

## Advocacy

# Arthritis and discrimination

**Discrimination:** “an act or policy of unfavourable treatment based on prejudice”.

OXFORD CANADIAN DICTIONARY

**Many different groups face discrimination** for a wide variety of reasons —on the basis of age, gender, race, sexual orientation, religion, disability status, for example—and these types of discrimination are generally recognized and understood by the public. What is less often acknowledged is that people living with certain diseases frequently face unfair, unequal treatment based on the type of disease they have. Arthritis is one of those diseases.

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Quite simply, people who are living with arthritis face discrimination on a daily basis. It occurs on many different levels—from a friend refusing to believe a child can have arthritis, to an employer refusing to modify a workspace, to one level of government refusing to pay for the treatments proven effective by a different level of government.

*“Quite simply, people who are living with arthritis face discrimination on a daily basis.”*

The discrimination that people with arthritis are facing, day in and day out, can feel like it comes from every direction. Negative effects of discrimination against people with arthritis range from feelings of loneliness and isolation, to unemployment and poverty, to disability, joint destruction, and even death.

This is not a well-understood form of discrimination, but it is real, as anyone who has faced it can attest. The proof can be found in the numbers.

One of the many areas of discrimination against people with arthritis involves the amount of government investment into research about how to prevent, treat, and potentially cure different diseases. Arthritis Consumer Experts has

taken a close look at federal government research investments across four different diseases. Because research tells us that many types of arthritis are potentially fatal, we have chosen to look at three other serious, often fatal, diseases: cancer, HIV/AIDS, and diabetes.

To see a clear pattern of discrimination, one need only compare the number of federal research dollars spent each year to combat these three diseases, compared to those spent on arthritis research. The numbers are telling. Quite rightly, the federal government has invested many millions of dollars into researching effective prevention, treatment and future cures for cancer, HIV/AIDS, and diabetes. These dollars go a long way towards fighting these terrible diseases and are money well spent.

- In 2005, the Canadian Institutes of Health Research funding for HIV/AIDS research was \$42.4 million. This figure will climb to \$84.4 million in 2008-2009. The federal government has pledged an additional \$111 million for the Canadian HIV Vaccine Initiative [reference: <http://pm.gc.ca/eng/media.asp?id=1544>].
- In 2005-2006, the Canadian Institutes of Health Research spent \$118 million on cancer research [reference: <http://www.cihr-irsc.gc.ca/e/32860.html>]. These monies were in addition to the millions spent on cancer research and control in other areas of the federal government budget.
- In 2005-2006, the Canadian Institutes of Health Research spent \$6.6 million on diabetes research.

These numbers equate 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. [See “Arthritis and discrimination – a close look at the numbers”]

*continued on page 2*

**Discrimination** *continued*

In direct comparison, the Canadian Institutes of Health Research, through its Institute of Musculoskeletal Health and Arthritis, spent \$3.7 million on arthritis and bone research (<http://www.cihr-irsc.gc.ca/e/31093.html#3>). **That equates to only a 93¢ research investment in every person currently living with arthritis in Canada.**

Again, to be clear, levels of research funding for HIV/AIDS, cancer and diabetes research and treatment are as they should be. Arthritis Consumer Experts applauds the high levels of research investment and support available for people living with these diseases. But for more than 4 million Canadians living with over

100 different types of arthritis, government is doing far too little to invest into the search for cures and improved treatment and care. People living with chronic or life-threatening arthritis should and must have equal access to research advances—advances that lead to new, safe and effective medications, improved ways of delivering treatment and care in both urban and rural communities, and many, many more kinds of improvement in quality of life and care.

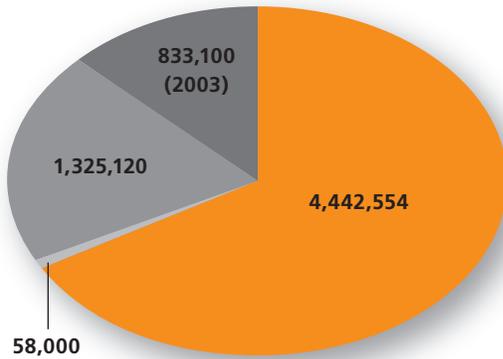
One way to work towards the elimination of discrimination in arthritis is to speak out about the unjust levels of funding for research and treatment in Canada. The voices of 4 million Canadians must be heard. The voice of arthritis must start asking federal and provincial

government representatives:

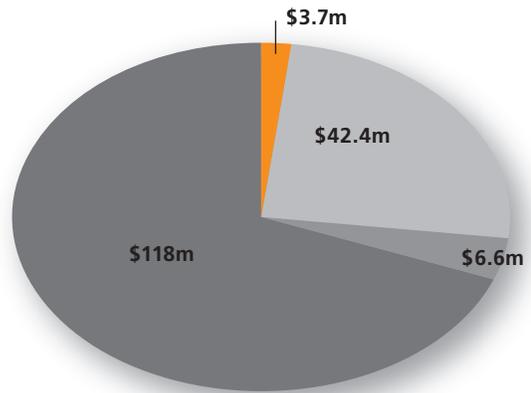
- Why does research into arthritis receive such a small share of federal research funding?
- Why do people with arthritis wait years for medications to be reviewed and added to provincial medication reimbursement plans?
- Why must people with arthritis jump through so many “hoops” to qualify for proper treatment?
- Why is there such a scarcity of rheumatologists—fewer than 270 in Canada?
- Why have wait-lists for joint replacement surgeries been allowed to grow so long?
- Why is information about arthritis not available as part of primary and high-school health education curricula? ☹

## Arthritis and discrimination—a close look at the numbers

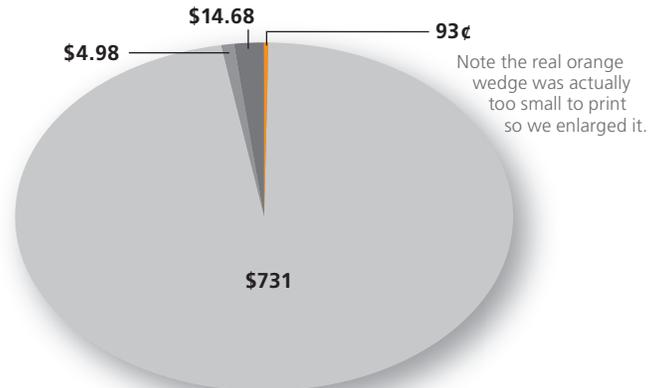
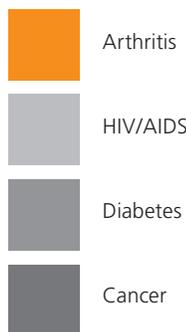
**Number of people living with disease in 2005 in Canada**



**Federal research dollars spent in 2005 in Canada**



**Federal research dollars per Canadian patient**



# Arthritis in the media: the forgotten disease

As anyone who has arthritis knows, public perception of arthritis is nothing like the reality of living with it. In newspapers, magazines and on television, editorial content and advertising tends to represent arthritis as a mild, “nagging” disease of the elderly; a disease that is an inevitable part of aging and something that is a relatively minor health issue; a nuisance rather than a killer.

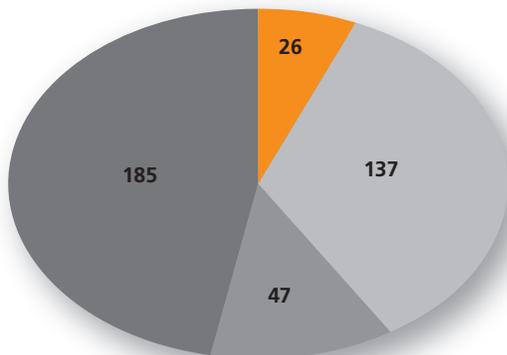
At Arthritis Consumer Experts, we often hear from people living with arthritis who say that public understanding of their disease is non-existent. People living with devastating forms of

importance, Arthritis Consumer Experts looked at all of the health and general news items, editorials and letters to the editor printed in Canada’s two national newspapers, the *Globe and Mail* and *National Post*, in 2006. We compared the number of stories written about HIV/AIDS, cancer, diabetes and arthritis, and looked at these numbers in relation to the number of people in Canada who live with these diseases. For the purposes of this search, only articles specifically about each of the disease groups were counted; articles referring to the

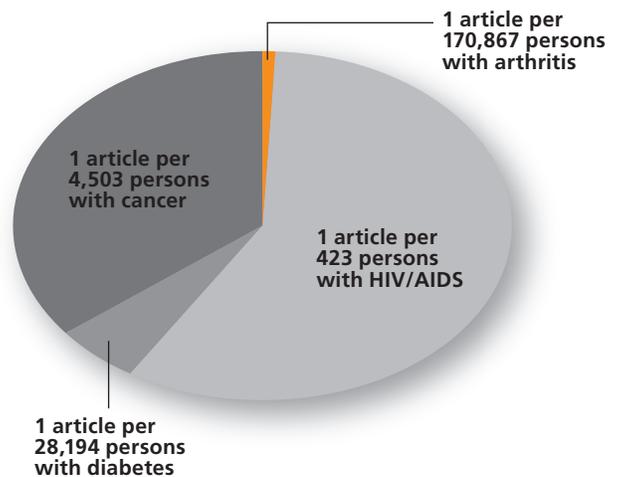
and approximately 833,100 living with cancer (note: the Canadian Cancer Society collects data about the number of people living with cancer, but reports with a four-year time-lag; thus, the number used for this article and the chart on Page 2 of this issue is from 2003.)

To put these numbers in perspective, there was one news item on arthritis for every 170,867 people living with the disease in Canada. For every story about their diseases, there are 28,194 Canadians living with diabetes, 4,503 living with cancer and 423 persons living with HIV/AIDS.

**2006 media stories  
Globe & Mail and National Post**



**Canadian patients  
per media story**



the disease must constantly educate the people they encounter in their daily lives—from family members, co-workers and employers to the check-out clerk at the grocery store. Time and time again, we hear from people telling us how exhausting it can be to live with a disease that is so grossly misunderstood by the public.

The media plays a major role in shaping public opinion by choosing to cover—or not cover—the important issues of our day. At a time when health news is more widely written and read about than ever before, the lack of coverage about the issues people with arthritis face every day is staggering.

Because we believe this issue is of paramount

importance, Arthritis Consumer Experts looked at all of the health and general news items, editorials and letters to the editor printed in Canada’s two national newspapers, the *Globe and Mail* and *National Post*, in 2006. We compared the number of stories written about HIV/AIDS, cancer, diabetes and arthritis, and looked at these numbers in relation to the number of people in Canada who live with these diseases. For the purposes of this search, only articles specifically about each of the disease groups were counted; articles referring to the

and approximately 833,100 living with cancer (note: the Canadian Cancer Society collects data about the number of people living with cancer, but reports with a four-year time-lag; thus, the number used for this article and the chart on Page 2 of this issue is from 2003.)

In 2006, **only 26 newspaper items focussed on arthritis appeared in the *Globe and Mail* and *National Post*, combined.** This compares to 185 items printed with a focus on cancer, 137 about HIV/AIDS and 47 about diabetes.

To put these numbers in perspective, there was one news item on arthritis for every 170,867 people living with the disease in Canada. For every story about their diseases, there are 28,194 Canadians living with diabetes, 4,503 living with cancer and 423 persons living with HIV/AIDS.

It is important to remember, when thinking about these numbers, that the number of people living with arthritis is far greater than any of the other disease groups examined here. In 2005, 4,442,554 people in Canada were living with arthritis. This compares to 58,000 living with HIV/AIDS, 1,325,120 living with diabetes,

But the numbers, shocking as they are, only tell half of the story. The content of these news items, and the perceptions and biases brought to what is written—and not written—is equally telling.

News stories about arthritis tended to focus on medication side-effects and product recalls, and occasionally about wait lists for joint-replacement surgeries. In glaring contrast, writings about cancer were focussed on the personal side of the disease; stories including profiles of celebrities and regular people living with cancer, stories about the financial toll that the disease can take on families, and positive news about advances

*continued on page 4*

## Media *continued*

in cancer treatment were all prominent. The difference, not only in how much arthritis and other diseases are written about in the media, but in *how they are discussed*, contributes to the public's misperceptions about arthritis.

We must be very clear: it is completely appropriate that the public be thoroughly educated about cancer, HIV/AIDS and diabetes. People living with these diseases deserve to be understood, and the personal and economic tolls exacted by these diseases are vast. This is not in dispute. The bottom line is simply that people living with arthritis deserve the same level of understanding, consideration and attention to their disease.

If the public is ever to understand what arthritis is really like—the crippling joint damage,

devastating pain and overwhelming fatigue associated with inflammatory arthritis, for example—the media must begin to paint a true picture of the personal, social and economic costs associated with the disease. For this to happen, we need your help. People living with arthritis

*“People living with arthritis are the true experts and moral authorities, and your voices must be heard.”*

are the true experts and moral authorities, and your voices must be heard. We urge you to write letters to your local community, provincial and

national newspapers asking why arthritis is not being covered in fair proportion to the number of people living with the disease in Canada.

We also urge you to speak out, and tell your own story to whatever degree you are comfortable. People living with arthritis can and must take an active role in educating the public about what it really means to live with arthritis. Until the people in your community—your grocer, your neighbour, your child's teacher, your boss—begin to understand the true impact of arthritis, there is no hope of challenging the misperceptions that allow discrimination against people living with arthritis to flourish.

For some tips about writing a letter to the editor, please see the side bar on page 5 reprinted from our February 2007 issue of JointHealth™ monthly.

## Spotlight on rheumatoid arthritis

*We are always happy to present information requested by our readers, and are excited to be receiving requests for spotlight features on different types of arthritis. Please contact us at [info@arthritisconsumerspecialists.org](mailto:info@arthritisconsumerspecialists.org) if you would like us to profile a specific type of arthritis.*

There are over 100 different types of arthritis affecting more than 4 million Canadians. While some types of arthritis are very rare, others are quite common; while several forms of arthritis have fairly mild symptoms, many can be painful, disabling and even deadly.

Rheumatoid arthritis is an autoimmune disease with hallmark symptoms of inflammation and resulting pain. It is a disease process (like cancer or diabetes) where the body's immune system mistakenly attacks its own healthy joints. It is a relatively common disease – approximately 300,000 or 1 in 100 Canadians get it – and is often devastating to a person's body if not treated properly. The disease process causes swelling and pain in and around joints and can affect the body's organs, including the eyes, lungs and heart. Rheumatoid arthritis most commonly affects the hands and feet. Other joints often affected

include the elbows, shoulders, neck, jaw, ankles, knees and hips. When moderate to severe, the disease reduces a person's life span by as much as a dozen years.

Interestingly, rheumatoid arthritis affects women two out of three times more often than men, and like many forms of inflammatory arthritis, it tends to strike people in the prime of their lives; most commonly, people are diagnosed between the ages of 20 and 50, though rheumatoid arthritis can strike at any time—people of every age from toddlers to senior citizens have been diagnosed with the disease.

### Diagnosis of rheumatoid arthritis

Rheumatoid arthritis has several “hallmark” symptoms when the disease first presents itself. These include:

- Morning stiffness, lasting longer than 30 minutes
- Pain and/or inflammation in the same joints on both sides of your body
- Pain in three or more joints at the same time
- Loss of motion in affected joints
- Severe fatigue

If you experience two or more of these symptoms, you should speak with your family physician. Be sure to tell your doctor about any history of rheumatoid arthritis in your family. While there is no known cause of rheumatoid arthritis, research indicates that heredity likely plays a role in that a susceptibility to the disease may be inherited.

If your doctor believes you may have rheumatoid arthritis, you will usually be referred to a rheumatologist – a specialist in

the treatment of arthritis. Rheumatologists have many years of extra training on top of their regular medical schooling, and are experts at diagnosing and treating all forms of arthritis, including rheumatoid arthritis.

To confirm a diagnosis of rheumatoid arthritis, a doctor may run a number of tests. These may include:

- blood tests, including those to look for abnormal blood antibodies and to get baseline liver and blood counts
- x-ray imaging, to check for joint damage or deterioration
- bone scans are infrequently used but sometimes can help to check for joint inflammation
- joint fluid tests, or arthrocentesis, in which a small amount of joint fluid is extracted using a needle and then analyzed in the laboratory

### Treatment of rheumatoid arthritis

Once a rheumatologist has diagnosed rheumatoid arthritis, there are effective treatments available to help a person manage the symptoms and minimize joint damage. While there is no known cure for rheumatoid arthritis, good treatments now exist and rheumatologists are the best people to discuss these with and formulate a treatment plan to address all aspects of the disease.

Treating rheumatoid arthritis early and aggressively is vitally important and can help to prevent crippling joint damage. Today specialists recommend a treatment plan that includes education, medication – often a combination of several different types

Contact information for Canada's national newspapers:

**National Post**

300 - 1450 Don Mills Road,  
Don Mills, Ontario, Canada, M3B 3R5  
Phone: (416) 383-2300  
Fax: (416) 442-2212

- For letters to the editor, email [letters@nationalpost.com](mailto:letters@nationalpost.com)

**The Globe and Mail**

444 Front Street West,  
Toronto, Ontario, M5V 2S9  
Phone: (416) 585-5000

- To make a general comment or suggestion about the contents of the Globe and Mail, send an e-mail message to

[Newsroom@globeandmail.com](mailto:Newsroom@globeandmail.com)

- For letters to the editor, email [Letters@globeandmail.com](mailto:Letters@globeandmail.com)

## Writing a Letter to a Newspaper

1. If you are writing a "letter to the editor" of a newspaper in response to an announcement or news item, do it quickly – the same day or next day is best. Letters that go in three or more days later typically do not get published because the interest in the news item is less.
2. Letters to the editor should not exceed 250 words; as such, your letter needs to be "to the point".
3. Remember that facts and numbers help to support your argument.
4. Send a copy of a letter you write to your elected official to your local, provincial or national newspaper as well.

At right is a letter that was published in the National Post to use as an example. It was written in response to a story about a woman living in New Brunswick whose expensive arthritis medication is not being covered by her province's drug benefits plan.

<http://www.arthritisconsumerexperts.org/pdfs/natpostnov29.pdf>

of medication will be used in a person's treatment plan – social support, appropriate amounts of range-of-motion, cardiovascular and muscle strengthening exercises, rest, vitamins and mineral supplements and a well-balanced diet.

Along with educating oneself about rheumatoid arthritis, medications are a cornerstone of a rheumatoid arthritis treatment plan. There are five major medication groups used to treat the disease. These are:

- Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen (for example Advil® or Motrin IB®), naproxen (or Naprosyn®), diclofenac (or Voltaren® and Arthrotec®)
- COX-2 inhibitors, such as celecoxib (Celebrex®)
- Corticosteroids, such as prednisone
- Disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate, sulfasalazine, hydroxychloroquine, leflunomide and azathioprine
- Biologic response modifiers (or "biologics"), including abatecept (Orencia®), adalimumab (Humira®), anakinra (Kineret®), etanercept (Enbrel®), infliximab (Remicade®), and rituximab (Rituxan®), all of which have been approved in Canada for use in treating rheumatoid arthritis.

These medications can work alone or in combination with one another. Today's "gold standard" of treatment looks like this:

**Step 1:**

A person with newly or recently diagnosed with moderate to severe rheumatoid

arthritis is typically started on methotrexate, and possibly one or two other DMARDs in combination with methotrexate such as sulfasalazine and hydroxychloroquine (triple therapy). While waiting for the drugs to take effect, an NSAID or COX-2 inhibitor or in some cases prednisone, can be used to reduce inflammation quickly.

**Step 2:**

If a person does not respond, or does not respond well enough to the above combination therapy (which is to say their inflammation is not well controlled), then they would be considered a good candidate for a biologic response modifier medication (only one is used at any given time). They are usually used in combination with methotrexate.

This medication approach is very similar to

*"This medication approach is very similar to that used to treat cancer."*

that used to treat cancer. In cancer, aggressive medication therapy is used to stop or reduce the size of tumours or lesions. In rheumatoid arthritis, early and aggressive medication therapy is used to stop or markedly reduce inflammation – inflammation is the equivalent of a tumour.

Because people with active, moderate to severe rheumatoid arthritis are at high risk for irreparable joint damage caused by the disease's symptoms, it is very important for them to closely follow their treatment regime.

It is this regime that helps to prevent or reduce joint damage and disability and delivers the highest quality of life possible.

Exercise is also a very important component of a successful treatment plan in rheumatoid arthritis. Appropriate stretching and strengthening of muscles and tendons surrounding affected joints can help to keep them stronger and healthier and is effective at reducing pain and maintaining mobility. In addition, moderate forms of aerobic exercise can help to maintain a healthy body weight and lessens unnecessary strain on joints. Swimming, walking and cycling are often recommended but they must be done at a level which safely "challenges" a person's aerobic capacity. A physiotherapist trained in rheumatoid arthritis is the ideal person; to recommend a safe and effective exercise program for people living with the disease.

Heat and cold can be used to decrease pain and stiffness. Hot showers can often relax aching muscles and reduce pain; applying cold compresses – like ice packs – to swollen joints can help to reduce heat, pain and inflammation and allow a person to exercise more freely, or to recover from exercise more quickly.

Finally, maintaining a healthy lifestyle is also a critical part of a rheumatoid arthritis treatment plan. A nutritionally sound diet that includes appropriate levels of calcium, vitamin D and folic acid is important. Managing stress levels, getting appropriate amounts of rest, and good old-fashioned relaxation lead to a higher quality of life. ☺

## 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

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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