

## Education, Research and Advocacy

# "Arthritis 101"

## Helping government better understand the complexity of arthritis

On February 17, Arthritis Consumer Experts (ACE), the Arthritis Research Centre (ARC) of Canada [www.arthritisresearch.ca](http://www.arthritisresearch.ca), and the Canadian Arthritis Patient Alliance (CAPA) [www.arthritis.ca/caps](http://www.arthritis.ca/caps), hosted a research-based arthritis awareness raising event for Members of the Legislative Assembly (or "MLAs") in British Columbia. The event, titled "Arthritis 101: Making BC the Best in Arthritis Care in Canada", consisted of a breakfast followed by an arthritis screening clinic.

### This issue of JointHealth™ monthly

highlights the MLA Breakfast hosted by Arthritis Consumer Experts (ACE), the Arthritis Research Centre of Canada (ARC) and Canadian Arthritis Patient Alliance (CAPA), in Victoria February 17, 2005. The topics covered in this issue of JointHealth™ monthly are:

#### Education

- 2005 workshop schedule – Registration is open, and free!
- MLA Breakfast in Victoria

#### Research

- Employment, work and arthritis

#### Feedback

- Community FAQs
- Listening to You
- Update your email or postal address

#### Arthritis Consumer Experts (ACE)

- Who we are
- Guiding principles and acknowledgement
- Disclaimer

Twenty-two MLAs (4 of them ministers) and 14 MLA assistants and legislative staff attended – one of the best turnouts ever for an event of this kind.

The success of the breakfast was due in large measure to the "Arthritis 101" presentation given by Dr. John Esdaile, the Scientific Director of the Arthritis Research Centre of Canada. Dr. Esdaile provided MLAs with an overview of:

- The state of arthritis in BC
- Recent arthritis research advances
- Components needed to create an excellent arthritis care environment

The presentation also included recommendations on what the government could do to improve arthritis treatment and care for 500,000 British Columbians. A key recommendation was to create an Arthritis Prevention and Care branch within the BC Ministry of Health, that includes:

#### Prevention

- Develop a public health campaign around arthritis prevention and care (in partnership with ARC, ACE, CAPA.)
- Introduce an arthritis prevention education program in primary and secondary schools across BC.
- Establish and promote safe and effective exercise guidelines for British Columbians living with arthritis.

- Develop healthy eating guidelines for British Columbians living with arthritis.
- Support the ARC initiative to promote swimming and water-based exercise.
- Diagnostically screen children for musculoskeletal developmental issues.

#### Education

- Develop an evidence-based arthritis section in the personal health guide (with ARC, ACE, CAPA)
- Provide nurse practitioners with adequate training in the identification and treatment of inflammatory arthritis (e.g., rheumatoid arthritis) and non-inflammatory arthritis (e.g., osteoarthritis).

#### Medication

- Establish a Pharmacare structure for inflammatory arthritis drugs similar to the one for cancer and HIV/AIDS (the costs of drugs for arthritis and musculoskeletal diseases are the first or second fastest growing drug category in the world.)
- Provide immediate listings to arthritis medications stuck in the Pharmacare review back-log.
- Provide Pharmacare coverage for biologic response modifiers being prescribed "off label" to treat ankylosing spondylitis and psoriatic arthritis.

#### Research

- Mandate the Michael Smith Foundation to lead an arthritis research initiative that will focus on improving arthritis health outcomes.

*continued on page 2*

# The Spring Workshops

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 or to register, please go to [www.arthritisconsumerexperts.org](http://www.arthritisconsumerexperts.org) or call 1-866-974-1366.

## Plan to Win with Ankylosing Spondylitis (AS) new

Burnaby, BC	April 20
Quebec City, QC	May 19 (F)
Edmonton, AB	May 25

## JointHealth™

Nanaimo, BC	April 21
Calgary, AB	May 3
Montreal, QC	May 10 (F)

## Plan to Win with Rheumatoid Arthritis (RA)

Saskatoon, SK	April 6
Sherbrooke, QC	April 19 (F)
Lethbridge, AB	May 4
Abbotsford, BC	May 10
Prince George, BC	May 18
Kelowna, BC	May 19

(F) = workshops conducted in French

## "Arthritis 101" *continued from page 1*

- Provide a \$10.8 million grant to the Vancouver Hospital/ UBC Centre for Hip Health through the BC Knowledge Development Fund, (to match the Canada Foundation of Innovation award it received.)
- Provide the Vancouver-based Arthritis Research Centre of Canada with \$300,000 for five years to fund arthritis prevention research.

### Quality of life

- In true partnership with consumers/patient groups, create a model for consumer/patient involvement that is consultative, collaborative and accountable.
- Restore funding to in-patient and out-patient arthritis physiotherapy and occupational therapy services in acute and tertiary care settings across the province.
- Provide an additional \$100 million to hospital budgets to clear joint repair or joint

replacement surgery waitlists.

- Conduct a total review of home care and home support as it relates to involving and mobilizing The Arthritis Society and other health agencies and disease specific volunteers in the multi-disciplinary care team in the home.
- Develop an "aging in place" strategy for those living with chronic disability due to arthritis.
- Commit to quality end-of-life care so people with arthritis can die with dignity, pain free, surrounded by their loved ones in a setting of their choice.
- Commit to the federal government's six-week Compassionate Leave Benefit.

To view the entire recommendations document, visit [www.arthritisconsumerexperts.org/healthcare.cfm](http://www.arthritisconsumerexperts.org/healthcare.cfm) and click on the left side on Improving Health Care in British Columbia.

Following the breakfast, MLAs and their staff were invited to take part in a first-ever arthritis screening clinic held right in the Legislature

building. Three rheumatologists (Dr. Esdaile, Dr. Kimberley Northcott and Dr. Diane Lacaille) screened 40 people over a two hour period.

As one might imagine, they discovered five new cases of inflammatory arthritis. These people were encouraged to visit their family physician for medical follow-up.

Media coverage was excellent and we have been invited back to Victoria to meet with members of the Standing Committee on Health and the Liberal Health Caucus to discuss how to make arthritis care in BC the best in Canada.

Help make arthritis care in BC the best in Canada. ACE invites you to write your MLA and voice your comments and concerns about your healthcare needs. To find your MLA, click here [http://canada.gc.ca/direct\\_e.html](http://canada.gc.ca/direct_e.html). To learn more about how to make your voice heard by the health care system and government, visit [www.arthritisconsumerexperts.org](http://www.arthritisconsumerexperts.org). Click on **Arthritis and the Healthcare System** on the menu bar at the top. <

## Community : FAQs

### Biologics are not covered by the drug plan in Newfoundland and Labrador. Is this the only province not covering these drugs? What is the criteria for coverage and does this vary greatly, province to province?

Good news for people with rheumatoid arthritis who have been prescribed a biologic response modifier to treat their uncontrolled disease but who could not afford to pay for it. Three biologic response modifiers, adalimumab (Humira®), etanercept (Enbrel®) and infliximab (Remicade®) have been added to the drug benefit list in

Newfoundland and Labrador on March 21, 2005. Coverage for these medications begins on April 1, 2005.

The criteria to qualify for coverage of these drugs are not available until the end of April. For now Health Newfoundland is assessing people case by case.

To check for information updates, visit [www.health.gov.nl.ca/health/](http://www.health.gov.nl.ca/health/). Click on Prescription Drug Program – NLPDP. This takes you to the health and community services page. Scroll down to Criteria for the Coverage of Special Authorization Drugs and click on Search or Download Information on Special Authorization Drugs. Use the scroll down bar

to search for the drug name and click search. This will provide information on medical plan coverage for the three biologic response modifiers, when it becomes available.

If you live somewhere other than in Newfoundland and Labrador, the criteria for biologic response modifier coverage may differ province-to-province. An overview of coverage availability can be found on the ACE web site at [www.arthritisconsumerexperts.org](http://www.arthritisconsumerexperts.org). Click on the menu bar at the top, Arthritis and the Health Care System. Then click on the bottom left box on Pharmacare drug coverage – changes that affect you. <

# Employment, work and arthritis

Employment is viewed as an important role by society. It not only pays the bills but also provides people with a sense of identity and helps people feel good about themselves (self-esteem) and their accomplishments (competence).

But what happens when an employee gets a chronic, degenerative disease like arthritis? The leading cause of long-term physical disability in adults is arthritis. Pain and loss of ability to do certain things are two of the most important reasons why individuals with arthritis give up their job. In fact, arthritis and problem of bones and muscles, are the most common health reasons why Canadians stop working.

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*“The leading cause of long-term physical disability in adults is arthritis.”*

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The research, to date, has mainly focused on looking at people with arthritis and job loss. Not much attention has been given to how people with arthritis make changes to stay in the paid work force.

The following is a review of a study by Monique Gignac et al, recently published in Arthritis and Rheumatism [Arthritis Care & Research], Vo. 51, No.6, December 15, 2004, pp. 909-916. called, “Managing Arthritis and Employment: Making Arthritis-Related Work Changes as a means of Adaptation”.

This study looked at the adjustments employees with arthritis make in order to remain in the workplace. The study also looked at:

- the relationship between how many changes an employee makes and depression;
- how people with arthritis view their own worth as an employee now and in the future;
- whether to tell their employer about their arthritis or not.

The study involved 491 employed adults (383 women and 109 men) with arthritis as study participants - mostly rheumatoid arthritis (RA) and osteoarthritis (OA). On average, study participants had arthritis for nine years. The average age was 51 years old, and most were well-educated with annual incomes over \$40,000.

Approximately 25% had not told their employer about their arthritis, and 11% expected to leave their jobs in the following year due to disability from their arthritis. This means over 120 people were trying to manage their arthritis and work without any support from the workplace. It would be interesting to know if these same people had a good support system outside their work environment.

Seven work changes due to arthritis were assessed in the study over a six month period. Over 70% of the participants reported at least one change. The type of changes people made included:

- daily work interrupted for 20 minutes or more;
- days absent;
- changed the type of work they did;
- changed the number of work hours;
- used vacation days to manage arthritis;
- unable to take on new projects;
- unable to seek promotion or job.

Workplace changes were also associated with increased reports of depression. Research suggests that more attention needs to be given to the effects of work changes on the psychological well-being of persons with arthritis. If depression is present, then help is needed to keep people working or help them return to work.

In addition, the results of this study suggest the importance of understanding how an employee with arthritis views their disability, what are their expectations for work and their

decision to tell their employer about their arthritis.

Most people expected to stay employed and of these the ones who viewed their arthritis as affecting their work ability, made more changes. Interestingly, this was independent of whether they told their employer about their arthritis or not.

Employees who expected to continue working, who told their employer they had arthritis but viewed their disease as having minimal impact reported more changes than before. This may be due to proactive changes made by both the employee and employer.

People that expected to have to leave their employment and who told their employer they had arthritis reported more work changes due to the impact from their disease. On average, people expecting to leave work made more changes than people not expecting to leave their employment.

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*“... more attention needs to be given to the effects of work changes on the psychological well-being of persons with arthritis ...”*

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The study suggests that more research looking at the workplace environment and interpersonal relationships would be helpful. Perhaps people do not want to make many changes to manage their arthritis at work because, without disclosing the arthritis, other employees and employers might view the changes as poor work performance.

If you would like to share your experiences about employment and arthritis, or have questions related to this topic, please mail or email us at: [info@arthritisconsumerexperts.org](mailto:info@arthritisconsumerexperts.org) <

## Update your email or postal address

Please let us know of any changes by contacting ACE at:

[info@arthritisconsumerexperts.org](mailto:info@arthritisconsumerexperts.org).

This will ensure that you continue to receive your free email or print copy of JointHealth™ monthly.

## 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](mailto:info@arthritisconsumerexperts.org).

Through your ongoing and active participation, ACE can make its work more relevant to all Canadians living with arthritis.

## En quelle langue lisez-vous?

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.

## 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](http://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™.



### Acknowledgement

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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. <

  
Arthritis Consumer Experts™  
910B Richards Street, Vancouver BC V6B 3C1

