JointHealth™ monthly
Arthritis research, education and advocacy news : October / November 2004

Advocacy & Treatment

Rheumatoid arthritis should be considered a medical emergency

The research is becoming clearer: People with rheumatoid arthritis (RA) need a timely and accurate diagnosis to get the *best treatment early* in order to maintain their health, mobility and quality of life.

In last month's issue of JointHealth™, we reported that there is now a strong body of research suggesting that early treatment of RA results in better long-term health "outcomes" for persons with the disease – such as control of inflammation to prevent or minimize joint damage. But what does timely treatment look like? How is it defined?

Based on the research literature and the recommendations of the Canadian Rheumatology Association, the following is critical to getting the person with new RA timely treatment:

- The family doctor must be able to recognize the hallmark signs and symptoms of RA – pain, swelling and stiffness in the joints, and fatigue
- The family doctor must promptly refer the person with the above signs and symptoms to a rheumatologist
- The family doctor's referral letter must highlight the reason for the referral – suspected diagnosis, list of signs and symptoms, how long the symptoms have been present, blood test results, and copies of X-ray reports and reports of any other diagnostic tests
- The rheumatologist must try to get the person with new RA into their office within weeks.

Once a diagnosis is established and medication started, the next step is education and a plan to win against the disease. There are programs in Canada where a team of healthcare professionals provide support and education for people recently diagnosed with RA. An example is The Arthritis Program (TAP) in Newmarket, Ontario. Teams of seven professionals (that includes a pharmacist, physical and occupational therapists, dietitian, rehabilitation assistant, kinesiologist and rheumatologist) provide three weeks of treatment, education and specialized and focused therapy. (For more information, contact Southlake Regional Health Centre at 905 895 4521 or at www.southlakeregional.org)

As well as establishing a treatment plan with a health care team, there is a list of things a person with newly diagnosed RA can do for them self to get started on an effective treatment plan:

- Learn about RA and what a good treatment plan consists of – education, support, medication, exercise, are just a few of the components
- Develop a support system made up of family and friends and educate them about RA and what a good treatment plan consists of
- Learn to work with the rheumatologist to reach agreement on the diagnosis and develop an early, aggressive treatment plan – ideally within the first three months of diagnosis.
- Access physiotherapy and/or occupational therapy services, as needed
- Use evidence-based complimentary therapies like massage and nutritional supplements, as needed. Remember to discuss these therapies with your doctor and only try one therapy at a time in order to know what works and what does not.

The above ideas are important to getting timely treatment. However, it may take some doing on your part, such as clearly expressing your needs to your health care team, or, by writing letters to your local government representative.

For example, if you are facing a long wait list for joint replacement surgery or have having trouble getting reimbursement coverage for your RA medications (such as biologic response modifiers and others), it is important to write to your MLA or MPP to tell them about how these challenges are affecting you or your family member. The bottom line is this: You, your family and friends can make a difference in the kind and quality of health care you receive, but it takes being an active participant in "the system" to get it. And remember, ACE and other arthritis groups across Canada are there to help you.

To learn more about how to make your voice heard by the health care system and government, visit the ACE web site at www.arthritisconsumerexperts.org, or contact our office. We would be happy to send you helpful letter writing tips, sample letters, and information on how to link up with arthritis advocacy and self-help groups in Canada. ‹

In this issue:

This issue of JointHealth™ focuses on topics related to rheumatoid arthritis (RA), although some of it also applies to other forms of arthritis. Please let us know what you think and offer ideas for future issues.

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Education

Physiotherapy for rheumatoid arthritis

Physiotherapy is used as part of a treatment plan to deal with the physical symptoms of rheumatoid arthritis (RA). Physiotherapists are trained to diagnose problems with body movement and to help the person with RA develop a plan, with achievable goals, aimed at gaining back physical mobility and well-being. Regular visits can help maintain joint function and prevent joint damage.

The first step of a physiotherapist's work is to do a physical assessment, including:

- A functional assessment (things like walking and other daily activities, including posture)
- Evaluation of muscle strength and joint range of motion
- Evaluation of pain and swelling.

Your first step is finding the right physiotherapist, preferably one with training specific to arthritis. Here are a few tips on how to find a physiotherapist:

- Ask your doctor for a referral to a physiotherapist trained in arthritis care
- Contact The Arthritis Society office nearest you;
- Look in the yellow pages under physiotherapists and look for "arthritis" listed in the ads.

Note: Insurance coverage for physiotherapy treatment varies both by province and the many private extended health plans.

Following is a brief description on the types of physiotherapy and rehabilitative treatment used in rheumatoid arthritis.

Heat and cold therapies are probably the most common techniques used for people with arthritis. If a person with RA is having a flare, cold is generally applied, while heat is used at other times, particularly before exercise. Physiotherapists use various techniques from traditional hot and cold packs to infrared radiation or paraffin (for heat) and nitrogen spray or cryotherapy (for cold).

Electrical stimulation is used to provide temporary relief for joint pain. The most common method is called TENS (transcutaneous electrical nerve stimulation).

Water therapy (hydrotherapy) and water-based exercise have a long history in helping people with rheumatism relax. Body weight is reduced by 50% to 90% in water, making moving joints and exercising easier. At the same time, the body relaxes in water, bringing a sense of well-being.

Therapeutic Exercise plays an important role in helping people manage their RA. Maintaining muscle strength is important, not only for general function, but also to help protect and stabilize joints. A physiotherapist can develop a customized exercise program, taking into consideration the extent of the disease, a person's age and current level of fitness.

Range of Motion Exercises can be learned with a physiotherapist and continued at home on a daily basis. Note any pain during exercise should be reported to your physiotherapist immediately.

Strengthening Exercises are very important for people with arthritis. Work with a physiotherapist to set reasonable and achievable goals. There are two main types of strengthening exercises: Isometric and isotonic.

Isometric Exercise involves contracting a muscle without any movement of joints. These exercises can be done daily, any place any time. The benefits of this type of exercise include:

- Maintaining muscle size and improving muscle tone
- Developing muscle strength needed for weight-bearing activities
- Developing muscle strength in preparation for joint surgery or replacement.

Isotonic exercise involves both muscle resistance and joint movement. This type of exercise increases endurance, improves blood flow, promotes strong bones and cartilage as well as maintains or improves muscle strength. Because the joints are involved, extra care is needed to perform the exercises correctly and to note how the body responds. Ask your physiotherapist to advise you on how often you should do the exercises and the number of repetitions of each exercise.

Assistive devices and adaptive equipment can help maintain stability, mobility and reduce the risk of falling. It may be difficult to think about using a cane, but this simple device can reduce pressure on the weight bearing joints as well as increase stability and maintain mobility. For more ideas on ways to make the home more "arthritis-friendly", please refer to the article on "Living Independently with Arthritis" in the September 2004 issue of JointHealth™ monthly.

Research

TNF inhibitors, and bone and joint surgery in rheumatoid arthritis

There are risks with every type of surgery; however, one of the most common is the risk of infection after surgery. People with rheumatoid arthritis (RA) are often at greater risk because their immune systems are weakened by the disease-modifying medications they are taking.

Because they are relatively new in the treatment of RA, it is not known what effect TNF inhibitors (a type of biologic response modifier), such as adalimumab (Humira®), etanercept (Enbrel®), and infliximab (Remicade®) have on the people who are on them and undergoing orthopaedic surgery. A recent study conducted by researchers at Johns Hopkins University and presented at the American College of Rheumatology scientific meeting in October 2004, suggests that there is an increased risk of infection in the first 30 days following bone or joint surgery in those people on TNF inhibitors.

In the study, 10 out of 91 participants developed a serious infection within 30 days after surgery. Of the 10, 7 of the 35 (20%) that received TNF inhibitors before their surgery compared to 3 of the 56 (5%) that did not receive TNF inhibitors got an infection. This is a significant finding and one that warrants further study, as physicians and patients need more than one study to base their medical decisions on.

Two other very important questions the Johns Hopkins University research team intends to investigate are whether stopping TNF inhibitors before surgery will reduce the risk of infection after surgery and when is it safe to restart them after surgery.

In the meantime, for people with RA and on TNF inhibitors who need bone and joint surgery, the researchers at Johns Hopkins University suggest the following:

- adalimumab (Humira®) – stop one month before surgery
- etanercept (Enbrel®) – stop two weeks before surgery
- infliximab (Remicade®) – stop eight weeks before surgery.

For all TNF inhibitors, the researchers recommend restarting no sooner than two weeks following surgery, however, some Canadian rheumatologists recommend different restart times for each TNF inhibitor.

Another unknown is how RA disease flares

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Feedback

ACE Consumer/Patient Survey on NSAID use in Canada

Patient-physician communication is key in making informed health care decisions, especially around medication usage. Non-steroidal anti-inflammatory drugs (commonly referred to as "NSAIDs") are the most widely used type of medication by people with arthritis. There are two types of NSAIDs – selective and non-selective.

Selective NSAIDs are "COX-2 NSAIDs", such as valdecoxib (Bextra®), celecoxib (Celebrex®), and rofecoxib (Vioxx® - removed from the market September 30, 2004.

Non-selective NSAIDs include, naproxen (Naprosyn®), diclofenac (Voltaren®), indomethacin (Indocin®), Arthrotec® and meloxicam (Mobicox®), among others.

To help ACE understand what you think and know about your NSAID medication, please answer the following questions and return this form by mail or fax:

1. Are you currently taking a NSAID medication as part of your treatment plan?

☐ Yes
☐ No

If yes, is it effective in controlling your arthritis symptoms?

☐ Yes
☐ No

2. What type of NSAID are you currently taking?

☐ None
☐ Non-selective – like naproxen (Naprosyn®), diclofenac (Voltaren®), indomethacin (Indocin®), Arthrotec® and meloxicam (Mobicox®), among others
☐ Selective – like valdecoxib (Bextra®), celecoxib (Celebrex®), and rofecoxib (Vioxx® - prior to its removal from the market September 30, 2004)

3. Did you know the benefits and risks of the NSAID prescribed for you before taking it?

☐ Yes
☐ No

4. A. Please indicate where you got your information about the risks and benefits of NSAIDs:

☐ Doctor
☐ Internet
☐ Arthritis group/organization
☐ The Arthritis Society
☐ Friend/family
☐ Newsletter/pamphlets/books
☐ Other

B. How satisfied were you with the information?

VERY SATISFIED	SATISFIED	NOT SATISFIED
☐	☐	☐

5. How much did you participate in deciding what medication was prescribed for you?

A GREAT DEAL	SOME	NOT AT ALL
☐	☐	☐

6. Please rate what is important to you when choosing a medication by selecting one of the choices offered in the three columns:

	VERY IMPORTANT	IMPORTANT	NOT IMPORTANT
Effectiveness (for example, at reducing pain)	☐	☐	☐
Possible side effects (like stomach ulcers or increased blood pressure)	☐	☐	☐
Medical plan coverage for payment for drugs	☐	☐	☐

In order for us to know more about the people answering this survey, please provide the following information. Please remember that your individual identity remains anonymous to us:

Age:

☐ Under 65 years of age
☐ 65 years of age or older

Gender:

☐ Female
☐ Male

Postal Code:

Has a doctor diagnosed your arthritis?

☐ Yes
☐ No

What is your arthritis diagnosis?

☐ Osteoarthritis
☐ Rheumatoid arthritis
☐ Other

Responses received before January 3, 2005, will be included in the analysis and final report. This is an anonymous survey. No personal identification can be made based on the information you have been asked to provide.

If you prefer to take the on-line version of this survey, go to the ACE web site home page www.arthritisconsumerexperts.org and click on "Arthritis Medication Survey".

Thank you again for taking the time to participate in this important survey. The results will be shared with you and the arthritis community in the February 2005 issue of JointHealth™ monthly. ‹

What language do you read in?

JointHealth™ is produced in English and French. To sign up and receive a free copy delivered to your email inbox or home, please email or write your request to ACE.

JointHealth™ est publié en français et en anglais. Pour vous abonner et recevoir gratuitement un exemplaire par courriel ou par la poste, adressez votre demande à ACE par courriel ou par écrit.

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Research *continued from page 2*

affect a joint undergoing surgery. It may be that by stopping the TNF inhibitor, the joint may become inflamed and may worsen the post-surgery recovery. Also, if a medication was used to treat the disease flare such as glucocorticoids (prednisone), there may be problems with infection and post-surgery recovery.

Finally, what is known is that studies like the one reviewed in this article are important to both people with RA undergoing surgery and on TNF inhibitors and their health care team. The knowledge gained from a study like this is critical to developing "best practice" guidelines and helps physicians and patients use breakthrough medications like TNF inhibitors as safely as possible. ‹

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.

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 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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Arthritis Research Centre of Canada

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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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