JointHealth™ monthly
Arthritis research, education and advocacy news : September 2004

Research

The Role of the Consumer in Research Decision Making

The idea of an "arthritis consumer" is a relatively new one. For many people in the health profession, it takes a shift in perspective to understand that people with arthritis (or, indeed, other chronic diseases) have valid concerns and important contributions to make in every aspect of the health care system, beginning with research.

We are fortunate in Canada to have several opportunities to become directly involved with arthritis research. Here are a few ways consumers are helping to direct the future of arthritis research in Canada:

Arthritis Research Centre of Canada Consumer Advisory Board

This group is comprised of volunteer advocates with arthritis who bring personal experience and arthritis knowledge to research decision making. They ensure the consumer perspective is represented on research matters related to prevention, treatment and self-management of arthritis. They communicate research information and findings to arthritis consumers, professional organizations and the general public.

This group plays a key role in making sure that information is provided to the public in less complicated language, so that more people can understand what the research is and what impact it will have on quality of life for people living with arthritis.

Participation in this group is through application – refer to the website for further information: www.arthritisresearch.ca.

Canadian Arthritis Network Consumer Advisory Council

This diverse group of people with arthritis ensures the work of the Canadian Arthritis Network (CAN) is relevant and accessible to people with arthritis. The council is responsible for articulating to CAN directors, management and members the needs and concerns of people with arthritis as they relate to research initiatives. Council members participate in all of CAN's committees and are involved in the peer-review process for awarding CAN grants.

Volunteers are trained to be effective

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Treatment

Treatment of Rheumatoid Arthritis – The Earlier the Better

Researchers have identified a "window of opportunity" where there may be significant long-term beneficial effects of early aggressive treatment of rheumatoid arthritis (RA). As more and more studies are being published, it seems clear that there are better results when people are treated as early as within three months of the onset of the disease.

What the Research Says

In a study published in July 2004 (Rheumatology, 2004; 43:906-914), researchers compared people who had very early RA – an average of three months disease duration – to those who had the disease for twelve months ("established RA"). The researchers followed these two groups of people for three years. While the two groups were treated with the same types of medications throughout the study (methotrexate, sulfasalazine, chloroquine, cyclosporin A, or a combination of these medications), those with very early RA did better. Here's how:

- **Functional disability** – The group who had established RA at the beginning of the study had disability scores 150% higher than the very early RA group at the end of the study;
- **Disease activity** – The very early RA group had less disease activity overall than the established RA group; and
- **Disease progression** – When x-rayed, the established RA group had much higher joint deterioration and at a much greater rate than the very early RA group. This is significant because at present, there is no way to biologically "reverse" joint damage.

The results of these studies support the idea of early RA as a medical emergency, where getting to a rheumatologist, receiving a proper diagnosis and beginning disease-modifying anti-rheumatic

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participants in the process of reviewing research proposals. They commit to a two-year term, which includes teleconference calls, as well as some travel. Volunteers are recruited through the various arthritis organizations, including ACE. Regional representation helps ensure that different perspectives are included. In addition to being involved with research decision making, members commit to work with one another, mentoring and supporting each other in their efforts to advance the cause of raising awareness about arthritis research. To read about the people who currently serve on the Consumer Advisory Council, go to the website at www.arthritisnetwork.ca/consumer_advisory_council/consumer_board.asp.

Canadian Arthritis Patient Alliance Research Committee (CAPA)

CAPA is a volunteer organization that encourages consumer involvement at all levels of research:

- determining the central issue;
- writing the research proposal and protocol;
- participating as research subjects, investigators and advisors;
- interpreting project outcomes; and
- writing and disseminating research results.

CAPA supports the idea that research findings must travel from the research "bench" to "the bed", where they can be put to use by both clinician and patient. But it's a two-way street - the process of knowledge transfer isn't complete until the clinician and patient communicate their research needs from "the bed" back to the research "bench". To read more about CAPA, go to the CAPA website at www.arthritis.ca/capa.

The Cochrane Musculoskeletal Group

This group is committed to helping people make informed decisions about health care. It provides reviews of the effects of health care treatments in language that is easy to understand. Consumers bring the patient / consumer perspective to research and work to get the word out about new research. Consumers help decide which research to communicate, as well as write the actual summaries and translations. Consumers are also needed to work in disseminating the information.

The Cochrane Consumer Reviews are an invaluable resource for people with all types of arthritis – they are available by visiting the Cochrane web site at www.cochranemsk.org/consumer and choosing Consumer Summaries in the last paragraph.

Treatment *from page 1*

drug (DMARD) treatment as quickly as possible will have a direct and important impact on the individual's ability to stay as mobile and healthy as possible.

What the Canadian Rheumatology Association Says

The Canadian Rheumatology Association (CRA) represents Canadian rheumatologists and promotes their pursuit of excellence in arthritis care and research in Canada through leadership, education and communication. Its Therapeutics Committee recently developed treatment guidelines to help improve the outcomes of people with early RA. This comprehensive document outlines the current research and identifies the critical issues in managing early onset RA. The complete document can be found on the CRA website at www.cra-scr.ca.

The CRA recognizes that "a significant number of RA patients will quickly go on to develop major disabilities and almost 50% will experience work loss within 10 years of diagnosis." There are an estimated 300,000 Canadians with RA,

> *"There are an estimated 300,000 Canadians with RA..."*

and the CRA estimates that "there may be up to 50% of patients with RA who have never seen an arthritis care specialist."

Clearly, if early diagnosis and treatment can have such a profound effect on the management of the disease, receiving appropriate care is paramount. The CRA Therapeutics Committee is making four specific recommendations:

1. DMARD therapy should be instituted as quickly as possible in patients with early RA, within the first 2 – 3 months after the disease is diagnosed.
2. Early referral to an arthritis specialist (usually a rheumatologist).
3. Further research into what barriers to treatment people with early RA face, including the challenges primary care physicians have recognizing persistent synovitis (joint swelling).
4. Encourage rheumatologists receiving referrals for very early RA patients to see them as quickly as possible.

Listening to you

Please help us provide the information you want. Take a moment to tell us what interests you, what you want to learn more about, and how you think we can make a difference to Canadians living with arthritis. Email us at: info@arthritisconsumerexperts.org, fax to 604.974.1377 or write to Arthritis Consumer Experts, 910B Richards Street, Vancouver BC V6B 3C1.

Other strategies to reduce barriers to early therapy may include lay public education about RA and more training of primary care physicians to recognize synovitis and the need for early referral and treatment.

What the ACE Community Says

ACE applauds the CRA for providing its ongoing leadership on the issue of timely diagnosis and treatment of very early RA. Its recommendations are an important first step in ensuring that Canadians gain access to appropriate care when it can have the biggest impact on their disease and on their quality of life over the long term.

In addition to the CRA's recommendations, the ACE community advocates the following:

1. Ensure that private and public drug plans provide equitable and timely reimbursement coverage for all drug therapies for those with early RA. This is a significant barrier at present, one that must be corrected to ensure that Canadians with early RA stand the best chance to live the highest quality of life possible and carry on their daily activities at home and at work.
2. Increase arthritis research funding to a level commensurate to the burden the disease poses on the health care system. Arthritis and musculoskeletal disease represent 10% of the costs of all diseases in Canada, yet less than 1% goes towards the arthritis health research budget.
3. Provide adequate funding to Canada's medical schools each year to train an additional 50 rheumatologists per year for the next 10 years. At present, there are only 270 rheumatologists to treat approximately 4,000,000 Canadians with arthritis.

Independent Living with Arthritis

Independence and being able to carry out the activities of daily living is important for all of us, especially for people with mobility challenges, such as arthritis. In fact, nearly all types of arthritis affect how our bodies move and our ability to function. The effects can range from difficulty turning on a water tap to not being able to hold a toothbrush, let alone walk to the bathroom in the morning. Stairs are a challenge as well, and falls represent one of the major risks to people with mobility problems.

Today, 55% of people over 65 self-report having some form of arthritis, and as our population ages, so does the importance of maintaining independent living – also referred to as "aging in place". Simply put, "aging in place" means being able to continue to live a quality life in your home and community. According to Canadian Housing and Mortgage Corporation (CMHC), aging in place is "a process which enables elderly people to grow older in the familiar and comfortable surroundings of their homes while providing them with the assistance necessary to maintain a relatively independent life style" (CMHC, 1996). Since 93% of people over 65 live in the community (not in intermediate or full care homes), this is a very important concept – especially since the baby boomer generation begins to retire in 2012. Approximately one-third of the Canadian population is made up of baby boomers.

Design and housing modifications can help some of the aging in place challenges people with arthritis face. New houses can be built using "Universal Design", a concept developed by Robert Mace in the early 1980s. This design provides a safe living, barrier free environment for everyone, whether raising a young family or enjoying retirement years.

Some key features of Universal Design include:

- reinforced bathroom walls for future need for grab bars;
- wider hallways to accommodate walkers and wheelchairs;
- a knee space under the sink, with a removable cupboard door, for ease of use for someone in a wheelchair;
- lower counters and a wall oven with side shelf, again for ease of a person in a wheelchair;
- garage door entrance to the house at the same level, without stairs;
- front entrance is either flat or has the potential for a ramp with side rails; and
- space for an elevator shaft that works as moveable storage shelves until the elevator is needed. With all the reinforcement and wiring already in place and space provided, any future renovations are not as costly.

Although the Universal Design concept does not fit all individual needs, minor tailoring to suit one's needs is relatively easy and inexpensive.

The same ideas apply for people doing home renovations - thinking about future needs will cut down on costs and make it easier to stay in the same home longer. Here are a few changes that would help people with mobility challenges like arthritis:

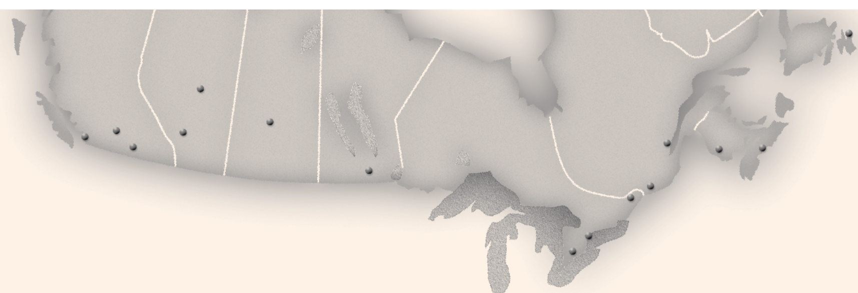
- when renovating a bathroom, add wall reinforcements so grab bars can be easily installed in the future;
- use levered handles for water faucets and door handles as they require less physical effort;
- build walk-in showers with grab bars;
- build in bathtub grab bars and seats;
- design kitchen work and storage areas with the future in mind;
- choose loop handles on drawers and cabinet doors;
- locate electrical outlets 18 inches or more from the floor to allow access from a sitting position; and
- place light switches 36-44 inches above the floor with easy-touch switches.

For seniors 65 and older, CMHC has a program offering financial assistance with the cost of home adaptations. The CMHC web site is www.cmhc-schl.gc.ca. Another useful site for home adaptations is at www.sdc.gc.ca – use the search function and type in "Aids to Independent Living".

The Fall Workshops

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

For further information or to register, please go to www.arthritisconsumerexperts.org or call 1-866-974-1366.



Plan to Win with Inflammatory Arthritis Workshops		
Halifax, NS	September 21	Dr. Dianne Mosher
Winnipeg, MB	October 5	Dr. Hani El-Gabalawy
Calgary, AB	October 7	Dr. Avril Fitzgerald
Quebec City, QC	October 13	Dre. Angèle Turcotte
Please note: The Quebec City workshop will be conducted in French		
JointHealth™ Workshops		
Ottawa, ON	September 18	Dr. C. Douglas Smith
Montéal, QC	September 25	Dr. Boulos Haraoui
Calgary, AB	November 6	Dr. Sharon LeClercq

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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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, 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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