

## ARTHRITIS FIGHT IT!

**To get the best results, you need to form close ties with your healthcare team and become a full partner in your healthcare treatment.**

**Learning daily living strategies to manage your arthritis gives you a greater feeling of control and a more positive outlook.**

*To support arthritis research or to learn more, contact The Arthritis Society:*



**1.800.321.1433**



**[www.arthritis.ca](http://www.arthritis.ca)**



Canadian Rheumatology Association  
Société Canadienne de Rhumatologie



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# Ankylosing Spondylitis

**KNOW YOUR OPTIONS**



## ARTHRITIS FIGHT IT!

# Ankylosing Spondylitis

## DID YOU KNOW?

- Ankylosing Spondylitis (an-kih-LOW-sing spon-dill-EYE-tiss) affects between 150,000 and 300,000 Canadians.
- Ankylosing Spondylitis (AS) affects men three times more often than women; however, women can be just as severely affected as men.
- People of any age can develop AS, but it usually appears between the ages of 15 and 30.

**There is no cure for AS, but when you are diagnosed early and start the right treatment, you can take control of your disease and avoid severe damage to your joints.**

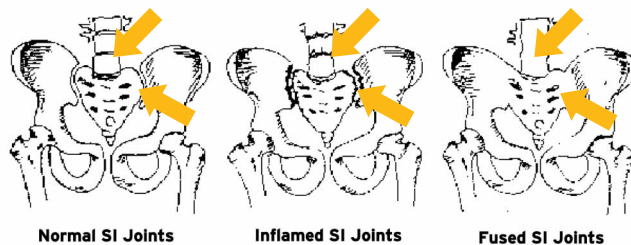
**Most people with AS can lead active and productive lives with the help of the right medication, surgery (in some cases), exercise, rest and joint protection techniques.**

## WHAT IS ANKYLOSING SPONDYLITIS (AS)?

Ankylosing Spondylitis (AS) is a type of inflammatory arthritis and an autoimmune disease.

An autoimmune disease is one where the body's immune system becomes confused and begins to "attack" the body. In AS, the joints in the spine are the target of the immune attack resulting in pain and stiffness (inflammation) in the back.

The first symptoms of AS typically start in late adolescence or early adulthood (ages 15-30). The inflammation (pain and stiffness) of AS usually starts at the base of the spine where the spine attaches to the pelvis (sacroiliac (SI) joints). This inflammation can spread upwards to involve other parts of the spine, and in the most severe cases, it can involve the entire spine. As the inflammation continues, new bone forms



as the body tries to repair itself. As a result the bones of the spine begin to "grow together" (fuse) causing the spine to become very stiff and inflexible. Even though new bone has formed the existing bone may become thin (osteoporosis) increasing the risk for fractures.

AS can cause pain and stiffness (inflammation) in peripheral joints such as the hips and shoulders. It can also cause inflammation of the tendons surrounding the joints. This is called enthesitis (en-thees-EYE-tis). Some of the common spots for enthesitis are the back of the heels (Achilles tendonitis), underneath the bottoms of the feet (plantar fasciitis), on the outside of the hips (trochanteric bursitis), and along the breast bone (costochondritis).

When the immune system is confused (autoimmune disease) it can attack other parts of the body other than the joints and tendons. In AS this immune attack may also cause inflammation in the eye, a condition called uveitis (You-vee-EYE-tiss) or iritis (EYE-rye-tiss), and, rarely, the lungs and heart can be affected.

AS is a highly variable disease that causes very different symptoms. Some individuals may only experience episodes of mild back pain, while others will have severe chronic pain accompanied by stiffness of the spine affecting their posture and daily activities. The most universal symptom, however, is chronic low back pain that seems to come (flare) and go for no apparent reason. It is generally worse in the morning when rising from bed and improves with stretching and exercise.

## WHAT ARE THE WARNING SIGNS OF AS?

The warning signs of ankylosing spondylitis include:

- The onset of new back pain/stiffness in a younger person (age 15-30).
- Back pain and stiffness which is worse in the morning; typically lasting more than 30-60 minutes before you “loosen up” and start feeling better. However, the pain and stiffness can be with you (to some degree) most of the day even causing discomfort while you try to sleep at night.
- Pain and tenderness in other parts of the body including the backs of the heels (Achilles), under the feet (plantar fascia), on the outside of the hips (trochanteric bursa), and along the breastbone.
- Sometimes one or a few joints may swell up for no reason (knee and ankle, for example).
- Recurring inflammation in the eyes causing pain, redness, blurred vision, and sensitivity to bright light requiring the use of steroid drops into the eyes.
- A family history of ankylosing spondylitis.

## WHAT TO DO IF YOUR FAMILY DOCTOR THINKS YOU HAVE AS?

If your family doctor believes that you have AS, it is important to see a rheumatologist to begin treatment. A rheumatologist is a doctor who is an expert in arthritis. You must get a referral from your family doctor to see a rheumatologist. The Arthritis Society maintains a list of rheumatologists across Canada. To find out which rheumatologist is nearest to you, call our toll-free Arthritis Information Line at 1.800.321.1433.

## HOW DOES THE DOCTOR DIAGNOSE AS?

There is no specific test to diagnose AS. In fact, some people live with mild AS for many years without ever knowing they have it. However, any one or several of the symptoms previously mentioned may alert your doctor to the possibility of AS.

The best way for your doctor to diagnose AS is to talk to you and carefully listen to your symptoms followed by a thorough physical examination.

Your doctor may then choose to perform blood tests to look for inflammation in the body. These blood tests are called ESR (erythrocyte sedimentation rate) and CRP (C-Reactive Protein). Your doctor might also test for the HLA-B27 gene.

Finally, X-rays may be taken to determine if there are changes in the joints at the bottom of the spine (sacroiliac joints), however changes in these joints occur slowly over time and may not be present in early stages of the disease. Sometimes further imaging is done with a CT scan or an MRI.

## WHY IS EARLY TREATMENT SO IMPORTANT?

Remember that AS causes inflammation (swelling, pain and warmth) in the spine and sometimes other joints (often hips and shoulders). This inflammation usually results in stiffness of the spine and other joints. The goal is to keep the spine flexible and the joints moving with the hope to prevent or delay permanent damage.

Remember the “Tin Man” from the Wizard of Oz? In the movie, he constantly needed to have his joints oiled so he could keep moving. Otherwise he stiffened up and couldn’t move. People with ankylosing spondylitis are often compared to the “Tin Man”. However, instead of oil to keep moving they use exercise and medications.

## WHY DO PEOPLE GET AS?

The majority of people (90%) with AS have a gene called HLA-B27. There are a few things to remember about this gene:

1. Not everyone with AS carries this gene; therefore, if your doctor tests you and you don't have it you may still have AS.
2. If you have this gene it does not mean you will develop AS. Remember this gene does not cause AS but increases your risk of getting it. In fact, only a very small number of people with this gene will ever develop AS.
3. There is discussion among researchers that other genes in the immune system may also lead to the development of AS.

The current thought is that another “trigger” is needed to set off the disease. Unfortunately, we don't know what the “trigger” is that starts AS but some believe it may be a viral infection or something else in our environment. There may be more than one trigger. Many dedicated scientists are looking for the “trigger”, and many clues have been found but nobody has been successful yet. The Arthritis Society funds a number of leading edge research projects that bring vital new insights, resulting in new and better treatments for AS.

## HOW CAN I MANAGE AS?

Once your diagnosis is confirmed there are many treatments that can help decrease your pain and stiffness, and increase your mobility.

The typical treatment plan is usually made up of several components:

- Medication
- Other healthcare support (physiotherapy, occupational therapy etc)
- Daily-living adjustments

Being actively involved in developing your prescribed treatment plan is essential to decrease your pain, and maintain your movement and function.



## WHAT MEDICATIONS HELP AS?

The general approach to treating AS is to reduce the joint inflammation to improve your pain, stiffness, function and mobility with the hope of preventing long-term damage to the spine and joints. Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) are the most commonly used medication to treat the pain and inflammation of AS.

Disease-Modifying Anti-Rheumatic Drugs (DMARDs) such as methotrexate and sulfasalazine can be used in combination with NSAIDs although they generally don't work as well for inflammation in the spine. They are sometimes used for inflammation in joints away from the spine or with inflammation of the eyes (iritis). Corticosteroids (steroids) are sometimes used to try and control symptoms during flares of AS.

A relatively new class of medications (biologics) has revolutionized the treatment of AS over the past few years. These medications suppress inflammation and may help prevent damage to the joints of the spine.

### Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) are a class of medications used to treat the pain and inflammation of arthritis such as AS. They do not contain steroids, hence the name "Non-Steroidal". NSAIDs are a very large category of medications, some of which you can obtain without a prescription, such as ASA (Aspirin®, Entrophen®, Novasen®) and ibuprofen (Advil® or Motrin®). The list of NSAIDs is long with over 20 currently available today.



There are studies in AS to show that taking NSAIDs on a regular basis may have long-term benefits and, as a result, most doctors advise the regular use of NSAIDs for AS. You may need to take the NSAIDs for a few weeks to feel the full effect.

Indigestion, heartburn, stomach cramps and nausea are the most common side effects of NSAIDs. NSAIDs can affect the protective lining of the stomach making you more susceptible to ulcers and bleeding. If you develop signs of stomach bleeding, such as vomit that looks like it has "coffee grounds" in it, vomiting blood, or black, tarry bowel movements, while taking NSAIDs, stop the NSAID and see a doctor immediately. COXIBs are NSAIDs that have been custom-designed to minimize the risk of stomach problems.

Health Canada has reviewed all of the available studies on NSAIDs and COXIBs and found that NSAIDs and COXIBs are both associated with a small increased risk of cardiovascular events (angina, heart attacks, and strokes). The risk is greatest in those patients who use these medications for long periods of time and have risk factors for, or a history of, cardiovascular disease. Please discuss this with your doctor.

### Corticosteroids

Cortisone is a hormone produced naturally by the body's adrenal glands. In the 1950s physicians found that giving extra cortisone to patients with rheumatoid arthritis dramatically improved their symptoms. From this discovery, corticosteroids, also known as steroids, were developed and are some of the oldest, most effective, and fastest-working medications for inflammatory arthritis.

In AS, steroids are usually used for short durations to quickly relieve a flare of symptoms or get a newly diagnosed disease under control. They are usually injected into a joint or taken orally (prednisone).

Corticosteroids often cause an increased appetite and result in weight gain. Therefore it is important to follow a healthy diet and exercise (as best as possible). They can also increase your risk of infection so see your doctor if you develop a fever, chills, or other symptoms of infection. When used for long periods of time, steroids can thin your bones (osteoporosis) increasing your risk of fracture, thin the skin causing easy bruising, and cause cataracts. A very rare side effect of corticosteroids, osteonecrosis, results in loss of blood supply to the end of a long bone. The most common place for this to happen is in the hip bone (femur) but occasionally the knee or shoulder could be involved. If you develop sudden severe pain in one of the groins, contact your doctor immediately.

Traditional Disease-Modifying  
Anti-Rheumatic Drugs (DMARDs)

DMARDs (pronounced DEE-mardz) are a class of medications used to treat inflammatory types of arthritis. DMARDs slow down the biologic processes that are the driving force behind the persistent inflammation (pain, swelling, & stiffness) in the joints.

The most commonly prescribed DMARDs for AS are methotrexate and sulfasalazine.

DMARDs work best for peripheral joint symptoms (joints away from the spine such as the hips and shoulders) but don't seem to work as well to improve inflammation in the spine.

Side effects and blood monitoring

All DMARDs have potential side effects. Each one is different and you must learn from your doctor what to

expect from each drug you try. In most cases, DMARDs require regular blood tests to monitor side effects. Some people require an adjustment to their dosage or a change to a different type of medication.

Biologic DMARDs

The biologics are a class of medications specially designed to treat rheumatoid arthritis but they have also been shown to improve the signs and symptoms of AS. Unlike the traditional DMARDs, they have been shown to improve the spinal arthritis associated with AS, arthritis in other joints, and enthesitis.

Biologics used in AS are specifically designed to block a protein called Tumour Necrosis Factor (TNF) which is present in the blood and joints in excessive amounts where it increases inflammation (pain & swelling). Adalimumab (Humira®), Etanercept (Enbrel®), and Infliximab (Remicade®) are medications specially designed to block the action of TNF.

By blocking TNF, biologics work to suppress the body's immune system. Although this suppression can make it slightly harder to fight off infections, it also helps to stabilize an overactive immune system.

Depending on the biologic prescribed; they are either given by injection at home or by an intravenous infusion at a clinic. Side effects occasionally seen with these medications include mild skin reactions at the injection site, headaches or dizziness, colds or sinus infections, and nausea or diarrhea. Your doctor will discuss all of the other side effects of these medications before he or she prescribes them.

Commonly Prescribed DMARDS for AS

BRAND NAMES	PRODUCT	COMMON DOSE	HOW GIVEN
Methotrexate	Methotrexate	7.5 to 25 mg once weekly	Tablets or injection under the skin
Salazopyrin	Sulfasalazine	1000-1500 mg twice per day	Tablets

Commonly Prescribed biologics for AS

BRAND NAMES	PRODUCT	COMMON DOSE
Enbrel	Etanercept	50 mg injection once a week or 25 mg injection twice a week
Humira	Adalimumab	40 mg injection every other week
Remicade	Infliximab	Intravenous (IV) infusion at 0,2,6 and then every 8 weeks

## What else should I know about Biologics?

### Precaution

Biologics work by suppressing your immune system which can make it slightly harder for you to fight off infections. Please inform your doctor if you are prone to frequent infections. It is advisable to stop your medication and call your doctor if you develop a fever or if you have or think you have an infection. Before starting biologics, your doctor should check for other infections, such as tuberculosis.

### Cost

Biologic treatments are costly, and can range anywhere from \$15,000 to \$25,000 per year. Depending on the type of insurance coverage you have, treatments may be fully covered or you may be required to share the cost. Generally, provincial plans or private insurance companies will require patients to attempt conventional treatments before they will cover biologics.

## A WORD ABOUT MEDICATION SAFETY

The need to effectively monitor new drugs once they have been approved and introduced into the market has been a key advocacy issue for The Arthritis Society for several years. This advocacy helps to ensure that unfavourable side effects are reported, documented, and addressed. **For regular updates on medications available in Canada, visit [www.arthritis.ca/tips/medications](http://www.arthritis.ca/tips/medications).**

All medications have potential side effects whether they are taken by themselves or in combination with other herbal, over-the-counter and prescription medications. It is therefore important for patients to discuss the benefits and potential side effects of all their medications with their doctor.

Health Canada's Marketed Health Products Directorate operates the MedEffect program, which provides centralized access to new safety information about health products in an easy to find, easy to remember location. MedEffect was developed to help build awareness about the importance of submitting adverse reaction reports to identify and communicate

potential risks associated with certain drugs or health products. MedEffect aims to make it as simple and efficient as possible for health professionals and consumers to complete and submit adverse reaction reports. To find out more or to report an adverse reaction visit: [www.healthcanada.gc.ca/medeffect](http://www.healthcanada.gc.ca/medeffect) or call toll-free 1.866.234.2345.

## WHAT ELSE CAN I DO TO MANAGE MY DISEASE?

### Watch your eyes

About 30% of people with AS will develop iritis. This is a rapid onset of inflammation in the front of the eyeball. The eye may feel irritated and there may be pain in the eye or surrounding area. There may be a headache, blurred vision and sensitivity to light.

It usually happens in one eye only. If you think you may have iritis, you need to see an ophthalmologist (eye specialist) urgently, usually within 24 hours. Simple eye drops can stop the attack and potentially prevent vision loss that can occur.



### Take care of your bones

People with AS may develop a fused spine. Often, the fused spine can become brittle and become prone to easy breaks (fractures). Generally people with AS should be taking calcium and vitamin D supplements and should reduce other risks for osteoporosis, such as excessive consumption of alcohol and smoking. Activities involving forward bending or heavy lifting should also be avoided. Fractures are more common in AS when the spine is fused. A medic alert™ bracelet may alert others to the risk of fracture and spine fusion in the event a person with AS is unconscious.

## Exercise

Exercise is one of the most important ways to successfully manage AS because it keeps joints moving and reduces pain. It will also help reduce stiffness and strengthen the muscles surrounding joints. Exercise should be done for four major reasons:

- **To reduce pain and stiffness**
- **To maintain or restore spinal mobility**
- **To maintain or improve posture**
- **To maintain chest expansion**

Consult a physical therapist to design a program with range of motion exercises to target areas that are particularly prone to pain and stiffness, such as your neck, mid and lower back. It is important to perform these exercises daily to obtain the maximum benefit from them. Generally low impact sports like cycling or swimming are well tolerated and contribute to overall fitness and flexibility.

Strengthening exercises are also important, specifically those that target back muscles, to help keep you upright and prevent you from stooping forward. Gentle stretching is often recommended in addition to these exercises to prevent stiffness and changes in your posture as a result of AS.



## Heat and Cold

**Heat** applied to an arthritic area can help relax aching muscles, and reduce pain and soreness. It promotes blood circulation, which nourishes and detoxifies muscle fibers. Taking a hot shower is a great way to help reduce pain and stiffness. To avoid making symptoms worse, heat should not be applied to an already inflamed joint.

**Cold** applied to inflamed joints reduces pain and swelling by constricting blood flow. Applying ice or cold packs appears to decrease inflammation and is recommended when joints are inflamed. You should not use ice if you have circulatory problems such as Raynaud's disease.



## Protect your Joints

You should always use your joints in ways that avoid excess stress. This allows you to experience less pain, perform tasks more easily, and protect your joints from damage. Techniques to protect your joints include:

- **Pacing** by alternating heavy or repeated tasks with lighter tasks or breaks or frequently changing positions reduces the stress on painful joints and conserves energy by allowing weakened muscles to rest.
- **Positioning joints wisely** promotes proper alignment and decreases excess stress. Do this by maintaining proper posture and carrying heavy objects close to you. Lie on your stomach daily to promote upright posture.
- **Adapting your daily activities and using helpful devices** can help to conserve energy and make daily tasks easier. Avoid positions that may cause excess stress, such as bending forward. Instead, raise seat levels to decrease stress on hip and back joints. Extend mirrors in your car to help with driving; use reaching aids to help with bending over.
- **Sleep on a firm, supportive mattress** to maintain good spinal alignment. Support your neck with special neck supports or pillows.
- **Talk to your rheumatologist** about seeing an occupational therapist or physiotherapist who may prescribe splints, braces, or orthotics (shoe inserts), to help align and support your joints.

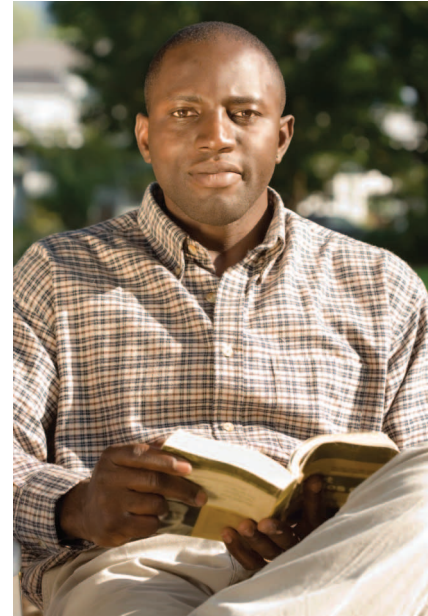
## Relaxation & Coping Skills

Stress and over-activity can sometimes trigger a “flare” of your arthritis. Developing good relaxation and coping skills can help you maintain balance in your life giving you a greater feeling of control over your arthritis and a more positive outlook. Relaxing the muscles around an inflamed joint reduces pain. There are many ways

to relax. Try deep breathing exercises. Listen to music or relaxation tapes. Meditate or pray. Another way to relax is to imagine, or visualize, a pleasant activity such as lying on the beach, or sitting in front of a fireplace. Getting a good night's sleep is often a challenge for people with AS because of night pain, and this should be one of your goals when you discuss management plans with your doctor.

## Surgery

People with severe, advanced AS may require surgery for badly damaged joints. Surgery usually involves replacing a joint with an artificial joint. This is most commonly used for the end stage of damage to the hip joints, called a total hip joint replacement. Benefits include less pain, better movement and restored function. Spinal surgery is complex and is only used in those with severe deformity.



## WHAT QUESTIONS SHOULD I ASK MY RHEUMATOLOGIST?

**A recent study found that patients who learned more about their treatment and talked to their doctor about it had fewer symptoms, including less pain, and greater mobility.**

**It's important to get all the information you need to make an informed decision about the right treatment for you.**

Be sure to talk with your doctor about your AS, and ask questions about the disease and the different kinds of treatments. Before making a decision, you should understand what you can expect from a medication, what its possible side effects are and other important information. Also, ask what steps you can take yourself to get your disease under control.

To help you get started, here are some common questions you may want to ask your doctor about AS treatment:

- What local resources are available so I can better educate myself about AS?
- Should I be referred to a physiotherapist or occupational therapist?

In regards to my medications:

- What are the possible side effects and how often do they occur?
- What should I do to minimize the chances of side effects?
- How can I keep track of the blood test results used to monitor me?
- How will I know if the drug is working, and how long will this take?
- Who do I contact if I have concerns about the medication?
- Will this interact with my other drugs?
- Are there drugs that I should stop taking now that I am beginning this new treatment?

## HOW CAN I LEARN MORE?

The Arthritis Society offers a number of services designed to help you live with arthritis.

### **Arthritis Information Line – 1.800.321.1433**

Dial The Arthritis Society's toll-free number to connect with staff or trained volunteers in your province or territory. You can request free information about different forms of arthritis or programs and services that are available. You can also get the names of health professionals in your area who specialize in arthritis.

### **Website – [www.arthritis.ca](http://www.arthritis.ca)**

Regularly updated educational materials, informative articles, 'ask the expert,' authoritative, expert-reviewed resources and a virtual community in our "Open Forums" of people with arthritis are just a mouse-click away at the official website for The Arthritis Society.

### **Free Arthritis Registry – [www.arthritis.ca/registry](http://www.arthritis.ca/registry)**

The Arthritis Society can help you understand your disease and what's happening to your body. By joining the free Arthritis Registry you will receive the specific information you need to manage your arthritis and improve your quality of life.

### **Arthritis Self-Management Program (ASMP)**

Managing arthritis means more than just visiting your doctor and taking the right medications. The Arthritis Society's six-week program of two hours per week will help you understand your type of arthritis, its treatments and teach you ways to cope with chronic pain. ASMP also offers a forum to share your personal experiences and challenges of living with arthritis.

### **AS Specific Information**

The Ontario Spondylitis Association has a variety of educational materials ([www.spondylitis.ca](http://www.spondylitis.ca)) and the Spondylitis Association of America has excellent information and resources ([www.spondylitis.org](http://www.spondylitis.org)).

### **Arthritis Friendly Products**

The Arthritis Society is proud to be able to recognize manufacturers that have designed products that are easy to use for people living with arthritis. There is quite a list of products that have been commended by The Arthritis Society and deemed "Arthritis Friendly". A full list and more information is available online at [www.arthritis.ca/arthritisfriendly](http://www.arthritis.ca/arthritisfriendly).