

## WORKING WITH YOU

to improve JointHealth<sup>™</sup>

## THE SURVEY

**Always on the lookout** for ways to improve arthritis consumer satisfaction, each year Arthritis Consumer Experts (ACE) runs JointHealth<sup>™</sup> Program Satisfaction and Interest surveys. From your valuable input, we learn what you want and need from ACE and its JointHealth<sup>™</sup> suite of programs. We value your input because it helps us to better serve you by showing us where we need to improve our programs, activities, and communications tools.

The survey asked people living with arthritis about:

- **the healthcare services they use;**
- **the challenges they face;**
- **the kind of information they would like;**
- **the importance of ACE's JointHealth<sup>™</sup> programs, website, and the National Arthritis Awareness Program (NAAP); and**
- **where they get their information about arthritis.**

### And the survey says . . .

Most of you who completed the survey were between the ages of 55-65 and lived in urban centres across Canada.

Most people who filled out the survey were women with arthritis, which reflects research that shows that, with the exception of a few disease types (gout, vasculitis, and ankylosing spondylitis, for example), women more commonly have arthritis than men. We intend to highlight women and arthritis in our next month's issue of JointHealth<sup>™</sup> monthly.

Our survey also found that after family doctor and rheumatologist, the healthcare service most commonly used was the pharmacist. Pharmacists are particularly relevant for those who live with arthritis because they are already going into the pharmacy for over-the-counter NSAIDs, acetaminophen (e.g., Tylenol<sup>®</sup>), splints, and more, so they tend to see their pharmacists frequently and enjoy relatively easy access to pharmacies in urban or rural locations. Read our June 2012 issue of JointHealth<sup>™</sup> monthly to learn about the pharmacist as

an important member of your healthcare team.

There tended to be few problems accessing a family doctor. Approximately 15% of respondents said they waited longer than three months to see a rheumatologist, but did not have any other problems, though some pointed out there simply are not enough rheumatologists in their communities or in Canada as a whole.

The service least used was a vocational or career counsellor, with only 4% of survey participants having gone to one. The reason for some was that they simply did not know about the service.

The biggest challenges cited on the survey were "leisure and athletic activities", "fatigue", "talking with your doctor who manages your arthritis", "public drug plan coverage for your medications" and "working".

The three areas of information that people viewed as being most important were arthritis medications, exercise, and symptom management. Particularly striking was the interest in arthritis medications as a topic, which was "extremely important" to 73% of respondents.

We are happy to see that respondents appreciate ACE's JointHealth<sup>™</sup> programs, with the three most valued ones being expresses, monthlies, and the medications guide. Survey participants' favourite areas on the JointHealth<sup>™</sup> website were "About Arthritis", "Getting Better Healthcare", and "Resources". Of all our efforts related to the National Arthritis Awareness Program (NAAP), the one most valued was the Arthritis Broadcast Network ([arthritisbroadcastnetwork.org](http://arthritisbroadcastnetwork.org)).

Most people get their information about arthritis from their rheumatologist or online, followed by their doctor or primary healthcare provider.

To the many people from all over Canada who filled out our survey, thank you! Armed with this knowledge, Arthritis Consumer Experts will direct its efforts toward covering these topics in more depth.

# WORKING

## YOUR COMMENTS

We also asked you to tell us what ACE can do to provide better information for your life with arthritis. Your comments were both positive and constructive. Here is a sampling of your comments:



**"I would like to see more information about the psycho social issues that affect people. A Q and A section might be helpful. I like to see special issues focusing on specific diseases. And any new developments in terms of care centres at hospitals or wherever. People do not know what is available in their own community."** *Great ideas. We will include them in future JointHealth™ monthlies.*



**"Re: JointHealth™ monthly and expresses sent by email. First ask if I want English or French so that I can have the full screen of info instead of just the left half. As I get older, I need bigger font."** *That is a very good suggestion. That feature will be coming soon!*



**"Create online discussion groups where specific arthritis patients can share symptoms and treatment therapies"** *We like that idea. A lot. That's why we have the Arthritis Broadcast Network (ABN), [arthritisbroadcastnetwork.org](http://arthritisbroadcastnetwork.org). It's not just a site for getting information about arthritis, we have bloggers who live with arthritis and talk about their experiences. You can be one too. Also, you are free to comment on their posts and the ABN's many articles.*

We do not have the space to share all your comments, but we read them and we are working toward accommodating all of your suggestions into our upcoming JointHealth™ programs.

**Arthritis and related bone and joint diseases** are the most common cause of work disability in Canada. Some of the most common reasons that may contribute include:

- **The pain, fatigue, joint damage, physical limitation, and depression that often go with inflammatory arthritis:** These most common symptoms of inflammatory arthritis can make the simple act of getting out of bed difficult, so working a full day can sometimes be impossible.
- **Symptom fluctuations:** The symptoms of arthritis can change from day to day. Disease activity tends to flare and then subside. The unpredictable nature of flares makes it difficult to make plans and commit to future tasks.
- **An employer's level of knowledge and understanding of arthritis:** Employers who do not understand the symptoms of inflammatory arthritis and the seriousness of the disease are less likely to make adaptations for it in the work environment.
- **The physical requirements of the job, and the employee's physical ability to complete necessary tasks:** People with arthritis who have physically taxing jobs (for example, jobs that require prolonged standing, heavy lifting, and hand strength) are more likely to become work disabled.
- **Distance between home and work:** Commuting by car or public transit can be harder for people living with active disease.

Research has shown that 25-50% of people with rheumatoid arthritis (RA) will have to stop working within ten years of being diagnosed. If you are in your 20s, 30s or 40s, that can be devastating because that means you only have a few years to accomplish as much as you can, to earn enough money to support yourself for the rest of your life, and you may have to forgo saving up for your children's education. Take heart, however, because many people have found ways to continue working in spite of severe arthritis.

### How can you avoid work disability?

There are many ways people with arthritis can manage work and arthritis to prevent work disability. Here are some strategies you may find helpful:

1. **Attend appointments with your doctor and other health professionals, consistently take necessary medications, and practice a healthy lifestyle.**  
If you live with arthritis, you may feel you are barely managing your work and family responsibilities. You may feel you do not have the time or energy to properly care for yourself. But if you don't, your arthritis symptoms may worsen and make it harder for you to work. Try to take care of yourself because it is a good investment in your career.
2. **Use the resources available to you.** Healthcare professionals, such as occupational therapists, social workers and vocational rehabilitation counsellors may be able to help develop strategies for balancing arthritis and work or help you find a job or career that fits better with your arthritis.

*Since the workplace and working rated as one of the most relevant topics to JointHealth™ readers and subscribers, we are dedicating this section to what leads to work disability and how to avoid it.*

**3. If possible, try to negotiate flexible work arrangements.** The ability to work from home, or work part-time, or modify a work schedule allows you to plan your work while considering your arthritis. This may improve productivity and reduce sick days. People with greater flexibility and autonomy at work are less likely to stop working.

**4. Ask for an ergonomic assessment from a professional trained in arthritis issues.** Simple modifications and proper equipment can make an enormous difference in creating a physical work environment that does not increase your arthritis pain. People who have ergonomic modifications at work more than double their chances of remaining employed.

**5. As much as you are comfortable, educate your coworkers and employers.** Many people do not understand what it means to have inflammatory arthritis. Fatigue can be misinterpreted as laziness, unpredictable flares may be seen as a lack of reliability, and physical limitations can be ignored or resented by employers and coworkers. Only education can change these attitudes.

**6. Try to remember that it's your arthritis, not you, that causes these challenges.** Arthritis may diminish a person's self image. People who have always seen themselves as reliable and diligent workers can experience blows to their self-esteem when faced with limitations caused by their arthritis. Try to remember that you are still the same hardworking person you have always been. It is arthritis that is unpredictable and unreliable, not you.

**Ergonomics is the study of efficient workplace design, so that work equipment (office desk and chair, for example) allows the body to be placed in the safest and most comfortable position.**

Here are a couple of modifications you can make to your office to help make life easier and improve your productivity:

- When seated at a desk, position your legs at a 90 degree angle to your body with your thighs parallel to the ground. Try to avoid crossing your legs. Instead, place your feet flat on the floor. For shorter people, that may mean having a footrest. No time to shop and you need one now? A makeshift footrest can be made by duct taping phone books together to the right thickness. (What else are you going to use them for?)
- Try to find a chair with adjustable height. Set the chair at a height that allows you to look straight ahead at your computer monitor, rather than having to bend your neck or hunch your shoulders.
- Ideally, your chair should have good back support. If not, try a cylindrical pillow, or make that shape with a rolled up towel, to support your lower back.

Even with these changes, it is still a good idea to get up every 15 minutes to move around and stretch.



## STUDY

### Do you live with inflammatory arthritis? Are you struggling to keep working?

If so, you may want to participate in a study designed to improve people's ability to do their jobs.

Recruitment is under way for this randomized control trial, which is funded by the Canadian Institute for Health Research (CIHR) and led by Dr. Diane Lacaille of the Arthritis Research Centre of Canada.

The five-year study will compare people who participate in the program to those who do not. So, if you meet the eligibility requirements, you will have a 50-50 chance of doing the online program or receiving printed materials on employment issues.

Those who are randomly picked for the program will receive:

- 5 web-based learning modules on work and arthritis
- 5 online group meetings (software for HD video conferencing will be supplied)
- In-person meetings with an occupational therapist and a vocational rehabilitation counsellor

For now the study is only available in British Columbia, but in future the program will be offered in Alberta and Ontario. Recruitment is ongoing for the next two and a half years.

If you would like to receive more information about this study, please call Pam Rogers, the Study Coordinator in Richmond, BC at the local number: **604.207.4016** or toll free at **1.877.878.4558**. Or fax your request to her at **604.207.4056**. Pam will contact you to provide you with more details about the program and to assess your eligibility.

Learn more about this study by visiting [www.arthritisresearch.ca](http://www.arthritisresearch.ca). Click on **Research > Current Research**, then under "**Rheumatoid Arthritis**" choose "**Arthritis and Employment: Making it Work! (Phase 3)**".

# 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](http://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

Over the past 12 months, ACE received unrestricted grants-in-aid from: AbbVie Corporation, Amgen Canada, Arthritis Research Centre of Canada, Bristol-Myers Squibb Canada, Canadian Institutes of Health Research, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Janssen Inc., Pfizer Canada, Takeda Canada, Inc., and UCB Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks these private and public organizations and individuals.



Suite #200A 1228 Hamilton Street  
Vancouver BC V6B 6L2  
t: 604.974.1366

e: [feedback@jointhehealth.org](mailto:feedback@jointhehealth.org)  
[www.jointhehealth.org](http://www.jointhehealth.org)

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.

© ACE Planning & Consulting Inc. 2013

## 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.



Suite #200A 1228 Hamilton Street Vancouver BC V6B 6L2

