

Arthritis and disability— the human cost

Imagine this:

You are sitting in your doctor's office in agony. Several months ago you woke up one morning in excruciating pain. Your joints were so hot, stiff and swollen you hardly recognized them as part of your own body.

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JointHealth Monthly is available in print and online in English and français.



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Over the past several months, you have been on a painful, frustrating journey, one that has taken you from doctor to doctor to doctor. You have had to insist to your regular doctor that something is very wrong, you have been forced to wait agonizing weeks and months for an appointment to see a specialist and you have had to tell your story again and again. At home, you have gone from being a fiercely independent woman to a person who depends on others for everything. The simplest tasks, things like brushing your teeth or getting dressed, are no longer things you can do for yourself. You haven't been able to work since the first day you got ill. Your employer has been patient, but you know that if you do not get back to work soon, your job will be gone.

So here you are, in the office of a rheumatologist you hope will finally be able to help you. She looks at you across her desk, and tells you that you have psoriatic arthritis. You are stunned. At 32, you never expected that arthritis was something that could touch your life.

Your rheumatologist tells you about psoriatic arthritis. She describes how the disease progresses; how it attacks the joints and causes crippling damage. Then she tells you that good treatments are available, and that with a proper treatment plan you will likely be able to regain many of the things you have lost. She tells you about biologic response modifiers – a class of medications

effective at treating psoriatic arthritis – and how in combination with other aspects of a "gold standard" treatment plan there is a good chance your disease will be forced into remission, or at the very least, incredibly well managed.

Then, just when you are beginning to feel hope, your rheumatologist tells you that the medications you need are not part of your province's drug reimbursement formulary. This means that treatments exist, but you are not able to access them because they are too expensive for you to pay for on your own. You are devastated, knowing that you could be effectively treated, but that someone in government has decided that giving you back your life is not "cost effective".

For thousands of Canadians, this scenario is all too real. While treatments for psoriatic arthritis, as well as for other inflammatory forms of the disease, have improved dramatically in the past decade, appropriate medications are often simply not being made available to the people who need them. Often, the cost of providing these medications is high enough that it is impossible for a person of low or modest income to pay for the treatment they need.

Quite often, governments cite "cost effectiveness" as a reason for not listing medications. In truth, very often the cost to government of not paying for these treatments is much higher than the cost of the medications themselves. See our article, "Dollars and sense" in this issue of JointHealthTM monthly.

The simple truth of the matter is that "cost effectiveness" arguments are costing people their lives. It is unconscionable that this can happen in Canada, where every person is supposed to have equal access to medical treatment regardless of ability to pay. ☹

The path to better care

—a roadmap for excellence in arthritis prevention and treatment in Canada

People with arthritis, and the doctors who dedicate their lives to treating them, know that a new model of arthritis care in Canada is desperately needed. Across the country, people with arthritis face barriers to proper care at every point of contact in the health care system—barriers people with other diseases are much less likely to face.

We know that governments are often reluctant to spend money to fight arthritis. In the November issue of JointHealth monthly, Arthritis Consumer Experts released clear evidence of the discrimination faced by people who live with arthritis. Arthritis is the focus of far less federally-funded research than cancer, HIV/AIDS, and diabetes, and medications which can halt the progression of arthritis are often not made available on provincial drug benefit plans.

All of this amounts to a system of inequitable access to treatment, both for people with arthritis compared to people living with other diseases, and also between people living with arthritis in different parts of the country.

Here are some of the problems, and some sensible solutions to help make arthritis treatment and care in Canada the best it can be for the nearly 4 and a half million Canadians who live with the disease:

■ Problem:

People across the country wait months beyond the recommended four weeks to get an appointment to see a rheumatologist (an arthritis specialist). Fewer than 270 rheumatologists are actively practicing in Canada, and almost four and a half million people live with one of over 100 forms of arthritis. Research indicates that people with inflammatory arthritis (of whom there are more than 600,000 in Canada) who are treated solely by a general practitioner are far less likely to receive treatment in line with current best practice guidelines than those patients treated by a rheumatologist.

Solutions:

1. All relevant health professionals must be able to perform a valid, standardized, age appropriate musculoskeletal screening assessment (ACAP priority standard #2).
2. General practitioners must be educated about all forms of arthritis disease, and must be knowledgeable enough to immediately refer complicated and/or severe cases of inflammatory arthritis to rheumatologists. As well, general practitioners must be trained in current best practice treatment guidelines for all forms of arthritis, so that they are able to properly treat moderate and/or uncomplicated disease themselves.
3. The shortage of rheumatologists in Canada

must be addressed. More rheumatologists must be trained; for this to happen, more training spaces must be developed for young doctors who wish to specialize in rheumatology.

■ Problem:

Provincial medication reimbursement plans vary widely from province to province—for example, a person with ankylosing spondylitis in Quebec has access to three different biologics on their provincial drug reimbursement plan; if you live in Ontario, two biologics are on the provincial reimbursement plan; in Alberta, British Columbia, Manitoba, and several other provinces, people with AS have no biologics at all listed on their provincial formularies.

The provinces, with the exception of Quebec, all participate in the Common Drug Review (CDR), which examines cost-effectiveness of new drugs which have been approved by Health Canada, and makes recommendations about whether those drugs should be listed on provincial formularies. However, once the CDR has made a recommendation, the provinces each do their own review, and decide individually whether to list a drug.

Solutions:

1. Any drug that receives a “recommendation to list” result from the Common Drug Review should be immediately listed on the provincial drug reimbursement formulary for each province within two months of the recommendation.
2. For medications that do not receive a Common Drug Review “recommendation to list” but have strong peer-reviewed scientific evidence showing clinical superiority to current treatments, governments should provide reimbursement through a provisional drug reimbursement formulary listing for those patients most in need and assess cost-effectiveness over a 6- to 12-month period.
3. Provincial formulary decision-makers must finally tackle the “budget-silo” dilemma by considering the costs of un- or under-treated disease – costs that appear in budgets other than that of the drug reimbursement formulary.

■ Problem:

People with arthritis living in rural parts of the country have very limited access to the care they need, often being forced to travel hundreds of kilometers to visit a rheumatologist or access rehabilitation programs.

Solutions:

1. Provide more in depth training on arthritis and other musculoskeletal diseases to rural general practitioners and allied health professionals and link them electronically and offer tele-

medicine facilities in order to work as a team on complicated inflammatory arthritis cases.

■ Problem:

Public awareness of the more than 100 types of arthritis is stunningly low, and media coverage of arthritis diseases, when compared to cancer, diabetes and HIV, is pathetically small.

Solutions:

1. All children should be educated about arthritis, starting in health care education classes as part of their elementary schooling. Children would be taught strategies to prevent some forms of arthritis, like osteoarthritis, and to recognize the early signs of arthritis from childhood onwards.
2. People with arthritis, and groups representing people with arthritis, must write to media and tell their own personal story of arthritis, and make sure that arthritis is accurately portrayed in all forms of media.

■ Problem:

Arthritis receives far less federal research funding than do other serious, life threatening diseases. For each person with arthritis, the government spends just 94 cents on research. This is compared to a research investment of \$731 for every person living with HIV in Canada; \$14.16 for every person diagnosed with cancer, and \$4.98 for every person living with diabetes, respectively.

Solution:

1. Governments must make the same research investments into arthritis as are made into other serious, life-threatening diseases. Musculoskeletal diseases (arthritis and osteoporosis) are the number one cause of disability in Canada, costing the economy approximately 16.4 billion dollars per year, and people with arthritis deserve the same research resources as people living with other diseases.

ACAP's priority standards

In an effort to clearly lay out what needs to change in arthritis treatment and care in Canada, the Alliance for the Canadian Arthritis Program (ACAP) has created three priority standards. These priority standards are:

1. Every Canadian must be aware of arthritis.
2. All relevant health professionals must be able to perform a valid, standardized, age-appropriate musculoskeletal screening assessment.
3. Every Canadian with arthritis must have timely and equal access to appropriate medications.

These priority standards form the basis for a well-rounded plan to create excellence in arthritis prevention, treatment and care in Canada.

Dollars and sense—the cost of disability in Canada

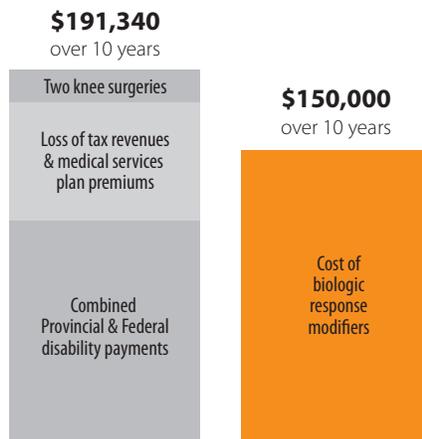
Often, when medications are being discussed at the government level or in the media, the cost of treatment is the focus of the conversation.

In a recent interview, ACE president Cheryl Koehn was asked by CBC radio host Sheila Coles to justify the cost of providing biologic response modifiers to treat people with ankylosing spondylitis. Koehn responded that we, as taxpayers, are paying and will continue to pay much more to keep people disabled than we would pay to treat them well and prevent disability.

In so many ways, the cost of preventable disability is much greater than the cost of proper treatment. According to the Canadian Institutes of Health Research, musculoskeletal diseases (arthritis and osteoporosis) cost Canadians \$16.4 billion every year. Of this total, \$2.6 billion is in direct costs, such as physician and hospital care and medications, and \$13.7 billion is in indirect costs, including premature disability and death¹.

Leaving aside the quality of life of our citizens and the terrible emotional and social costs associated with uncontrolled arthritis, in terms of dollars and cents, it is simply more costly for government, in almost every case, to support someone who has been disabled by arthritis than it would be to treat them early and aggressively in line with current best practice guidelines.

Here is a very simple example: A single woman, aged 45, who has been working for 25 years and earns \$30,000 per year, is diagnosed with severe rheumatoid arthritis. She lives in



“... the cost of preventable disability is much greater than the cost of proper treatment.”

BC. The cost to government to pay for the biologic response modifier her doctor says she needs is \$15,000 per year. If she stays on the medication for ten years (not a given, since with early aggressive treatment some patients will achieve remission and be able to slowly wean off biologics), the total cost for the medication will be \$150,000.

On the other hand, if the government has not added the medication she needs to the provincial drug reimbursement plan in the province where she lives, this woman will not be able to afford to pay for the medication on her own. In that case, there is a high likelihood she will be unable to work—studies show that work disability is a leading outcome for RA—and will need to depend on government programs for survival.

Here are just a few of the hard costs associated

with keeping this woman disabled:

Disability payments

Combined Provincial and Federal:

\$906/month = **\$10,872/year**²³

Surgeries –Knee replacement: **\$11,500**⁴

Loss of tax revenues, based on \$30,000/yr:

\$5,574 based on 18.58% combined federal and provincial⁵

Medical services plan premiums: \$32.40/

month/ **\$388/year**⁶

Totals over 10 years:

\$168,340 for income assistance and loss of tax/premium revenue

\$191,340 including 2 knee replacements

Put simply, if the government had paid for proper treatment when this woman first became sick, they would have saved more than they spent on medications.

As well, it is very important to remember that these numbers do not include many of the costs associated with supporting someone with disability. Costs like homecare, occupational and physiotherapy, and extra doctor visits and hospitalizations for a person with arthritis that is not well-controlled are difficult to estimate on a per-person basis, but they add significantly to the cost of disability in Canada. ☹

1 <http://www.cihr-irsc.gc.ca/e/24935.html>

2 <http://www.mhr.gov.bc.ca/factsheets/2004/DisabilityAssist.htm>

3 <http://www.hrsdc.gc.ca/en/isp/cpp/applicant.shtml#contrib>

4 http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20070205/boomers_age_070205/20070205?hub=Health

5 <http://www.health.gov.bc.ca/msp/infoprac/physbilling/payschedule/pdf/27%20orthopaedics.pdf>

6 <http://www.health.gov.bc.ca/msp/infoprac/physbilling/payschedule/pdf/8.%20anesthesia.pdf>

7 <http://www.taxtips.ca/calculators/taxcalculator.htm>

8 <http://www.hlth.gov.bc.ca/msp/infoben/premium.html#monthly>

What is possible: lessons from HIV/AIDS

Over the past 15 years, prevention and treatment of HIV has taken remarkable strides. A tremendous amount of ground-breaking research has come out of the BC Centre for Excellence in HIV/AIDS, Canada’s largest HIV/AIDS research, treatment and education facility. According to their website, the centre “provides care and treatment to those infected, educates doctors and healthcare professionals throughout the province, and promotes evidence-based social policy that helps protect people from acquiring the virus.”

This holistic model of research, education, prevention and treatment has been hugely

successful in HIV. One of the reasons it has been so successful is that it puts research, education, and treatment all under one roof, allowing top experts in the field of HIV to lead the way in driving innovative research and determining treatment protocols. In other words, the people in BC who make decisions about the treatment of people with HIV are the actual clinical experts in the field, and not bureaucrats with a focus on short-term costs.

Treatment is coordinated by the centre, providing a “one stop shop” for people who need to access to treatment. According to their website, “In B.C., all anti-HIV medications are distributed at no cost to eligible HIV-

infected individuals through the Centre’s Drug Treatment Program. Over 7,400 HIV-positive British Columbians have enrolled in the program since its inception in 1992.”

Knowing what we do about arthritis research, prevention, education, and treatment in Canada, it is likely that a similar centre, or network of centres for arthritis prevention and treatment would provide life-changing resources to many of the almost four and a half million people living with arthritis in Canada. The time has come for people with arthritis to have access to the same quality of care as people who live with other diseases. Anything else is, quite simply, unacceptable. ☹

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

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada / Wyeth Pharmaceuticals, Arthritis Research Centre of Canada, AstraZeneca Canada Inc., Bristol-Myers Squibb Canada, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck Frosst Canada, Pfizer Canada and Schering Canada.

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 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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