Ankylosing spondylitis

A guide to your condition and its treatment

Canadian Spondylitis Association

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Being diagnosed with ankylosing spondylitis, or AS, can be shocking and scary. What is it? What can I expect?

This booklet will help you understand AS, including some fast facts about your condition, symptoms you may experience, and treatment options available to you.

You should know from the start that there have been many advances made in AS therapy – so while there is no cure, there is hope.

And you should also know that you are not alone. Your doctor and health care team – which could include your rheumatologist, nurse, pharmacist, nutritionist, physiotherapist, occupational therapist and/or patient organization (for example, the Canadian Spondylitis Association) – are there to help you and answer questions along the way. Early diagnosis and treatment are key to managing your condition, so you'll work closely with your health care team to decide which options are suitable for you.

Let's begin our discussion by taking a closer look at what's happening inside your body when you have AS.

What is AS?

Ankylosing spondylitis (AS) is an inflammatory disease of the spine. Your body's immune system causes swelling, stiffness, and pain in the joints between the vertebrae (bones in your spine).

With the inflammation, new bone may form as the body tries to repair itself. As a result, bones in the spine can fuse ("grow together") causing the back to become very stiff.

That's actually why it's called AS: "ankylosing" means stiffening, or fusing together, and "spondylitis" means inflammation of the spine.

AS may also affect other joints, such as the hips, knees, feet, shoulders and chest wall (ribs).

Fast facts about AS

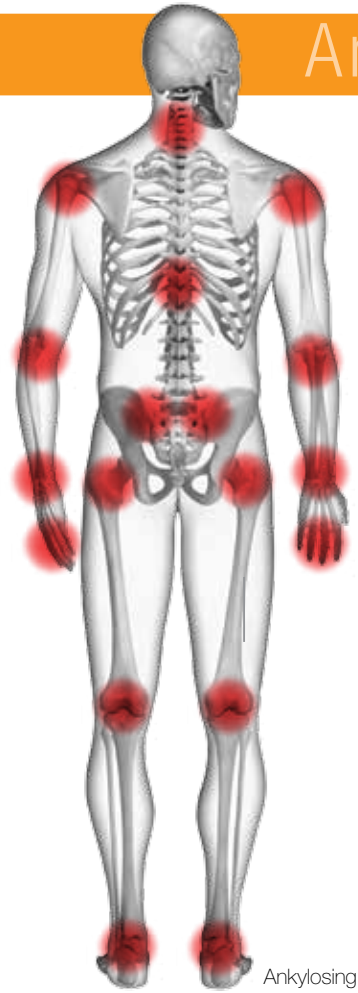
- AS afflicts from 150,000 to 300,000 Canadians
- AS occurs 3 times more often in men than women
- AS usually begins between 15 and 40 years of age, at an average age of 24
- Early signs of AS may be mistaken for common back pain
- AS is often diagnosed 8 to 9 years after symptoms begin
- AS may worsen over a lifetime if left untreated, but may go into remission when optimally treated

What causes AS?

No one knows exactly what causes AS. But medical researchers are working hard to find the answer, and their progress in recent years has revealed that AS runs in families.

In fact, over 90% of people with AS carry a specific inherited gene called HLA-B27.

This gene is not a direct cause of AS, but it increases the odds that a person will develop the disease.



It is now further known that there are additional genes that make it more likely that AS will occur but there are some that are also protective.

Signs and symptoms

AS usually starts with lower back or buttock pain. It may be on one side or the other, or can be both sides. Not infrequently it fluctuates from side to side over time. Symptoms vary from one person to another and progress at different rates over time. Some people only have mild symptoms while others endure severe symptoms that persist for years. While the problem typically begins in the low back, over time it tends to ascend and involve the mid back

and possibly the neck. It is most often characterised by its fluctuations. An episode of back pain and stiffness may last a day or two, a week or two, or even a month or two but will usually abate on its own, only to re-emerge again later. These episodes tend to recur over time. Another common feature is that of "morning stiffness" which commonly makes it difficult to move and get going on arising in the morning. This may last for half an hour or more. Essentially, no two cases of AS are alike.

Men

AS usually affects the spine and pelvis but may involve the ribs, shoulders, and hips. In children, the initial symptoms usually occur in the heels, the sole of the foot, around the knee and the outside of the hips with no spinal pain or involvement at all. The spinal problems may occur as the young individual gets into their teenage years.

Women

AS often affects the pelvis, hips, knees, ankles, and wrists. Spinal involvement is usually less severe in women.

If you have AS, you may experience one of more of these symptoms:

S – Stiffness in your back lasting longer than 30 minutes in the morning before wearing off. Pain while lying down at night that keeps you awake – you have to get up and walk around to find relief. Chronic lower back pain that persists for more than 3 months

T – Tenderness and pain in your ribs, shoulders, hips, heels, or spine, particularly where ligaments and tendons attach to bone. You may feel dull or widespread pain in the upper buttocks or sacroiliac joints, where the spine meets the pelvis, or in the hips

I – Inflammation of the spine or other joints. Inflammation occurring in the eyes, leading to redness, blurred vision, light sensitivity, and pain. About 40% of people with AS develop inflammatory eye conditions, such as iritis (also called anterior uveitis), at least once

F – Back pain that feels better after exercise but worsens after rest

F – Fatigue, a common symptom of inflammatory arthritis. Weight loss when there is a lot of inflammation in the body

Related conditions

Along with joints, AS may affect other body tissues. We've already mentioned a few, such as the eye and tendons.

AS belongs to a family of related diseases, including psoriatic arthritis and inflammatory bowel disease. Each of these conditions may occur along with or even before AS. All of these conditions are caused by inflammation in the body.

Eye inflammation

- Iritis occurs when the iris or coloured part of the eye becomes swollen and painful. It is important to see an eye doctor (ophthalmologist) immediately because when it's left untreated it may lead to severe vision loss or even blindness. He/she will treat the inflammation with eye drops.

Tender tendons

- Swelling of entheses (where tendons and ligaments link to the bones) can occur in people with AS. This is known as enthesitis (*en-thees-EYE-tis*). Examples of places where this can occur include the Achilles' tendon, and the points where the ribs join the breast bone (sternum) in the front of the chest.

Inflammatory bowel disease (IBD)

- IBD such as ulcerative colitis and Crohn's disease, may occur. Common symptoms are bouts of bloody diarrhea, abdominal pain, fever, and weight loss.

Scaly skin

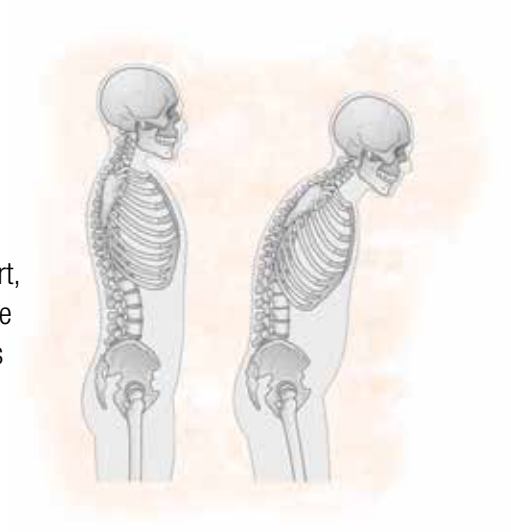
- Psoriasis causes red, scaly patches on the skin and scalp. Small, reddish bumps grow to form larger scaly plaques when inflammation causes the skin to shed too rapidly. Joint inflammation associated with psoriasis is called psoriatic arthritis.

Severe AS

If severe, and not well controlled by medicine, AS can cause significant pain in the back, and individuals may tend to stoop forward and round their spine as this may seem to be a more comfortable position. This over time can lead to a fixed stoop. The head may also tend to crane forward and the individual will be shorter and more rounded than they should be. AS can even restrict breathing, if joints in the rib cage become fused.

If spinal stiffness does occur, the bones of the spine may become thinner and weaker due to their not moving as much as they should. This can lead to easier spinal fracture and potentially dangerous neurological problems.

AS may disrupt electrical activity in the heart, or affect the heart's aortic valve, causing the valve to leak. Monitoring for both conditions will prompt your doctor to listen carefully to your heart during check-ups.



Treating AS

Although there is no cure, AS can be managed with early diagnosis and proper treatment.

Medical therapy, lifestyle changes and complementary therapies all work hand in hand to relieve symptoms and improve your daily life. Your doctor and health care team will help you decide which strategies are best for you, depending on your personal goals.

The following section gives an overview of the different ways your doctor may want you to manage your AS.

Cardiovascular risk considerations

People who have inflammatory diseases like AS may be at higher cardiovascular (CV) risk than the average person, meaning CV events can occur earlier than they would in the general population. A large American study showed that the incidence of CV disease may be higher and CV risk factors more common in people with AS compared to people without AS.

Proper assessment and understanding of your personal cardiovascular risk profile may be an important part of your overall health care.

The Framingham Heart Study identifies the common factors that contribute to cardiovascular disease by following its development over a long period of time in a large group of participants. It has led to the development of a number of “calculators” that provide an estimate of future risk of cardiovascular events, given a particular set of personal parameters.

One of these is the Coronary Heart Disease 10-year Risk Calculator, which estimates the likelihood of an individual developing coronary heart disease (impairment of blood flow through coronary arteries), which may cause angina or a heart attack.

This calculator can be found at http://www.framinghamheartstudy.org/risk-functions/coronary-heart-disease/hard-10-year-risk.php.

Lifestyle

Building your health care team is important. Besides your rheumatologist, nurse and pharmacist, getting acquainted with a physiotherapist, nutritionist and occupational therapist is a great way to take control of your disease.

A physiotherapist is a medical professional trained to assess problems in a person’s movement and mobility. They will evaluate your joints, spine and muscle mobility, advise you on ways to reduce pain and create an individualized plan to help improve your mobility, function, muscle strength and flexibility, and overall quality of life. They can also recommend safe ways to participate in hobbies and sports in such a way as to minimize pain and discomfort.

It may be recommended that individuals with AS follow a daily regimen of range of motion exercises for their involved spinal and peripheral joints. A daily exercise program, including range of motion, spinal extensor strengthening exercises, and aerobics, is one of the most effective ways to improve spinal movement and prevent joint stiffness and pain.

A physiotherapist, familiar with the management of arthritis, can do an assessment of your physical function and provide specific exercises and therapies to strengthen and increase spinal movement. Low impact activities such as walking, Nordic pole walking, swimming, bicycling or use of an elliptical machine are usually recommended. On the other hand, aerobic

exercise helps improve and maintain your chest expansion, endurance and ability to breathe normally. Other activities such as Yoga and Pilates may be recommended by your therapist based on your current joint mobility.

It is not recommended that spinal manipulation be utilized due to risk of spinal fractures.

Exercising regularly has also been shown to improve overall well-being, including decreasing pain, fatigue, stress and improving sleep. If you currently are a smoker, participation in a regular exercise program may help in maintaining or reducing your weight and could help you quit smoking. Even if you feel well with your current medication, a daily postural and aerobic program is important.

For more information on exercise, visit http://www.arthritis.ca/page.aspx?pid=966.

Make sure to consult your doctor before starting any exercise program.

When it comes to day-to-day activities, the ability to engage independently has been shown to increase well-being. An occupational therapist is a highly trained health care professional who can provide you with strategies to help you cope with pain, and identify, engage in and improve your function in activities of daily living.

They will assess and evaluate you in relation to occupational performance, and recommend ways to protect your joints and increase independence in performing activities like housework, shopping, and even working. They can also suggest new sleeping positions and the use of pillows to help keep pain from disturbing your sleep and to maximize rest. An occupational therapist will teach you new ways of doing things, to enable you to regain your previous lifestyle as much as possible.

To assist with pain and symptoms, some people try complementary therapies like deep tissue massage and acupuncture. If you go for a massage or acupuncture, make sure you find a qualified practitioner who works with people with AS and who recognizes the importance of using strict aseptic techniques.

You can also try relaxation exercises or even music therapy.

Don't forget to pay attention to what you put in your body! Extra weight puts an extra burden on your weight-bearing joints (back, hips, knees, ankles and feet). You should consider a balanced diet as a way to achieve and maintain a healthy weight. A nutritionist will give you professional advice on the most sensible diet to follow. They will teach you how to plan your meals and navigate food labels to ensure you are getting adequate nutrients. Remember

that healthy eating, based on Canada's Food Guide, also fuels your body with proper nutrients, providing adequate energy to complete your daily activities.

Heat and cold

HEAT can help relieve muscle pain and joint stiffness. A warm shower in the morning or before bed, especially when combined with stretching exercises, can be very helpful.

Other ways to apply heat include a hot water bottle, warm wheat pillow and electric blanket.

However, be careful not to apply direct heat to a swollen joint – this may cause more swelling!

COLD may help reduce joint swelling and pain. Wrap an ice pack or bag of frozen peas in a tea towel and apply to the swollen joint.

Cold, particularly icy cold, can burn the skin, so do not leave ice packs in place for more than 10 minutes. Observe the rule of 10s – 10 minutes on, 10 minutes off.

Surgery

Most people with AS don't need surgery. Surgery is rarely necessary to restore posture in the spine and neck. People with advanced AS may choose to have surgery to replace a severely damaged joint with an artificial joint. About 6% of people with AS have a hip replacement to restore their mobility and ease pain. Postoperatively you will likely require physiotherapy and rehabilitation. It is important to discuss goals of therapy as well as modifications to any existing exercise program such that you may protect the joint and reduce the risk of injuries.

Drug treatment options

The goal of medication is to reduce swelling, pain, stiffness and prevent damage to joints and other body tissues. Ask your doctor how medications differ and to explain their benefits and side effects.

Four types of medication are used to treat AS:

- Nonsteroidal anti-inflammatory drugs (NSAIDs)
- Corticosteroids (steroids)
- Disease-modifying antirheumatic drugs (DMARDs)
- Biologic response modifiers (biologics)

Your doctor may suggest one or a combination of these therapies to reduce your pain. Whatever your medication, it is very important to take it as prescribed and not to change without speaking to your health care team. AS requires ongoing treatment – even when symptoms appear to have gone away.

Your doctor will recommend a therapy that is best suited to you, taking into consideration your other medical problems and other medications.

Nonsteroidal anti-inflammatory drugs (NSAIDs)

NSAIDs are used to treat the pain and swelling of arthritis and other inflammatory disorders. People taking NSAIDs may experience benefits within a few weeks.

This group of drugs includes:

- Over-the-counter painkillers, such as ASA (e.g., Aspirin®, Anacin®) and ibuprofen (e.g., Motrin®, Advil®)
- Prescription NSAIDs include naproxen (e.g., Anaprox®), diclofenac (Voltaren®), indomethacin and piroxicam. They are used to treat moderately to severely painful, swollen joints
- COX-2 inhibitors, such as Celebrex®, may be prescribed to people who cannot tolerate traditional NSAIDs

All NSAIDs produce about the same anti-inflammatory effects. But individuals react differently to different drugs, and you may find that one NSAID provides more relief than another.

Common side effects of NSAIDs include: upset stomach, heartburn and nausea. Taking two different NSAIDs at the same time is generally not recommended as this increases the risk of side effects. NSAIDs are not for everyone, even if some are available over the counter. You should always consult your doctor before using NSAIDs.

Corticosteroids (steroids)

Corticosteroids are potent anti-inflammatory medications that can be taken orally (as a pill) or injected.

Oral corticosteroids, such as prednisone, help to decrease joint swelling and slow joint damage in severe AS. They are usually taken for limited periods of time, because of side effects. For severe pain and swelling, your doctor may inject a corticosteroid directly into a painful, swollen joint for immediate but short-term relief.

Side effects of corticosteroids include: facial rounding, greater appetite and weight gain, susceptibility to infection, and bone loss (osteoporosis).

Disease-modifying antirheumatic drugs (DMARDs)

DMARDs can be prescribed to treat several types of inflammatory arthritis (e.g., rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis) as well as inflammatory bowel disease (ulcerative colitis and Crohn's disease).

Early treatment with DMARDs can prevent the joint damage that occurs over time. DMARDs cannot reverse joint damage that has already happened, but they can save joints and other tissues from destruction.

In AS, DMARDs like methotrexate and sulfasalazine are used when there is inflammation in the peripheral joints (hands, knees, feet). They do not significantly improve spinal inflammation. DMARDs may need to be taken for weeks before there is a noticeable difference in pain and joint swelling.

DMARDs can be taken with other medications, such as NSAIDs and steroids. Other common DMARDs are gold therapy (Myochrysine®), leflunomide (Arava®) and azathioprine (Imuran®).

People with mild AS are usually prescribed a single DMARD. For moderate to severe AS, your doctor may prescribe two or three DMARDs to take at the same time for greater benefit.

Common side effects of DMARDs include: upset stomach, vomiting, diarrhea, and dizziness.

Regular blood work is needed for the monitoring of cell counts and liver function.

Biologic response modifiers (biologics)

Biologics are used to treat a variety of conditions such as rheumatoid arthritis, Crohn's disease, psoriasis, psoriatic arthritis and ankylosing spondylitis. Biologics help ease joint swelling and pain, and help prevent damage to your joints. They work within days or weeks in some people, but may take up to three months in others (e.g., human or animal).

Biologics come from different sources (human, animal, etc.), and use different mechanisms of action to control the inflammatory process.

They are prescribed to people who fail to respond to other AS therapy. Biologics can be combined with other medications to treat the most severe forms of AS.

The following biologics are indicated for AS in Canada:

- Humira® (adalimumab)
- Enbrel® (etanercept)
- Simponi® (golimumab)
- Remicade® (infliximab)
- Inflectra™ (infliximab)
- Remsima™ (infliximab)
- Cimzia® (certolizumab pegol)

Common side effects of biologics include: mild skin reactions at the injection site, upper respiratory tract infection and an increased susceptibility to infections. Biologics may make it more difficult for you to fight off infections because they suppress the immune system. Rarely, people who take biologics may develop serious infections, lupus-like reactions, nervous system diseases and cancer (including lymphoma).

Help your friends and family help you

If you are living with a chronic inflammatory illness, it is very important to open the lines of communication with family, friends and co-workers to help them understand what you're feeling.

Encourage your loved ones to learn about your condition, understand your symptoms better, and even attend appointments with you. There are many sources of reliable information to assist everyone, including libraries, websites, blogs and the Canadian Spondylitis Association. You can even give them this booklet to read!

Ask them to be there for you and to lend an ear if you need to talk. If sometimes you are limited by your condition, make sure to communicate that, and keep in mind that, with inflammatory conditions, there are always good days and bad days.

And if you've ever had to say, "You don't know what it's like," remember to sincerely express your feelings. This will give others the opportunity to help you.

Your doctor will help you decide what to do next

We hope you have found this information to be helpful and suggest that you speak to your doctor and the rest of your health care team about the most appropriate treatment for your condition. Don't hesitate to ask questions and get involved in decision-making regarding your AS. And keep in mind there are many options available to you, so if one approach doesn't work another one might.

Helpful websites

The Canadian Spondylitis Association	www.spondylitis.ca
The Arthritis Society	www.arthritis.ca
Spondylitis Association of America	www.spondylitis.org
WebMD	www.webmd.com
RheumInfo	www.rheuminfo.com

Questions to ask my doctor:

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