

# Ankylosing Spondylitis

(Axial Spondyloarthritis)

● **GUIDEBOOK**

Answers and practical advice

## ABOUT THE CANADIAN SPONDYLITIS ASSOCIATION (CSA)

The Canadian Spondylitis Association is a federally incorporated, not-for-profit organization. Our mission is to be the leader in Canada providing support, education and advocacy to the spondyloarthritis community.

Membership of the CSA can go a long way towards improving your health and lifestyle. ASAS, the Assessment of Spondyloarthritis International Society, recommends belonging to a patient organization as an additional treatment option.

Here are some reasons why you should become a CSA member today!

- You'll benefit from up-to-date information on treatment and research.
- Be notified about upcoming events, programs and campaigns.
- Receive our electronic newsletter providing you with current and credible information.
- Connect with others in our Facebook community
- Join an existing support group or start one in your community.

- Share your voice to the advocacy efforts that CSA provides on behalf of people living with AS.

*Get involved and support research into Ankylosing Spondylitis*

- Support other people affected by Ankylosing Spondylitis.
- Support our awareness plan to focus on early diagnosis, patient empowerment and self-management.

### To join CSA

If you'd like to join online, please go to our website at [www.spondylitis.ca](http://www.spondylitis.ca) or email us at [membership@spondylitis.ca](mailto:membership@spondylitis.ca)

**MEMBERSHIP IS FREE.**

**EMAIL: [info@spondylitis.ca](mailto:info@spondylitis.ca)**

**WEBSITE: [www.spondylitis.ca](http://www.spondylitis.ca)**

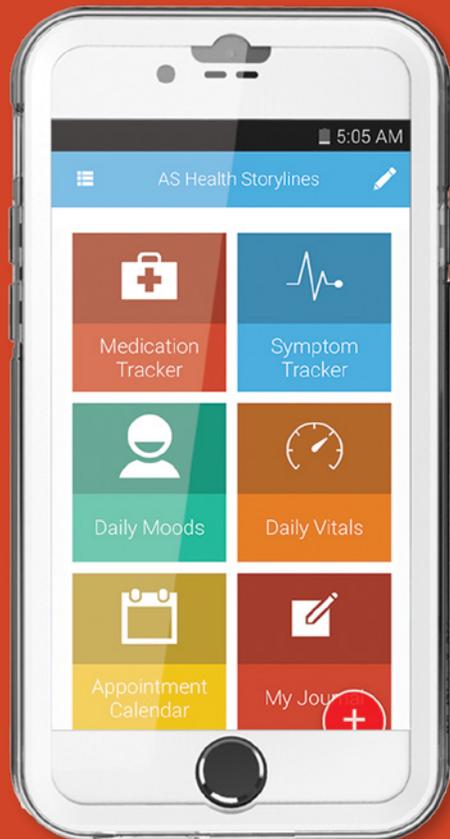
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# AS Health Storylines™

Created with input from people with ankylosing spondylitis (AS) so that the right health tools are available to you.



Now it's easy to record your symptoms, fatigue levels, moods and more. Choose what you want to track to build your own summary "My Storylines" to learn more about your health, and to share more – safely and securely – with your doctor about what happened between visits.

AS Health Storylines is developed in partnership with the Canadian Spondylitis Association, and is powered by the Health Storylines™ platform from Self Care Catalysts Inc.

Get the **FREE APP** now on the **Apple App Store** and the **Google Play** store.



You can also use the web version on your computer at [as.healthstorylines.com](http://as.healthstorylines.com).



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Ankylosing spondylitis is pronounced ANG-ki-low-zing spon-de-LIE-tis and is called AS for short.

AS is a painful, progressive form of inflammatory arthritis. It mainly affects the spine but can also affect other joints, tendons and ligaments.

Ankylosing means fusing together. Spondylitis means inflammation of the vertebrae. Both words come from the Greek language. Ankylosing spondylitis describes the condition where some or all of the joints and bones of the spine fuse together.

Other areas such as the eyes, bowel, lungs and heart can also sometimes be involved with AS.

AS affects an estimated 300,000 people in Canada. Research is still ongoing into the genetics of AS, but researchers believe that up to 30 different genes must be involved.

Symptoms usually begin in early adult life, with the average age of diagnosis being 24.

AS is a very variable condition. Some people with AS have virtually no symptoms whereas others suffer much more severely. Generally, people find that their symptoms come and go over many years.

There is currently no cure for AS. It is managed by a combination of pain relief and stretching exercises.

AS, especially in its early stages, can be an invisible condition. People with AS are often battling on a daily basis against pain, stiffness and fatigue. This can lead to feelings of isolation, particularly just after diagnosis.

As well as the inevitable pain of the disease, AS often generates feelings of frustration and fear. To help them adjust to their diagnosis, it is important that they have the support and encouragement of family, friends and work colleagues.

# CSA guidebook and practical advice

## AS is an inflammatory arthritis where the main symptom is back pain

It comes under the umbrella term of axial spondyloarthritis which includes:

### **ANKYLOSING SPONDYLITIS (AS)**

Where changes to the sacroiliac joints and/or the spine can be seen on X-ray.

### **NON-RADIOGRAPHIC AXIAL SPONDYLOARTHRITIS**

Where X-ray changes are not present but you have symptoms. Up to 70% of people with non-radiographic axial spondyloarthritis have visible inflammation in the sacroiliac joints and/or the spine when an MRI of the back is done.

This guide is for anyone with AS or non-radiographic axial spondyloarthritis. To keep things simple we have only referred to AS throughout the guidebook.

Terminology used for this condition can be confusing. Ankylosing spondylitis is still the term used by most people

because it is relatively easy to remember. But it is the term used to describe well-established disease with definite changes on spinal X-ray. Since the use of more advanced diagnostic technologies, such as MRI, we know that patients can present with symptoms years before the typical changes of spondylitis are seen on X-rays. In addition, not everyone develops X-ray changes in the spine typical of AS, even though they may have quite severe symptoms. It is important for patients to be recognized early after the onset of symptoms so that they get appropriate treatment and do not suffer unnecessarily.

Appropriate treatment may also prevent later functional disability. So doctors now want to make sure that this broader spectrum of patients, with both early as well as established disease, are recognized and appropriately and effectively treated. It is important to use terminology for the disease that captures patients at all stages of the disease. The term that is now used for this is axial spondyloarthritis (AxSpA). So patients with ankylosing spondylitis are at one end of the spectrum of axial spondyloarthritis, when features of the disease are clearly seen on the X-ray.

## What happens?

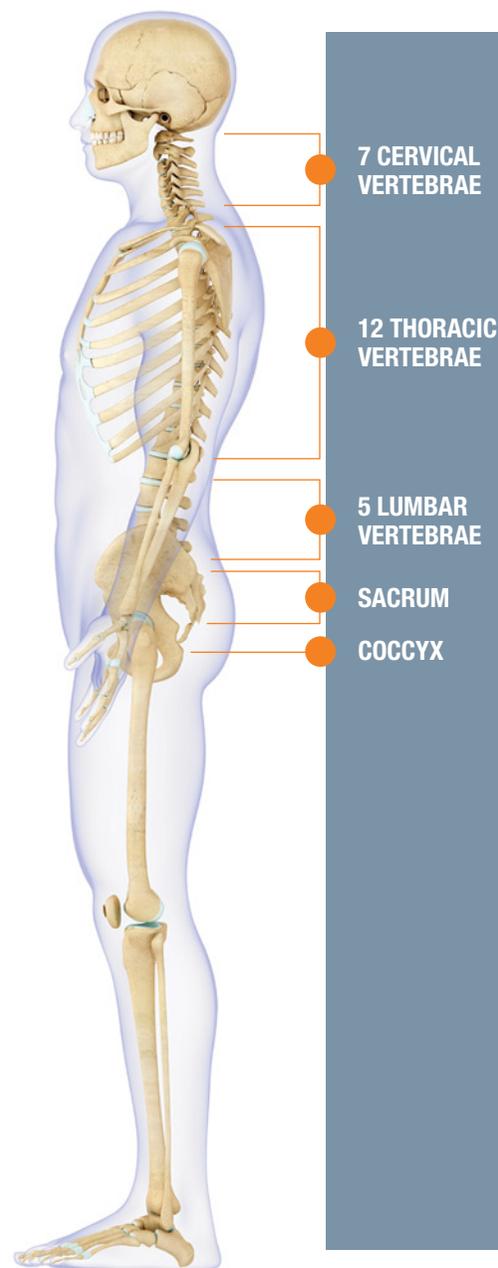
1. Inflammation occurs at the site where ligaments or tendons attach to the bone. This is known as enthesitis.
2. The inflammation is followed by some wearing away of the bone at the site of the attachment. This is known as enthesopathy.
3. As the inflammation reduces, healing takes place and new bone develops. Movement becomes restricted when bone replaces the elastic tissue of ligaments or tendons.
4. Repetition of this inflammatory process leads to further bone formation and the individual bones that make up your backbone (vertebrae) can fuse together.

## How will it affect me?

The effects are different for everyone. Some people with AS have virtually no symptoms whereas others suffer more severely.

## Typical symptoms of AS include:

- Slow or gradual onset of back pain and stiffness over weeks or months, rather than hours or days
- Early-morning stiffness and pain, wearing off or reducing during the day with movement
- Persistence for more than three months (as opposed to coming on in short attacks)
- Feeling better after exercise and feeling worse after rest
- Weight loss, especially in the early stages
- Fatigue
- Feeling feverish and experiencing night sweats (especially in the early stages)



## The spine

The spine is made up of 24 vertebrae and 110 joints.

There are 3 sections: cervical, thoracic and lumbar.

- The cervical, or neck section, is the most mobile.
- In the thoracic section each vertebrae has a rib attached to it on each side.
- Below the lumbar section is the diamond-shaped sacrum, which locks like a keystone into the pelvis.
- The joints between the sides of the sacrum and the rest of the pelvis are called the sacroiliac joints.
- This is usually the starting point of the condition where the low back pain and AS begin.

## What causes AS?

It is highly likely that AS results from some sort of environmental factor triggering the disease in genetically predisposed individuals. As yet, we don't know much about the possible trigger(s) for the disease, although infections are suspected. In contrast, over the last few years we have learned a lot about the genetic factors involved.

The risk of AS is considerably increased if an individual carries a particular gene called HLA B27. About 8% of healthy white Europeans carry this gene, but up to 85% of people with AS have it. However, only about 1 in 20 of the general population who are HLA-B27 positive actually go on to develop AS.

This figure probably doubles if the person has a first-degree relative with AS. From this we can deduce that while HLA-B27 is the main gene involved, it is certainly not the only gene responsible. Indeed, current research reveals there are at least 60 genes involved in this process in some way or another.

One of these genes, called ERAP1, works together with HLA-B27 to increase the risk of AS, but some variants of this gene actually protect against AS. Another gene (IL23R) affects the function of certain immune cells in the body to increase the risk of inflammation. By blocking these effects with drugs, it may be possible to treat AS in the future, and there are currently very promising clinical trials of these agents in AS.

## What is the risk of passing it on to my children?

If you have AS and you do carry the HLA-B27 gene, there is a 50% chance that your child will inherit the gene. But this does not mean that they will necessarily develop AS.

On average, the child of someone with AS has only a 7% chance of developing the condition. If the child has inherited the HLA-B27 gene, this risk doubles

to about 13%. The risk is much lower (probably less than 1 in 15) if it was a grandparent or uncle/aunt who was affected by AS.

Overall, therefore, there is a much greater chance (almost 10 to 1) that the child of someone with AS will not develop the condition than that they will develop it. This risk is increased if the child has inherited the HLA-B27 gene from their affected parent, but not to the extent that routine genetic screening would be recommended, unless the offspring developed symptoms suggestive of AS.

## Is AS common?

AS affects approximately 0.60% of the population in Canada or as many as 6 people in every 1000. This means an estimated 300,000 in Canada have AS.

It usually begins in early adult life with the average age of diagnosis being 24.

## How can I be sure I have AS?

If you suspect you have AS, your first step is to go to your GP or family physician. If your GP suspects AS, you should be referred to a rheumatologist at a hospital.

A rheumatologist is a doctor specializing in conditions such as AS. They will confirm if your condition is AS, decide the initial treatment, and oversee the long-term management of your condition.

Tests that might be used to help diagnose your AS include:

- Physical examination to assess your flexibility and areas of tenderness
- Blood tests
- X-rays and/or MRI which will show whether or not there is any inflammation or damage to your spine

## Does AS affect other joints?

### YES

AS sometimes causes aching, pain and swelling in the hips, knees and ankles. Any joint can be affected. In most cases the pain and swelling will settle down after treatment.

It's important to stretch the hip joint to prevent stiffening in a bent position, making you lean forward.

The heel bone can be troublesome, causing pain in two areas. Most common is the under-surface,

about 3 cm from the back of the foot. This is called plantar fasciitis.

It may help if a podiatrist gives you for your shoe an insole that is designed to take weight off that part of the heel.

You may also get pain at the back of the heel where the Achilles tendon is attached to the heel bone. Pressure from shoes may aggravate the pain

## Co-morbidities of living with AS

Individuals who receive a diagnosis of AS can be at risk of developing other conditions. We've included a few of the more prevalent co-morbidities below. Refer to our website for more information about the conditions and the signs and symptoms you should be aware of.

## Emotional impact of living with AS

Living with AS has its challenges beyond pain, stiffness, and fatigue.

People with AS are likely to experience depression, and also more likely to show co-morbid depression and anxiety in greater numbers.

There can be an emotional side to the disease, too. It's not unusual to get frustrated by your symptoms and find it harder to do simple tasks. You may worry about the cost of your treatment or how it affects other people.

You can deal with these emotions in a positive way. While you may not be able to cure your condition, you do have a say in how you handle it.

## Manage stress and anxiety

Any long-term illness comes with stress that can translate to:

- Low energy
- Poor sleep
- Being more irritable
- Changes in appetite
- Avoiding your social life

With AS, the stress can both worsen and trigger symptoms: A flare-up can raise your stress, which makes your pain and skin worse, which adds more stress.

Anxiety can lead to poor sleep, which leaves you feeling more tired and achy the next day, so you won't sleep as well. Worrying may even keep your treatment from working its best for you.

Also, stay active. It's good for your mood as well as your joints. If simple activities like walking are hard, get in the pool. The water supports your weight, so you can move more easily and without impact on your joints.

Consider yoga, tai chi, or qi gong, too. These gentle, meditative practices help you find a sense of centered calm and keep you flexible.

You may also want to try mind/body treatments such as progressive muscle relaxation, guided imagery, and biofeedback. They can teach you to control your body's reaction to stress -- including your heart rate, blood pressure, and muscle tension -- and manage pain.

## Managing depression

Individuals living with a chronic condition frequently experience some degree of depression. Depression is important to be treated and managed.

People with depression may feel:

- Sadness
- Guilt or worthlessness
- Irritability and anger
- No interest or pleasure in things they used to enjoy

Other common signs include:

- Trouble sleeping
- Fatigue
- A tough time getting out of bed
- Trouble concentrating, making decisions, or remembering
- Mood swings
- Staying at home and avoiding friends
- Weight loss or gain
- Headaches or stomach aches without a known cause

Depression can be treated through medication that can help reset the chemicals in your brain, and therapy can help you work through your troubles. Seeking out a psychologist to speak with can be very helpful or a support group in your area. Additionally, things like exercise, meditation, or yoga can also be helpful.

## AS and fatigue

Individuals with AS often complain of fatigue. It may be defined as an overwhelming, sustained sense of exhaustion and reduced capacity for physical and mental work. A large number of people with AS report fatigue on clinical evaluation. Changes in fatigue often reflect changes in the clinical disease activity. However, other factors contributing to fatigue such as poor sleep, anxiety, depression and chronic pain should be evaluated and managed. Discuss how you are feeling with your physician.

## AS and the eyes

AS can cause inflammation in the front part of the eye between the cornea (the clear window at the front of the eye) and the lens.

About 30% to 40% of people with AS will develop uveitis (or iritis specifically). The main symptoms are pain in the eye and sensitivity to light. The eye feels better with dark glasses. The eye is usually red and sore.

If you think you have uveitis, you should see an eye doctor (ophthalmologist) as soon as possible, ideally within 24 hours, to confirm this and start you on treatment. Early treatment (usually with steroid eye drops) reduces the risk of long-term damage to the eye.

## AS and the bowel

Around 1 in 12 people with AS also have inflammatory bowel disease (IBD). There are two types of IBD: Crohn's disease and ulcerative colitis.

- Crohn's disease can affect any part of the gut.
- Ulcerative colitis just affects the large bowel.

Remember that IBD can start before or after your AS symptoms.

## AS and the heart

Researchers believe that people with AS have a slightly higher risk of cardiovascular events than the general public. To lower your risk:

- Your AS should be well controlled,
- Your GP should evaluate your cardiovascular risk,
- If necessary, medications including cholesterol lowering drugs and blood pressure lowering drugs should be used,
- People with AS should not smoke, and
- People that are overweight should better manage their weight.



## AS and the lungs

Sometimes the rib joints at the back, where they attach to the spine, can become inflamed. This can lead to stiffening and even fusion.

In normal breathing the ribs move up and down with each breath. If the ribs become stiff at these joints, the ribs rise and fall less well, or even stop moving altogether. This means that breathing takes place using only the flat muscle below the lungs separating the lungs from the belly (diaphragm).

You don't stop being able to breathe if the ribs fuse, but tight clothing around the belly will be more uncomfortable as it will make it more difficult for you to breathe.

Breathing exercises encourage you to maintain your rib movements so you don't have to rely on your diaphragm muscle.

The inflammation of the rib joints or muscles attached to the ribs may cause pains that can be confused with the pain of cardiac angina or pleurisy (the pain with deep breathing that occurs when the outer lining of the lung is inflamed). Anyone experiencing symptoms of chest pain should seek medical attention to rule out a more serious condition.

Poor chest wall movement may result in reduced lung capacity, and a few people develop scarring or fibrosis at the top of the lungs, which is usually detected only by a routine chest X-ray. Sometimes people have functional lung impairment, which means that it can take longer for colds and other upper respiratory infections to heal.

It's very important that you don't smoke if you have AS.

## AS and the skin

A skin condition called psoriasis is associated with AS. Psoriasis causes scaly patches on the skin and scalp and can be itchy.

## AS and the bones

Low bone density (osteoporosis) can also be associated with AS.

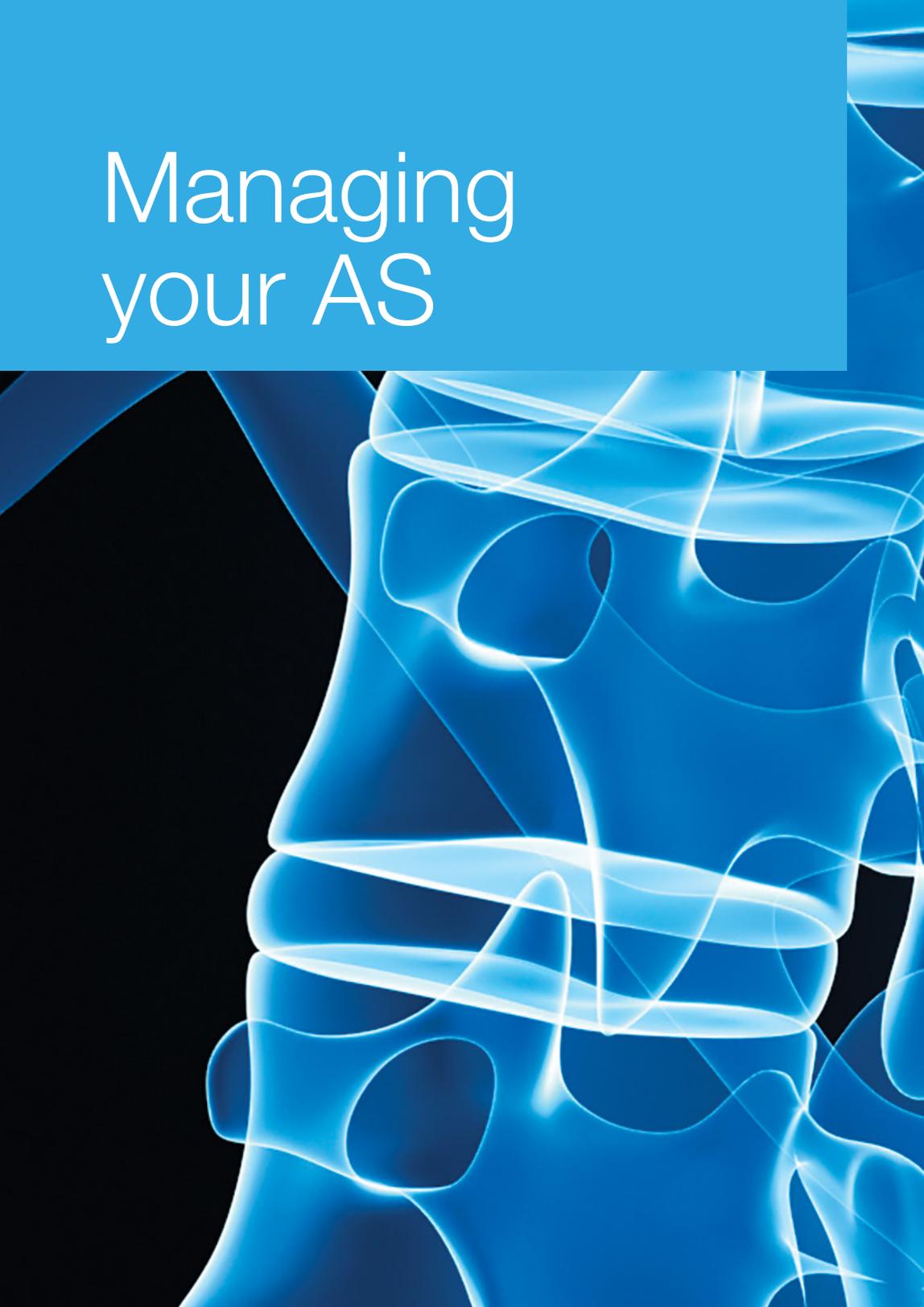
## What can happen over time

AS affects everyone differently, but generally people find that their symptoms come and go over many years. There is currently no cure for AS.

Over time, the lumbar spine can become stiff due to extra bone growth. The upper spine and neck can also stiffen up.

Keeping a good posture and making sure you exercise daily can really help with your long-term outcome.

# Managing your AS



AS is managed by a combination of medication, to reduce the pain and inflammation, and exercise. Optimal therapy is a combination of both.

## MEDICATION

Depending on the severity of your AS symptoms, your doctor may need to give you a combination of medications to help you with the pain, stiffness and inflammation. If you are having a flare-up of your AS, you may want to talk to your GP or rheumatologist about altering your medication. It is important you take your medication as prescribed.

### **MEDICATION: PHARMACOTHERAPY IS KEY TO THE MANAGEMENT OF AS.**

**Non-Steroidal Anti-Inflammatory drugs (NSAIDs):** Non-steroidal anti-inflammatory drugs (NSAIDs) act by blocking the inflammation that occurs in the lining of your joints. They can be very effective in controlling pain and stiffness. Usually you'll find your symptoms improve within hours of taking these drugs but the effect will only last for a few hours, so you have to take the tablets regularly. Some people find that NSAIDs work well at first but become less effective after a few weeks. In this

situation, it sometimes helps to try a different NSAID.

Like all drugs, NSAIDs can have side-effects, so your doctor will reduce the risk of these, by prescribing the lowest effective dose for the shortest possible period of time and selecting the best NSAID based on other health conditions you may have.

NSAIDs can cause digestive problems (stomach upsets, indigestion or damage to the lining of the stomach) so in some cases NSAIDs will be prescribed along with a drug called a proton pump inhibitor (PPI) that will help to protect the stomach.

NSAIDs also carry an increased risk of heart attack or stroke. Although the increased risk is small, your doctor will be cautious about prescribing NSAIDs if there are other factors that may increase your overall risk, for example, smoking, circulation problems, high blood pressure, high cholesterol or diabetes.

The most common NSAIDs prescribed for AS include Naproxen (Anaprox<sup>®</sup>, Naprosyn<sup>®</sup>, various generics), and celecoxib (Celebrex<sup>®</sup>, various generics). Others that may be prescribed include ibuprofen (Advil<sup>®</sup>, Motrin<sup>®</sup>, various generics), diclofenac (Arthrotec<sup>®</sup>, various generics), and ketoprofen (various generics).

**Corticosteroids** are powerful anti-inflammatory drugs that relieve severe pain and swelling. You take them by mouth or in the form of injections into the joint. Corticosteroids are often used for rapid relief of symptoms in cases where only one or a few joints are affected. Steroid injections are often recommended for joints that are particularly troublesome or when ligaments and tendons become inflamed.

Doctors typically prescribe only when really needed. If you use them for a long time, you could have serious side effects such as thinned skin, brittle bones, weight gain, and diabetes.

The most common oral corticosteroids that may be prescribed is prednisone (various generics). For intra-articular injections, methylprednisolone (Depo Medrol<sup>®</sup>, various generics) is most commonly used.

**Disease modifying anti rheumatic drugs (DMARDs):** are the first line of management along with NSAIDs, although they have not been shown to be very effective. These drugs aim to prevent AS from getting worse, and can take up to six months before you may notice any significant change.

For some DMARDs you'll need to have regular blood tests, and in some cases a urine test at regular intervals. The tests allow your doctor to monitor the effects of the drug on your condition but also to check for possible side-effects, including problems with your liver, kidneys or blood count.

You can take NSAIDs along with DMARDs, and some people may need to take more than one DMARD at a time.

There are many DMARDs available the most commonly prescribed is Methotrexate (Metoject<sup>®</sup>, Rheumatrex<sup>®</sup>, Methotrexate Sodium<sup>®</sup>, generics) and Leflunomide (Arava<sup>®</sup>, Generics). A newer DMARD that has been approved is Tofacitinib (Xeljanz<sup>®</sup>) which targets an enzyme responsible for inflammation.

Other DMARDs that may be used in certain situations includes sulfasalazine (Salazopyrin<sup>®</sup>, various generics), azathioprine (Imuran<sup>®</sup>, various generics), hydroxychloroquine (Plaquenil<sup>®</sup>, various generics) and cyclosporin (Neoral<sup>®</sup>, various generics).

**Biologic medications:** Patients with AS may not be adequately controlled by NSAIDs and DMARDs but can be treated by a new class of medications called biologics. These are prescribed by rheumatologists and are injected under the skin or given intravenously and work to prevent inflammation that may result from an overactive immune system. Currently, there are many anti-TNF options such as adalimumab (Humira<sup>®</sup>), certolizumab pegol (Cimzia<sup>®</sup>), etanercept (Enbrel<sup>®</sup>), golimumab (Simponi<sup>®</sup>) and infliximab (Remicade<sup>®</sup>). There are other options

that target IL-17 called Secukinumab (Cosentyx<sup>®</sup>) available which modulates inflammatory response.

**Biosimilars:** New types of biologics have been approved by Health Canada. These are called “biosimilars”. As the name suggests, they are similar (but not identical) versions of a previously approved biologic medication. Biosimilars are modelled after a previously approved biologic but because they are large, complex, and made in living cells introducing some level of natural variation they are not identical. Biosimilars approved for AS include infliximab (Inflectra<sup>®</sup>, Renflexis<sup>®</sup>) and etanercept (Brenzys<sup>®</sup> and Erelzi<sup>®</sup>).

## NERVE PAIN MEDICATIONS

Constant chronic pain can cause changes to the nervous system in some people. These changes may lead to persistent pain symptoms that can be treated differently than pain caused by inflammation. These medications are used to help treat the nerve pathways that lead to the pain sensations some patients experience. The pain that is felt is often described as a sharp, burning, electric shocks, tingling or crawling sensation under the skin.

It is important to understand and be educated on all medications you are prescribed and any over the counter medications you take.

You should discuss with your physician the medications that are available in Canada and which is the best one for you.

**Medical Cannabis:** You and/or your physician may feel that medical cannabis can be an effective treatment option. If you choose to, or are interested in trying medical cannabis, please work with your physician to explore the different compounds of medical cannabis and if they can be helpful in your treatment plan as an effective form of treatment. Please visit our website for more information.

## Analgesics (Pain Killers)/ Opioids:

Your doctor may prescribe other analgesics if pain still persists despite treatment with first line therapies.

## Stay up to date on the latest treatment options

As we discover the number of genes involved along with understanding their functions, it leads to possible new treatment options and new biologic drugs. For an up to date list of these options please visit our website at [www.spondylitis.ca](http://www.spondylitis.ca).

## ARE THERE SIDE-EFFECTS TO TREATMENTS?

There are always potential side-effects with any drugs either topical, oral or intravenous for any illness. Drugs used for the treatment of both AS and psoriasis are no exception. So make sure you discuss fully all prescription and non-prescription

medications you are taking (including vitamins, minerals, supplements, and eye drops) with your health care team. You can then make informed choices about your condition and how they will affect you and your lifestyle.

## CLINICAL TRIALS

A clinical trial is a research study involving volunteers. Trials are conducted according to a detailed protocol that meet research standards mandated by Health Canada. The protocol outlines the reason for the study, the outcomes being evaluated and who is eligible to participate. It also includes the tests and procedures required, the medication(s) being tested; including the dosages and frequency). The protocol also outlines the study duration (how long it will run) and how the results will be analyzed.

Clinical trials are conducted to determine:

- Safety and efficacy of the medication;
  - How it compares to existing medications;
  - The effectiveness of the medication compared to others for a particular group of patients;
  - Alternative ways to use an approved treatment to increase its effectiveness, ease of use, and/or decrease its side effects;
  - Different effects on untested populations (ie. children) of a new medication or approved treatments.
- Clinical trials can provide options for some people under certain circumstances. We encourage you to discuss clinical trials and if you are a candidate with your rheumatologist. As with most treatment therapies, clinical trials have their own benefits and risks.

## Physiotherapy and exercise

*This can have a big effect on the outcome of your AS.*

A physiotherapist can teach you an exercise and stretching routine for daily use and will remind you to be aware of your posture. You should learn how to increase the range of movement of your joints, particularly your spine and hips.

It's important to keep your muscles strong as lack of movement can weaken them, and it may take a long time to build them up again. You also need to learn how to stretch muscles that become shortened.

Cardiovascular exercise can help improve chest expansion, decrease fatigue and improve sleep. Swimming is a great choice – you can wear a snorkel if it helps. Vary your swimming strokes as much as possible, but we would recommend avoiding breast stroke, which puts excessive strain on the neck and lower back. Also, the leg kick can inflame the hips and pelvis. It's best to avoid contact sports and be careful with high impact sports, like running, as they may worsen your symptoms.

You are more likely to keep up with a physical activity if you choose something you enjoy. Whatever the activity, wearing running shoes with an impact absorbing insole will help lessen the jarring on your joints.

*We have included some exercises later on in the guidebook.*

### POSTURE

It's important to keep a good posture. Think tall all day. Stand sideways in front of a full-length mirror. Imagine dropping a weighted string from the top of your head to your feet. Stand so it passes straight down—through your earlobe, shoulder, centre of your hip, behind your kneecap, and in front of your anklebone.

### ALTERNATIVE THERAPIES

Do whatever you find helps, provided it is not likely to damage your spine. Forceful manipulative treatments should be avoided due to the extra bone formation and possible osteoporosis, which may increase your risk of sustaining a fracture.

If you do want to try alternative remedies, please make sure that your practitioner fully understands the nature of AS and is a member of their relevant professional body.

### SURGERY

Surgery plays only a small part in the management of AS. About 6% of people with AS need to have a hip replaced. This can successfully restore mobility and eliminate pain of the damaged joint. In rare cases surgery is used to restore a straighter posture of the spine and neck.

# Living well with your AS

## Get other people involved

People with AS can feel isolated, particularly just after diagnosis. To help you adjust to your diagnosis, it is important that you enlist the support and encouragement of your family and friends. Involve other people, by helping them, to understand about AS and how it affects you. They may even like to improve their own fitness and join you in your exercise and sports activities.

Think about joining your local CSA branch or support group where you'll meet other people with similar issues who will understand.

We also have a forum for CSA members on Facebook (Canadian Spondylitis Association) where you can chat with people who can relate to what you are going through.

## AS and work

Many people with AS continue to have normal working lives.

It's important to get the right advice and support at an early stage so start talking about it sooner than later.

Make sure you keep channels of communication open with your employer. It's hard for people to understand your problems if you do not discuss them.

Some common problems in the workplace for people with AS include:

- Pain and stiffness in the mornings means it is hard to get going first thing and get to work on time
- Sitting in one place or position can lead to pain and stiffness
- Problems with carrying out heavy manual work
- Not having the energy or stamina to work like you used to and getting fatigued easily

Think about asking your employer for a workplace assessment with an occupational therapist or an ergonomist. They may be able to make some simple suggestions that make a lot of difference to your work.

- Discuss swapping certain tasks with colleagues
- Take regular short breaks from work to stretch out

If you are a member of a union at work, approach your union representative to discuss your problems. They can assist you with understanding your rights in the workplace.

Bear in mind that the provincial and federal legislation requires employers to make reasonable changes to working practices or premises to overcome disadvantage caused by disability.

## Tips for employers

**Many people with AS continue to have normal working lives. However, some common problems for people with AS in the workplace include:**

- Pain and stiffness in the mornings means it is hard to get going first thing and get to work on time
- Sitting in one place or position can lead to pain and stiffness
- Problems with carrying out heavy manual work
- Not having the same amount of energy or stamina and getting fatigued easily

### **WE ADVISE EMPLOYERS TO:**

- Arrange a workplace assessment with an occupational therapist or an ergonomist. They may well be able to make some simple suggestions that make a lot of difference
- Allow your employee to take regular short breaks from work to stretch out

## AS and long term disability from work

Some people, depending on the type of work they do and the severity of their condition are unable to work. It's important to keep your rheumatologist informed of how you are managing at work and if you are experiencing any difficulties. Keeping your manager apprised of your condition is important as you may need support and accommodation on your journey. In the event you need to take time off work, your manager and human resources should work with you to manage the process with the insurance company.

## AS and driving

You may have increased pain and stiffness during long drives, so be sure to stop to stretch.

Use a small cushion behind your back to help keep a good position. Make sure your vehicle is fitted with correctly adjusted head restraints as even a relatively small impact can be serious for people with neck problems.

Your provincial law may require your physician to tell your provincial Ministry of Transportation about any condition that may affect your ability to drive safely.

Your province will review the medical information provided by applying the mandatory medical standards found in the Provincial Highway Act and the national medical standards: Canadian Medical Association's 'Determining Medical Fitness to Operate a Motor Vehicle' and Canadian Council of Motor Transport Administrators' medical 'Standards for Drivers'.

Your licence may be suspended or downgraded as a result. You will be provided with a letter advising what type of medical information is required to have your case considered for reinstatement.

## AS and accidents

If you have fusion your spine is more vulnerable to injury. So if you have an accident or fall it's important to take any new symptoms seriously.

Go to Emergency if you have an accident and have:

- New neck pain, or neck pain which is different from usual
- New back pain, or back pain which is different from usual
- Shoulder pain or injury
- Tingling, pain or "pins and needles" in your limbs
- Weakness in your limbs

Be sure to highlight that you have fusion in your back due to your AS and ensure that staff investigate fully. A great way to alert first responders and others is to wear a Medic-Alert bracelet or necklace. We have detailed information on medi-alert on our website.

## AS and your love life

AS should not normally interfere with lovemaking. If, however, you are having problems with your hips, your AS is in a flaring stage, or you have lost a considerable amount of spinal movement, you may need to use your ingenuity to find comfortable and satisfying positions. It is important to discuss these issues with your partner to make sure they understand your feelings. Good communication and a sense of humour will help you maintain a fulfilling sex life.

## AS and pregnancy

If you are planning a family, be sure to discuss it with your rheumatology team in advance. Do not stop taking your AS medication without talking to a rheumatologist first.

Women with AS generally have healthy babies and they carry them to full term.

Having AS does not have a harmful effect on the course of pregnancy or on the well-being of your unborn child. The rate of miscarriage, stillbirth, and small for gestational age infants among women with AS is similar to that of other healthy women. Women with AS are not more likely than healthy women to get pre-eclampsia or to go into premature labour.

During pregnancy the growing baby can pull your spine forward and increase pain when standing up. Use of a maternity support can help spread the weight of the pregnancy.

Try to increase your exercise/stretching program. After the first three months,

and provided your pregnancy is normal and you are supervised by your physiotherapist, hydrotherapy in a warm pool can help.

Sacroiliac joint or hip problems, even including a total hip replacement, should not necessarily stop you from giving birth naturally, although we do know that caesareans are carried out more frequently among women with AS. There are different positions that you can use that would make you more comfortable.

Make an appointment to talk to your anaesthetist in advance about pain relief during your labour. Lots of women opt for an epidural during labour, but sometimes it's not possible for someone with AS to have an epidural, especially if you've had a lot of changes to your spine from new bone formation. Your anaesthetist will be able to tell you about other options.

# Practical advice



## Get a suitable chair

The ideal chair has a firm seat and a high, upright, firm back. A chair with arms will help relieve weight from the spine. The seat shouldn't be too long, as you may have difficulty in placing your lower spine into the back of the chair. It should be at a height that allows you to keep a right angle with knee and hip joints.

Office chairs should be adjustable.

Avoid low, soft chairs and sofas as they will encourage bad posture and increase pain.

## Watch how you sit

Try to move your spine regularly, straighten it out, and stretch it by sitting tall and pulling your shoulders back. Try not to sit for too long. Stand up, walk around, and stretch. If you have a desk job, try a sit/stand desk.

## Choosing a bed

The ideal mattress should be firm and not saggy, but not too hard. Remember there's no single right bed to help your pain, and everyone is different. Take time to choose a mattress and pillow that you personally find supportive and comfortable.

Try to use as few pillows as possible. Choose a pillow that can be molded to suit any position and still give your neck good support.

## Try heat or cold

Many people find a hot bath or shower first thing in the morning or before bed reduces pain and stiffness, especially if you do some stretching exercises at the same time. Hot water bottles, heating pads or electric blankets can be useful in bed.

If you have an inflamed area, an ice pack may help. But take care as ice can burn: do not leave an ice pack in place for more than 10 minutes.

## Eat well

It is important to make sure you maintain a healthy weight as being overweight increases the burden on weight-bearing joints and can increase pain. Try to eat at least 4 portions of vegetables (including at least 1 leafy green vegetable) every day, along with 2 portions of fruit.

Add in protein in the form of fish, beans, pulses, nuts, eggs and meat. Calcium is important for bone health and you need around 700 mg a day – equivalent to 200 mL semi-skimmed milk, a 150 g pot of low-fat yogurt and a small matchbox-sized piece of cheese.

According to research, some AS patients may benefit from a low starch diet.

## Alcohol

Alcohol in moderation is not bad for AS. However, anti-inflammatory medication and alcohol can both affect the stomach lining and should not be taken together.

## Don't smoke

AS can reduce the capacity of the lungs. Smoking can make this even worse, making you more prone to lung infections and shortness of breath.

Research shows that smoking is associated with earlier onset of inflammatory back pain, higher disease activity, increased inflammation on MRI, increased structural damage on MRI and X-ray, poorer function and worse quality of life.

If you smoke, the best thing you can do for your health is to stop.

# Useful exercises

## Occupational therapy

Occupational therapy is a type of health care that helps to solve the problems that interfere with a person's ability to do the things that are important to them – everyday things like:

- Self-care - getting dressed, eating, moving around the house,
- Being productive - going to work or school, participating in the community, and
- Leisure activities - sports, gardening, social activities.

**OCCUPATIONAL THERAPY CAN ALSO PREVENT A PROBLEM OR MINIMIZE ITS EFFECTS AND HELP YOU BETTER MANAGE YOUR CONDITION AND THE IMPACT IT HAS ON YOUR LIFE. YOUR RHEUMATOLOGIST OR PHYSIOTHERAPIST MAY BE ABLE TO RECOMMEND SOMEONE LOCAL TO CONTACT**

## Physiotherapy

A team of healthcare professionals are likely to be involved in your treatment. Your doctor (usually a rheumatologist) will be responsible for your care. You may also see a physiotherapist, who can give you advice on exercises to help maintain your mobility.

### USEFUL EXERCISES

Regular exercise will help you manage your AS better

You should have an assessment from a physiotherapist who will then teach you some stretching exercises specific to your needs. These are a few examples of exercises that can help people with AS.

We have tried to show exercises suitable for most people. If you have any doubts about your ability to carry out any of the exercises, check with your doctor or physiotherapist first. CSA cannot take any responsibility for any problems arising from the exercises shown.

## Warming up

Always warm up before exercising. A warm-up increases the blood flow to your muscles – warming you up! This prepares your body to exercise and makes it less likely that you will injure yourself.

A warm-up could be marching on the spot or using a bottom stair for step-ups. It is always good to stretch as well. Some basic principles for stretching include:

1. DAILY
2. RESPECT THE PAIN
3. SLOW, PROLONGED STRETCH (15-20 SEC)
4. NO BOUNCING
5. BREATHE!

Health Canada recommends the following:

- ≥ 150 MINUTES MODERATE INTENSITY AEROBIC PHYSICAL ACTIVITY/WEEK
- OR
- ≥ 75 MINUTES HIGH INTENSITY AEROBIC PHYSICAL ACTIVITY/WEEK
- OR
- EQUIVALENT COMBINATION OF ABOVE
- PLUS
- MUSCLE STRENGTHENING ACTIVITIES ≥ 2 DAYS PER WEEK

### MODERATE INTENSITY

Brisk walking

Water aerobics

Doubles tennis

Ballroom dancing

General gardening

### VIGOROUS INTENSITY

Race walking, jogging, running

Swimming laps

Singles tennis

Aerobic dancing

Heaving gardening

Hiking up hills/with pack

We have included some exercises suitable for most people. If you have any doubts about your ability to carry out any of the exercises, check with your doctor or physiotherapist.



1



2



3

## POSTURE STRETCH

Stand with your back to the wall, with your shoulders, buttocks and heels as close to the wall as you can manage. Tuck your chin in and push the back of your head towards the wall. Keep your shoulders down.

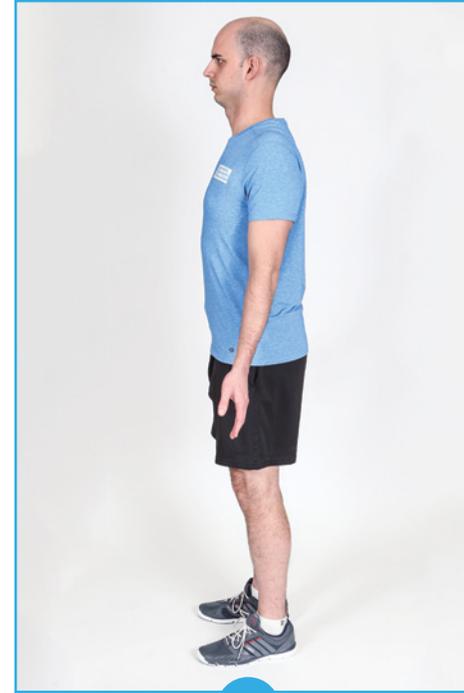
Stretch as tall as possible without lifting your heels.

Slowly raise both arms to the sides, keeping the backs of your hands against the wall.

Try to keep your buttocks in contact with the wall.

Slowly lower.

REPEAT  
**x5**



1



2

## TRUNK SIDE STRETCH

Keeping your buttocks and shoulders against the wall, slowly stretch your right arm down the outside of your leg as far as you can. You should feel a comfortable stretch. Repeat on the left.

REPEAT  
**x3**

## PELVIC TILTING

Lie down with your knees bent and with your head supported if required. Tighten your stomach muscles, pushing your back down into the floor. Hold for a count of 5.

Remember, this is a very small movement.

REPEAT  
**x5**



## BACK AND HIP ROTATION

Lie on your back with your knees bent and your arms out to the side.

Keeping your knees together, slowly lower your knees to the right, back to the centre, and then down to the left.

Try to keep your knees together and both shoulders on the floor.



REPEAT  
**x5**



## NECK ROTATION

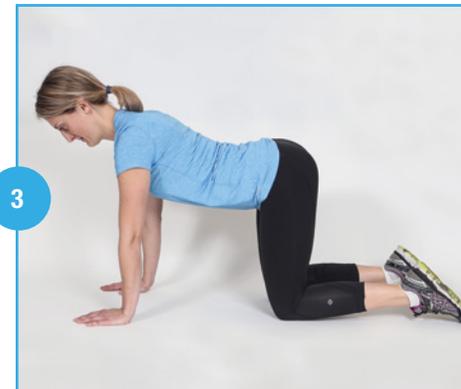
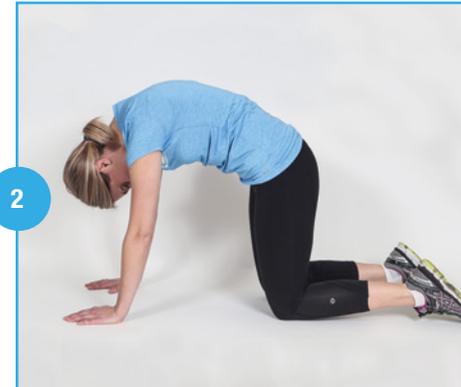
Sit upright in good posture and with both feet flat on the floor.

Hold the sides of your chair seat.

Turn your head to the right as far as possible without letting your shoulders turn. Repeat to the left.

This is an exercise we'd recommend you try to do every day, especially if you sit at a desk.

REPEAT  
**x3**



## CAT STRETCH

Kneel on all fours. Keep your hands shoulder width apart and directly under your shoulders. Keep your knees hip width apart and directly under your hips.

Keeping your elbows straight throughout, tuck your head down between your arms and slowly arch your back as high as possible.

Now lengthen your neck, keeping your nose parallel to the floor, and hollow your back as much as possible.

REPEAT  
**x5**



1



2

## SUPERMAN STRETCH

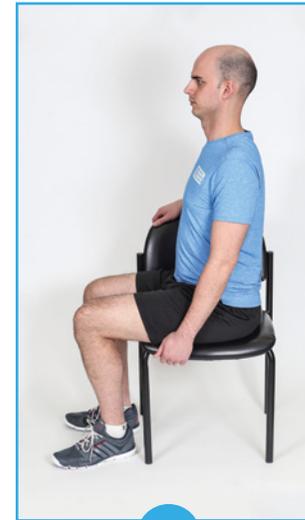
Go back to your starting position for the cat stretch.

Keeping your head in the same position, raise your right arm and your left leg.

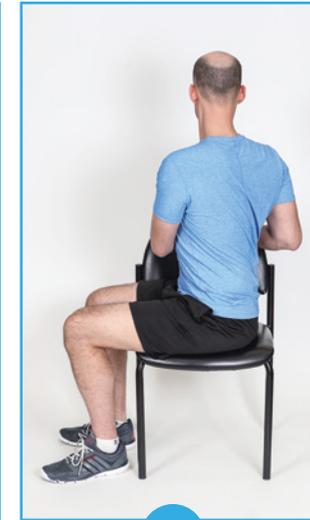
You are aiming to make a straight line with your body from your right hand to your left foot. Hold for 5 seconds.

Return, with control, to the starting position and change to raising your left leg and right arm.

REPEAT  
**x3**



1



2



3

## TRUNK ROTATION

Sit sideways on an armless chair in good posture.

Keeping your feet firmly planted on the floor, twist your upper body towards the back of the chair, and place both hands on the chair back.

Use your hands to help you rotate a little further around, keeping your good posture throughout.

Repeat on the opposite side.

REPEAT  
**x1**



## HAMSTRING STRETCH

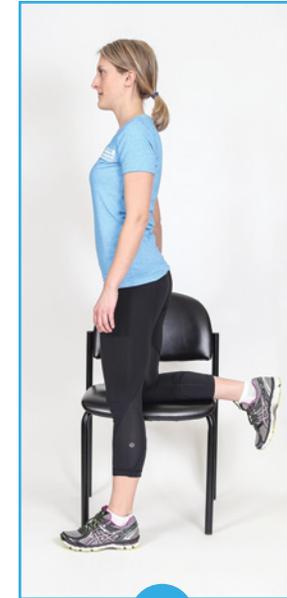
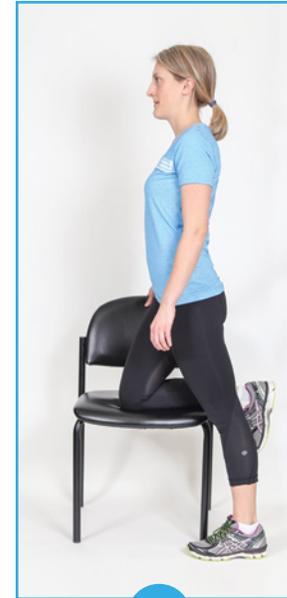
Move forwards so that you are sitting towards the front of your chair but still feel safe.

Straighten out your left leg with the heel resting on the floor.

Keeping your back straight, slide your hands gently down the front of your thigh. You should feel a good stretch in the back of your thigh. Try to hold the position for 10 seconds.

Repeat on the right leg.

Our top tip for this exercise is to make sure you are keeping your back straight and not rounding down over your leg.



## HIP FLEXOR STRETCH

Stand up facing the side of an armless chair and hold the chair back with your right hand.

Bend your right knee and place your right shin on the seat.

Move your left foot as far forward as possible, keeping your spine neutral (perform a posterior pelvic tilt to do this).

Bend your left knee as much as possible, keeping a good posture and straight back. You should feel a good stretch at the front of your right hip.

Hold it for a count of 10. Relax and then repeat twice, trying to stretch a little further each time.

Turn around to face the other side of the chair and repeat with the opposite leg.



## Resources

Useful websites:

### CANADIAN

Canadian Spondylitis Association [www.spondylitis.ca](http://www.spondylitis.ca)

The Arthritis Society [www.arthritis.ca](http://www.arthritis.ca)

Arthritis Consumer Experts [www.jointhealth.org](http://www.jointhealth.org)

RheumInfo [www.rheuminfo.com](http://www.rheuminfo.com)

Spondyloarthritis Research Consortium of Canada [www.sparcc.ca](http://www.sparcc.ca)

Canadian Arthritis Patient Alliance [www.arthritispatient.ca](http://www.arthritispatient.ca)

Arthritis Research Canada [www.arthritisresearch.ca](http://www.arthritisresearch.ca)

Arthritis Alliance of Canada [www.arthritisalliance.ca](http://www.arthritisalliance.ca)

Canadian Rheumatology Association [www.rheum.ca](http://www.rheum.ca)

### AMERICAN

Spondylitis Association of America [www.spondylitis.org](http://www.spondylitis.org)



## AS Health Storylines

Created with input from people with ankylosing spondylitis (AS) so that the right health tools are available to you.

Now it's easy to record your symptoms, fatigue levels, moods and more. Choose what you want to track to build your own summary "My Storylines" to learn more about your health, and to share more – safely and securely – with your doctor about what happened between visits.

Choose from the following health tools to better manage and monitor your AS or associated spondyloarthritis disease:

#### FATIGUE TRACKER:

Monitor your fatigue levels to learn more about your energy patterns.

#### BUILD ROUTINES TO HELP MANAGE YOUR PAIN:

Create routines and get reminders for exercising and taking breaks to relieve pain and stiffness.

#### MEDICATION TRACKER:

Track your medications and get reminders to help you take your medications on time.

#### SYMPTOM TRACKER:

Track symptoms and side effects to see patterns that you may need to share with your doctor.

#### SYNC A DEVICE:

Import data from other health and fitness apps that you use.

#### DAILY MOODS AND JOURNAL:

Track and understand your emotions and what might be driving them. Keep a journal as it has been shown to increase well-being.

#### FOOD DIARY:

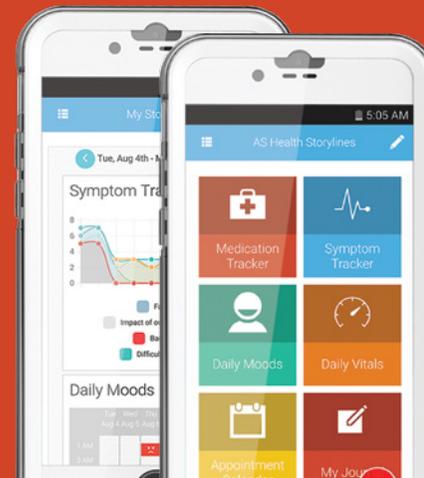
Track foods you eat and any reactions triggered if you have related Inflammatory Bowel Disease (IBD).

AS Health Storylines is developed in partnership with the Canadian Spondylitis Association, and is powered by the Health Storylines™ platform from Self Care Catalysts Inc.

Get the FREE APP now on the Apple App Store and the Google Play store.



You can also use the web version on your computer at [as.healthstorylines.com](http://as.healthstorylines.com).





This version edited by Dr. Richard Jacoby, Professor Paul Wordsworth and Claire Harris (AStretch) MARCH 2015.  
Reprinted May 2018.

Canadian version produced with the kind permission of National Ankylosing Spondylitis Society. Additional Canadian content provided by CSA medical advisors: Dr. Robert Inman (Rheumatologist), Dr. Nigil Haroon (Rheumatologist) and Brandon Wren (Pharmacist)

Print and distribution supported by UCB Canada Inc.

For more information, visit [www.spondylitis.ca](http://www.spondylitis.ca)  
Contact us at [info@spondylitis.ca](mailto:info@spondylitis.ca)

*All advice and information are provided for your general knowledge only and is not a substitute for the advice from and care by health professionals. Please consult your health care professional regarding details of symptoms, diagnosis and medication or treatment. Any information or links do not imply endorsement.*