

Education

Difficulties in diagnosing arthritis

Often, people think of arthritis as just the aches and pains of growing old. For people who have not been touched by the disease, the idea that there are more than 100 types of arthritis, and that many can be devastating, debilitating, and even fatal, is shocking.

One of the reasons it is often difficult to get a diagnosis of arthritis, or even a referral to a rheumatologist, is the staggering number of different, distinct types of arthritis. The symptoms of two types of arthritis may bear little or no resemblance to one another, and this can give general practitioners great difficulty when attempting to diagnose, treat, or refer a patient to a rheumatologist (arthritis specialist).

In this issue we focus on diagnosis and treatment.

Education

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Take, for example, two types of the disease: ankylosing spondylitis and juvenile idiopathic arthritis. Both are forms of arthritis, both require immediate, effective treatment under the care of a rheumatologist, yet their symptoms, and the types of people likely to be affected, are totally dissimilar. A general practitioner may not immediately recognize that the symptoms indicate arthritis and make the appropriate referral.

To give you an idea of the many types of this complex disease, here is a list of just 30 of the more than 100 different types of arthritis.

- Ankylosing spondylitis
- Bursitis
- Degenerative disc disease
- Diffuse idiopathic skeletal hyperostosis (DISH)
- Felty's syndrome
- Fibromyalgia
- Fungal arthritis (also known as: mycotic arthritis)
- Gout
- Gonococcal arthritis
- Infectious arthritis
- Juvenile idiopathic arthritis
- Legg-Calvé-Perthe's disease
- Lupus (also known as: systemic lupus erythematosus)
- Mixed connective tissue disease (MCTD)
- Osteoarthritis
- Paget's disease
- Polymyalgia rheumatica
- Pseudogout (also known as: calcium

- pyrophosphate dehydrate deposition disease)
- Psoriatic arthritis
- Raynaud's phenomenon
- Reactive arthritis
- Reiter's syndrome
- Rheumatoid arthritis
- Scleroderma
- Spinal stenosis
- Still's disease (also known as: adult onset Still's disease)
- Sjögren's syndrome
- Tendonitis
- Vasculitis
- Viral arthritis

For more information about many of these types of arthritis, visit The Arthritis Society website at <http://www.arthritis.ca>.

Because ACE believes that information and awareness are incredibly important in the ongoing fight against arthritis, we are introducing a new JointHealth monthlyTM feature called "spotlight". Each month, we will profile one of the more than 100 types of arthritis, including information on disease symptoms, people affected, and treatment options available.

Listening to you: If you would like us to profile a particular form of arthritis in our monthly "spotlight" feature, please email us at: info@arthritisconsumerexperts.org <



Treating inflammatory arthritis and osteoarthritis

While a diagnosis of arthritis may seem overwhelming and frightening, it is important to understand that treatment options do exist for inflammatory arthritis and osteoarthritis. Understanding the treatment options that exist for a particular form of arthritis, as well as the potential benefits of treatment, can help each person living with arthritis become an active part of their own care team. Research has shown that patients can positively influence their own health outcomes if they are actively involved in shared decision-making and provided with quality information and appropriate self-management tools (Abelson).

Treatment for inflammatory arthritis: start early

A diagnosis of any form of inflammatory arthritis can often come as a shock; because symptoms often appear very suddenly and with little warning, newly diagnosed patients are often left stunned and confused about what to do next.

Research has indicated that one of the most important components of any treatment plan for inflammatory arthritis is to begin early. Often, because of the shock of diagnosis and the suddenness of onset, patients would prefer to take a “wait and see” approach. Also, because of fears about side-effects and complications associated with drug treatment, newly diagnosed inflammatory arthritis patients often want to try “natural” treatments before progressing to pharmaceutical medications. While these fears and preferences are understandable, the research tells us that holding off on pharmaceutical treatments which have been proven effective can be very dangerous.

With some forms of inflammatory arthritis such as rheumatoid arthritis and ankylosing spondylitis, joint damage occurs because of the inflammation. To put it another way, attacking the inflammation that causes joint damage as early as possible can often limit the joint damage that causes long-term deformity and disability. Most importantly, it can also reduce premature death. For these reasons, it is important to work with your doctor to design and undertake a treatment plan that attacks your arthritis early, and effectively.

Treatment programs for more common and very serious forms of inflammatory arthritis, such as rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis, have several components.

The first course of treatment is often non-steroidal anti-inflammatory drugs (also called NSAIDs and COX-2s). Commonly known NSAIDs include ibuprofen (for example Advil or Motrin

IB), naproxen (or Naprosyn), diclofenac (or Voltaren and Arthrotec). The COX-2 group of NSAIDs includes celecoxib (Celebrex) and lumiracoxib (Prexige). Some NSAIDs require a doctor’s prescription. Different NSAIDs may work for different people, and some side effects may occur, so it is important to work with a doctor to determine the best course of NSAIDs to try.

Disease modifying anti-rheumatic drugs, or DMARDs, are sometimes called the second line of defense in treatment of more severe inflammatory arthritis. These medications work to relieve symptoms and prevent further joint damage, but cannot reverse joint damage which has already occurred. Examples of DMARDs are methotrexate, hydroxychloroquine and

sulfasalazine. Starting a DMARD early is the key to keeping disability at bay.

The newest drugs in the arsenal of treatments for inflammatory arthritis are called biologic response modifiers, or commonly, “biologics”. Biologics are a type of DMARD that works to block specific immune responses. In clinical trials, biologics have proven to be very effective at treating the most common forms of inflammatory arthritis, including rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis.

Biologics are proved to radically alter or suppress disease activity making them the most exciting advance in treatment for inflammatory arthritis ever. The research costs to develop a biologic was approximately \$1 billion, and

Spotlight on ankylosing spondylitis

Ankylosing spondylitis (AS) is one of the most common types of inflammatory arthritis. It is estimated to affect up to 1 in 200 people.

Ankylosing spondylitis primarily affects the spine, but can also involve the hips, knees, shoulders, and rib cage. The most common symptom of AS is long-term back pain, along with spinal stiffness in the morning or after a long period of rest (this is the main reason why AS is often misdiagnosed as ordinary “low back pain”).

Unlike in many other forms of arthritis where women are most affected, three out of four people diagnosed with ankylosing spondylitis are men. It tends to strike in the prime of life; while it can strike at any age, it is most common in people between ages 15 and 40. While it has no known cure, it is treatable; with the proper care, people who are diagnosed with AS can lead full, productive lives.

Diagnosis of AS

Many people with AS have family members who also have the disease, so a family history of AS should be considered a risk factor. If a person is showing signs of the disease it is vital

that their family physician and rheumatologist be made aware of any family history of AS.

Doctors may do blood tests to determine the presence of inflammation in the body, and to test for specific markers which indicate a genetic risk for AS. An x-ray may also be taken, but it is important to remember that often, signs of AS may not be visible until the disease has progressed to a point where joint damage has already occurred. This is why the site of the stiffness, characteristics of onset of pain, and the time of day when pain is worst, may be the most important factors to analyze when diagnosing AS.

As is the case with most forms of inflammatory arthritis, early diagnosis and treatment of AS can be key factors in preventing disability and deformity; if the inflammation associated with AS continues unchecked, changes to the spinal column are likely to result, causing spinal immobility and limitation of range of movement. If AS affects the hips, damage can result in the need for total hip replacement surgery.

Treatment for AS

There are several treatment options for AS, which include several different types of medication. For an in-depth look at treatment options, please see “Treating arthritis: inflammatory and osteoarthritis” included in this issue of JointHealth™ monthly.

because of their targeted mechanism of action they are very expensive to manufacture. For these reasons and others, a prescription for a biologic cost approximately \$20,000 per year. To date, provincial drug plans offer very restricted reimbursement criteria for biologics prescriptions. It is very important to have an open dialogue with your doctor about which medications are covered under your provincial plans, as well as any private extended coverage you may have.

In addition to medications, any treatment plan for living well with inflammatory arthritis includes paying attention to the health of your whole body. Rheumatologists and general practitioners agree that a nutritionally sound diet provides many health benefits for people living with inflammatory arthritis. In addition to keeping you strong enough to fight your disease, maintaining a healthy body weight takes pressure off your

load-bearing joints. If you have recently been diagnosed with an inflammatory form of arthritis, consider speaking with a dietician to design a plan to eat well and maintain a healthy weight. Visit www.dietitians.ca to find a registered dietician in your area.

For both inflammatory arthritis and osteoarthritis, exercise is a critically important component of any treatment plan. Our JointHealth podcast program includes a conversation with Dr Linda Li about exercise and arthritis. Click here <http://www.arthritisconsumerexperts.org/podcasts.cfm> to listen to this podcast.

Treating osteoarthritis—a comprehensive approach

Osteoarthritis is the most common form of arthritis. It affects 3,000,000 Canadians. It is

caused by the breakdown of cartilage in the joints, and most commonly affects the knees, hips, and hands. It usually starts after 40 years of age.

A healthy diet and exercise program can be one of the most important components of a treatment plan for osteoarthritis. Research shows that high risk for osteoarthritis can be clearly linked to high body weight. This may be because load-bearing joints are overstressed when they are supporting more weight. In any case, losing weight and/or maintaining a healthy body mass can help to prevent, or treat, osteoarthritis.

Many people find it difficult to get started on an exercise program because of their pain. In this case, many doctors recommend taking a pain reliever about 30 minutes prior to starting exercise.

Pharmaceutical treatment options for osteoarthritis are more limited than for inflammatory forms of the disease, although new drugs are being developed which may help to treat the underlying disease as well as the symptoms.

Usually, the first line of pharmaceutical treatment recommended is an analgesic (pain reliever), such as acetaminophen (Tylenol, Panadol). This is sometimes enough to treat the pain associated with mild osteoarthritis. These types of medications can help to relieve pain, but do not work to reduce inflammation.

If it is determined that a conventional pain reliever alone is not sufficient, traditional NSAIDs may be recommended. These NSAIDs are the same as those described earlier as part of treatment for inflammatory arthritis.

The newest type of NSAID, called a COX-2 inhibitor, has shown promise in treating osteoarthritis. COX-2 inhibitors work by blocking the COX-2 enzyme, and are thought to have a lower risk of causing gastrointestinal side-effects than traditional NSAIDs. They may, however, increase the possibility of cardiovascular side-effects in those at risk. The two COX-2s available are celecoxib (Celebrex) and lumiracoxib (Prexige). As always, it is important to speak with your doctor about the potential benefits and risks of any prescribed treatment.

Sometimes, a shot of corticosteroid, or cortisone, into the joint can relieve inflammation and pain. While an injection can sometimes provide very quick relief to a painful, swollen joint, injections should only be used rarely, as the corticosteroid can weaken the cartilage in the joint and actually promote joint damage.

When damage to the joints is severe, doctors may recommend surgery. Joint replacement surgery, most often performed on hips and knees, is one of the most common elective surgeries in Canada today. <

Tips for getting referred to a Rheumatologist

A rheumatologist is a doctor who specializes in treating arthritis. When living with the symptoms of inflammatory arthritis (most commonly, rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis), a rheumatologist can be a patient's best resource. These specialists have at least five years of additional training, on top of their regular medical schooling, in diagnosing and treating arthritis.

Often, it can be incredibly challenging to get a referral from a general practitioner to a rheumatologist. This may be because there are so many forms of arthritis, and general practitioners may not be familiar with many of the symptoms of the more than 100 different types of arthritis. As well, symptoms can mimic those of many other different types of disease, so arthritis may not be the first thing a general practitioner thinks of when presented with a less common form of arthritis.

Another problem which may make it challenging to get a referral to a rheumatologist is that there are simply not enough rheumatologists in Canada to care for all of the people living with some form of arthritis. Currently, there are less than 270 rheumatologists practicing in Canada. When you consider that 1 in 5 Canadians, or more than 6,000,000 people, in this country are living with arthritis, it becomes clear that there are simply not enough rheumatologists to treat all of the people who need treatment.

While this may seem discouraging, there are

some things you can do to better your chances of getting a referral to a rheumatologist.

Firstly, tell your doctor if you have the hallmark symptoms of inflammatory arthritis. These are:

- Ongoing joint pain and swelling
- Ongoing morning stiffness, lasting more than an hour after rising
- Inability to continue daily work and living activities.

Also, tell your doctor about any history of inflammatory arthritis in your family, as some forms of the disease may have a genetic component.

Once your general practitioner suspects inflammatory arthritis, he or she will need to write you a referral letter. This letter should include the following:

- The suspected diagnosis of inflammatory arthritis.
- A brief history and clinical findings. These may include morning stiffness, weight changes, fever patterns, and number and types of joints affected.
- Copies of all reports, including MRIs, x-rays, and letters from any other specialists consulted.

Studies show that people with inflammatory arthritis diagnosed by a rheumatologist do better. They are diagnosed more quickly and treated more appropriately, and appropriate treatment can prevent joint damage, decrease pain and swelling, and decrease the possibility of permanent disability.

If you are having difficulties getting a referral, be persistent. Remember that the people who end up getting the health care they need and deserve are often those who have refused to take "no" for an answer.

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

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