints affected.
- Copies of all reports: MRI (Magnetic Resonance Imaging), X-rays, and consultation letters from specialists, if available.

Early referral for diseases such as RA and AS can lead to early diagnosis and treatment with better long-term results helping to decrease pain and swelling, loss of joint structure and function, and possible permanent disability. <



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Education

Prevention and treatment of osteoarthritis

Until recently, little was known about the cause and course of osteoarthritis (OA), so family physicians had little to offer those experiencing the earliest symptoms of the disease. Most people were told OA was part of getting older, and to go home and cope with it the best they could. But times have changed, and so must the myths surrounding this most common type of arthritis. Something can be done to prevent and treat OA.

The first step to debunking OA myths is by understanding what the disease is. Osteoarthritis is now being classified into two types – “primary generalized” and “secondary”:

- **Primary generalized OA** affects many joints and is often inherited. In other words, it is part of a person’s genetic make up. It is a degenerative process that may be going on in one’s body at a very early age, but the person may only experience symptoms years later, once damage to a joint or joints has already been done. Therefore it is important to keep a record of your family’s medical history for yourself and for your general physician.
- **Secondary OA** occurs after repeated trauma to a joint over a period of time (months or years), like with a repetitive task at work or leisure, or after a few major traumas, like a sports injury. Both types of trauma change affect the physical structure of the joint and result in changes in the way it functions over time.

In addition to the above, there may be other things that promote OA. For example, there are strong links to diabetes, obesity, and cartilage disorders.

“But times have changed, and so must the myths surrounding this most common type of arthritis.”

The second step to debunking OA myths is to understand that there are prevention strategies that work. Foremost among those is educating the public about the need to prevent injuries at work and at leisure that lead to secondary OA. For example, if coaches and parents of kids taking part in school and community sports programs understood the basic principles of stretching and strengthening to prepare for sports activities, then injury prevention would become part of the foundation for participation.

Also, if a child is injured during a sport activity and the parent and coach understand the basic treatment and rehabilitation principles, then they can prevent recurring problems that may lead to secondary OA.

One OA myth that definitely needs debunking is that no effective treatments exist for OA. Nothing could be further from the truth. Of course, education is the foundation of any good treatment program. Along with ACE’s JointHealth™ workshops that focus on osteoarthritis education are programs run by *The Arthritis Society of Canada, Patient Partners in Arthritis* and other local arthritis groups.

Other research-based treatment strategies include:

- Weight loss
- Exercise
- Joint protection and energy conservation
- Walking aids, like canes and walkers
- Appropriate footwear
- Lateral-wedge insoles
- Assistive devices
- Joint surgery

Another important aspect of the effective treatment of OA is medications. Medications, so far, have not been conclusively shown to prevent the progression of OA. There are a number of different medications used, among them are:

- Acetaminophen (like Tylenol)
- Non-selective non-steroidal anti-inflammatory drugs (NSAIDs) and selective non-steroidal anti-inflammatories (COX-2 NSAIDs)
- Antidepressants (in low doses)
- Opioid analgesics (like codeine, or other narcotics used for more severe pain)
- Hyaluronic acid injections into the joint
- Steroids injections into the joint
- Glucosamine sulfate
- Topical therapies (such as capsaicin or NSAIDs in cream form).

Along with the above treatment strategies, it is important for the person living with OA to learn effective communication strategies around their disease, such as ways to explain how the disease affects their life, how to ask for help without making themselves and those around them feel helpless, how to access community and government support, among others.

So the next time someone tells you or someone you care about there is nothing that can be done about OA, debunk the myth by telling them what you know. <

Advocacy

Summit on Standards for Arthritis Prevention and Care, Nov. 1-3, 2005

As highlighted in the May 2005 issue of **JointHealth™ monthly**, the planning for the Summit on Standards for Arthritis Prevention and Care is well under way.

The Summit planning committee is actively gathering the research data to support the nine priority standards in the areas of arthritis prevention, manpower and models of care and awareness, and is actively talking with provincial, territorial and federal governments with the goal of having the health minister and the premiers from each province in attendance.

You can help the planning committee and Canadians with arthritis by writing your MLA, MPP or MP and encouraging them to support the attendance of their provincial health minister and premier and senior elected officials from the federal government.

It is vital that government officials attend the summit and see the importance of standards for arthritis prevention and care. Government is the key to making the changes needed that will benefit all Canadians with arthritis.

To learn more about the Summit, visit www.arthritisalliance.ca

MLA/MP/MPP Finder

To find your Member of Parliament (MP) go to http://canada.gc.ca/directories/direct_e.html. This site provides you both with email and mail addresses for MPs. If you do not have internet access call: **1 800 O-Canada (1 800 622-6232)**.

To find your Member of Legislative Assembly (MLA) go to your provincial government website and click on members and/or MLA finder. This site helps you find your MLA and how to contact them by typing in either your postal code, your community, name of MLA or your MLA’s constituency. If you do not have internet access call the general number for your provincial government located in the government pages of your phone book.

The effects of rheumatoid arthritis on relationships

Rheumatoid arthritis (RA), like most chronic diseases, can have a profound affect on the person living with the disease and their spouse or life partner. Along with experiencing pain, loss of function, and other physical symptoms, the person with RA deals with a rollercoaster ride of emotional feelings, like fear, anger, depression, isolation, and loss of self-esteem – and much of the time, so does their spouse or life partner.

Knowing how to deal with these things and understanding how they impact on relationships is important to learning to live the best quality of life possible with RA – whether you are the person with it or the spouse or life partner of someone living with it.

A recurring theme among people living with chronic, debilitating diseases such as RA, is that they feel a sense of helplessness. Many who are diagnosed with RA go from being fully able

bodied, doing all the things they want to do (and more), to doing very little of what they used to be able to do or accomplish in a day. One way to overcome feelings of helplessness is to ask for support, both physical and emotional. But asking for support is not always easy.

The best type of support is negotiated, that is, where two people have discussed why support is needed, what types of support can be provided and by whom, and what types of communication can be used to ask for or offer support. Having this type of discussion enables each person in the relationship to share their views on support as equals and leads to a deeper understanding about each other's needs.

Starting conversations about the impact of RA on one's sexuality, or one's ability or desire to have sexual relations can also be difficult, but a number of resources are available to help.

Among them, books on RA that include chapters specifically devoted to relationships and sexuality (*Rheumatoid Arthritis "Plan to Win"*, Oxford University Press, 2002; *The Arthritis Self-Help Book*, Arthritis Foundation); counselors with experience around sexuality issues; and health care professionals with expertise in issues related to the home environment, like occupational therapists.

Participants at ACE's workshops report that the sharing of people's experiences with arthritis during the hour long question and answer time is both helpful and enjoyable. ACE would like to further this sharing through our newsletter. If you would like to tell us your experiences as a person with arthritis or as a spouse, life partner, or friend, please write or email ACE at:

info@arthritisconsumerexperts.org <

Free Workshops : Fall Schedule

Every Spring and Fall, ACE offers free workshops in communities across Canada. These researched-based education workshops are conducted by leading rheumatologists (arthritis specialists) and patient advocates. The workshops are held at times which are convenient for people with commitments during the work week.

For further information including workshop location, or to register please go to: www.arthritisconsumerexperts.org or call **1.866.974.1366**.

Plan to Win with Ankylosing Spondylitis (AS)

New for 2005, the Plan to Win with Ankylosing Spondylitis workshops will focus on ankylosing spondylitis, a common type of inflammatory arthritis, that commonly affects the spine and other large joints in the body.



Workshops

Montreal, QC	September 22
Toronto, ON	September 29
Calgary, AB	October 11
St. John's, NF	October 18
Hamilton, ON	October 19

JointHealth™

JointHealth™ workshops will focus on two of the most common chronic diseases in Canada - osteoarthritis and osteoporosis. These diseases affect millions of Canadians making this a very popular workshop.

Taking an integrated approach to managing these two health challenges requires a whole-body perspective. More than ever, people need to develop a strong health care team to take advantage of all the opportunities to manage their health. These workshops will help you learn about prevention strategies and focus on what you can do to live well with osteoarthritis and osteoporosis.

Workshops

Halifax, NS	September 17
Coquitlam, BC	October 6

Plan to Win with Rheumatoid Arthritis (RA) workshop

These workshops provide you with the critical information you need to know to take control of rheumatoid arthritis, one of the most common forms of inflammatory arthritis.

Topics covered include:

- What rheumatoid arthritis is and about its effects
- Developing your own customized treatment plan (health care team, medications, exercises, work)
- Healthy living strategies
- Access to treatment and services in your community
- Latest arthritis research news
- "Question and Answer" session

Workshops

Charlottetown, PEI	September 13
Saint. John, NB	September 14
Halifax, NS	September 15
Ottawa, ON	September 19
Victoria, BC	September 27
Trois-Rivières, QC	September 28 (F)

(F) = workshops conducted in French

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

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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 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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