

What Is Ankylosing Spondylitis (AS)?



**Spondylitis
Association
of America™**

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Spondylitis: A family of related diseases

- **Ankylosing Spondylitis (AS)**
- Enteropathic Arthritis
- Psoriatic Arthritis (PsA)
- Reactive Arthritis (ReA)
- Undifferentiated Spondyloarthritis (USpA)



Information in this brochure cannot replace treatment provided by health care professionals. If you have questions as you read, it is important to consult further with your doctor.

The Spondylitis Association of America (SAA), in partnership with Abbvie Inc., has produced this brochure to provide you with practical information about ankylosing spondylitis (AS).

Whether you have AS or someone close to you has received this diagnosis, the disorder and its associated social, functional, and economic consequences make disease management an important issue. It is especially important to take charge of the disease, since the experts agree that taking an active role in managing the condition, backed by a sound knowledge base, can have a positive influence on its outcome. Thus, it is our hope that this pamphlet will make a solid contribution to that effort and provide important tools and valuable knowledge about AS.

Abbvie Inc., in partnership with the Spondylitis Association of America, is committed to advancing care by pioneering meaningful ways to help patients and the health care professionals who treat them.

What Is Ankylosing Spondylitis (AS)?

AS is a rheumatic disease (arthritis) that primarily affects the spine. It is one condition among a group of diseases called spondyloarthritis (SpA) or spondylitis. Though AS primarily affects the spine, other parts of the body can be involved.

All forms of spondyloarthritis, including AS, are chronic diseases. Hence, a person currently diagnosed with AS, given today's knowledge, will have it to some degree for the rest of his or her life. Although there is no cure for AS, there is much that can be done to help. Many important advances have been made in understanding the condition and treating it.

Classic Symptoms of Ankylosing Spondylitis

It is important to note that the course of ankylosing spondylitis varies greatly from person to person. This is also true of the onset of symptoms.

Typically, the first symptoms of AS are frequent pain and stiffness in the lower back and buttocks, which comes on gradually over the course of a few weeks or months. Sometimes this pain and stiffness can be severe. At first, discomfort may only be felt on one side, or alternate sides. This pain and stiffness is usually worse in the mornings and during the night, but may be improved by a warm shower or light exercise.

Pain and stiffness in other areas of the body, such as the shoulders, the ribs, hips, knees, and heels, may also be present.

Note that AS can present differently at onset in women than in men. Quoting Dr. Elaine Adams, "Women often present in a little more atypical fashion, so it's even harder to make the diagnoses in women."



Early Warning Signs

- Morning stiffness of the spine
- Duration of back pain is longer than 3 months
- Pain worsens gradually
- Under 40 years of age at onset
- Some improvement with exercise

Who Gets AS?

It is estimated that 1 out of every 200 adults (1.1 million people) has AS in the United States alone. Traditionally thought of as a "male" disease and more common in men than women, it is now thought that the ratio of men to women with the disease may be 2:1 or even 1:1. AS can occur early in life in juveniles and teens, or as late as age 40 to 50, but it usually begins in people in their 20s or 30s.

For a long time, researchers suspected that AS had a hereditary component, since about 20% of people with AS also have a family member with the disease. Then, in 1973, scientists found an association between the genetic marker HLA-B27 and AS. While the marker is found in 8%-9% of the general Caucasian population, more than 90% of Caucasian patients with AS will have the HLA-B27 gene. This means that HLA-B27 is a relatively common marker found in people who will never develop AS, but that a high proportion of people with AS have the marker. Thus, identifying the HLA-B27 gene itself does not diagnose AS, but can be an important clue in the diagnosis.

Although HLA-B27 does not by itself cause AS, it is thought by most researchers to possibly have a role in triggering the disease. However, as of yet, none of the proposed theories have been proven to fully explain the association between HLA-B27 and AS.

Diagnosis of AS

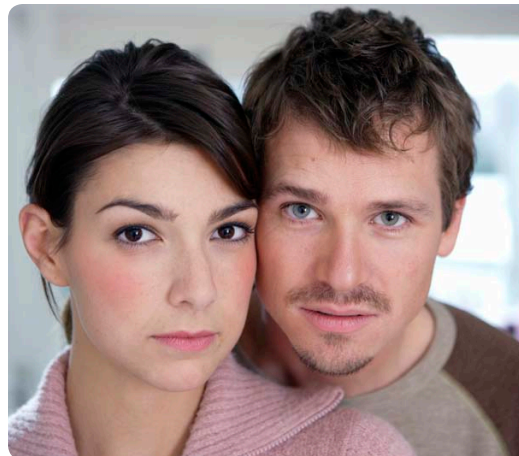
A rheumatologist is commonly the type of physician who will diagnose ankylosing spondylitis, since they are doctors who are specially trained in diagnosing and treating arthritic diseases. A thorough physical exam, including x-rays, individual medical history, and a family history (especially a family history of AS), as well as blood work including a test for HLA-B27, are factors in making a diagnosis.

The overall clinical points taken into account when making an AS diagnosis are:

- Onset is usually under 35 years of age
- Pain persists for more than 3 months (i.e., it is chronic)
- The back pain and stiffness worsen with immobility, especially at night and early morning
- The back pain and stiffness tend to ease with physical activity and exercise
- Positive response to NSAIDs (nonsteroidal anti-inflammatory drugs)

A physical examination will entail looking for sites of inflammation. Thus, the doctor will likely check for pain and tenderness along the back, pelvic bones, sacroiliac joints (where the spine meets the pelvis), chest, and heels. During the exam, the doctor may also check for limitation of spinal mobility in all directions and for any restriction of chest expansion. To make a definitive diagnosis of AS, your doctor will look at an x-ray of your pelvis and spine.

Other symptoms and indicators are also taken into account, some of which are reviewed on page 9.



Ankylosing Spondylitis & Inflammation

Inflammation plays a big role in AS. The hallmark of AS is involvement of the sacroiliac (SI) joint. This is the joint at the base of the spine, where the spine and pelvis meet. Sacroiliitis is the inflammation of the sacroiliac joints.

Research into the nature of inflammation has revealed that the inflammation itself can cause injury by releasing powerful chemicals that actually damage the surrounding tissues. In AS, inflammation occurs at the entheses. This is the site where ligaments and tendons attach to the bone. Over time, some of this inflammation may go away or resolve. As the inflammation resolves, the areas that are injured begin to heal by forming scar tissue. This scar tissue can lead to new bone growth in areas where none usually exists. Exercise and medication can't prevent AS, but they can help to relieve the symptoms associated with the disease, including pain and stiffness.



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How AS Affects a Person: Associated Complications & Disease Progression

Many complications are associated with AS. It is important to be aware of and discuss these potential complications with your doctor. Always contact your doctor if you notice any new symptoms in any part of the body. Referral to specialists to manage these complications may be necessary.

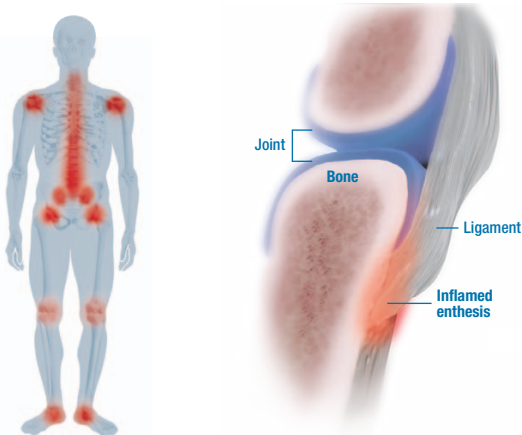
Other areas of the body can also become involved. Enthesitis (inflammation where the ligaments attach to the bone) can be felt in multiple areas of the body, (see enthesitis image on page 10). The sites are sometimes referred to as “hot spots.” Symptoms of enthesitis include swelling and tenderness at sites such as along the spine, where the spine meets the pelvis, the chest, and the heel.

Fatigue

Fatigue is a common complaint in AS. There are several known explanations for this. Fatigue can be a by-product of inflammation. If inflammation is extensive, then the body must use energy to deal with it. The release of certain cell messengers (cytokines) during the inflammatory process can produce the sensation of fatigue. These effects, along with disturbed sleep due to uncontrolled pain, may contribute to fatigue. It is important to tell your doctor if you feel fatigued or especially tired. Your doctor can work with you to help manage your fatigue.

Enthesitis

AS often affects the area where connective tissues, such as ligaments and tendons, attach to bone. This area is called the **enthesis**. Enthesitis is **inflammation** at those areas.



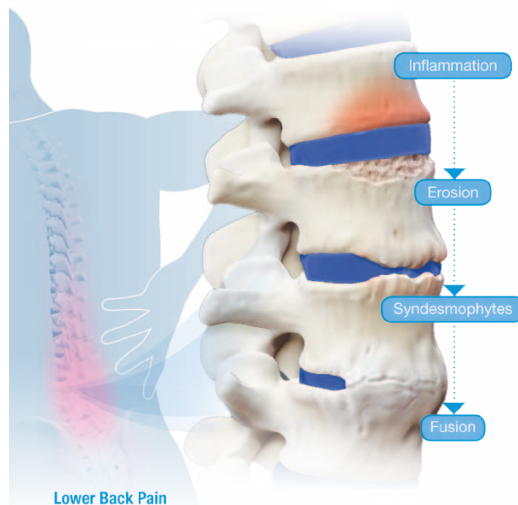
Common sites for pain associated with enthesitis

People with AS may feel pain in places such as the pelvis, along the spine, and the heels. Enthesitis of the heel may make mobility difficult for a patient

What Is “Fusing”?

In people with severe disease, the process of inflammation can lead, over many years, to a fusion of the bones in the spine and sometimes in other joints as well. This is called “ankylosis” which means “joining together.” This can reduce spinal mobility and lead to an increased risk of fracture because the new bone formed during fusion is inherently weak. Keep in mind, not everyone will progress to this advanced stage of AS. See the image on page 11 to see how fusion may progress over time.

Disease Progression



In severe disease, inflammation can lead to fusion of bones in the spine

Interventions and Treatment

Along with exercise and good posture habits, nonsteroidal anti-inflammatory drugs (NSAIDs) are the cornerstone of treatment and often work well for many people with AS. If NSAIDs are not capable of reducing your symptoms sufficiently, your doctor may suggest that you try a biologic (TNF-blocker). These drugs can be effective in treating signs and symptoms of active AS, such as pain and stiffness, although not everyone needs these types of drugs or will benefit from them. Your doctor may also consider other medications such as sulfasalazine for pain and swelling in your peripheral joints or corticosteroids to help reduce pain and inflammation.

All medications have side effects. Be sure to discuss the risks and benefits of your treatment options with your doctor to develop the most appropriate management plan for your AS.

To find out more about AS and related conditions, visit the SAA website at www.spondylitis.org.

Why Exercise Is So Critical in AS

According to doctors and patients alike, appropriate levels of exercise can be helpful in reducing pain and stiffness. However, pain relief isn't the only reason to exercise. The arthritis associated with AS and related conditions may limit your mobility and flexibility. Exercise can also help with this, counteracting some of the physical limitations that the disease can cause to your life. Exercise can contribute to many health benefits and can help retain flexibility, as well as reduce pain and stiffness. It's important to talk with your doctor before beginning an exercise program to determine what's appropriate for you.

We invite you to read our pamphlet, *The Role of Exercise in Spondyloarthritis*, for more detailed information on the benefits of exercise. To order, visit www.spondylitis.org.

Make Exercise Work for You



Morning Stretch. If you typically experience stiffness in the back or pain in the joints in the morning, this may be a good time to loosen up. You can do stretches to loosen up and save the range of motion exercises for later in the day after your stiffness lessens.

Make It Fun. If you don't like to exercise, be creative: exercise to your favorite music, or exercise with a friend.

Start Slowly. If you're afraid moving will hurt, start very, very slowly with gentle stretching and range of motion exercises.

Make Time. If you can't spare a big block of time all at once, try working in 15 minutes twice a day.

Be Comfortable. Wear comfortable clothing and try to relax by counting out loud. This helps with your breathing. Why is this important? Because relaxed tissues stretch more easily.



Talk to your doctor about which exercises are appropriate for you.

Warm Up

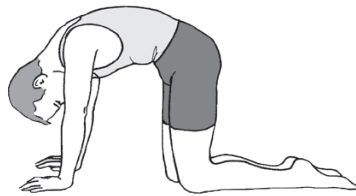
Only work within the limits of comfort

Vigorous marching on the spot for one minute with high stepping and arms punching upward for 20 seconds, forward for 20 seconds, and sideways for 20 seconds.

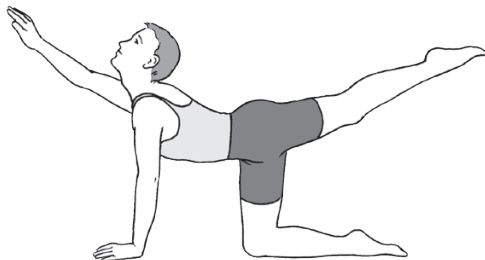
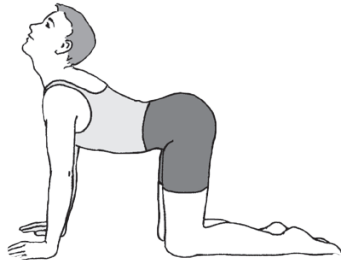
Stretching Exercises

Only work within the limits of comfort

Kneel on all fours. Keeping your elbows straight throughout, tuck your head between your arms, and arch your back as high as possible.



Lift your head and hollow your back as much as possible.

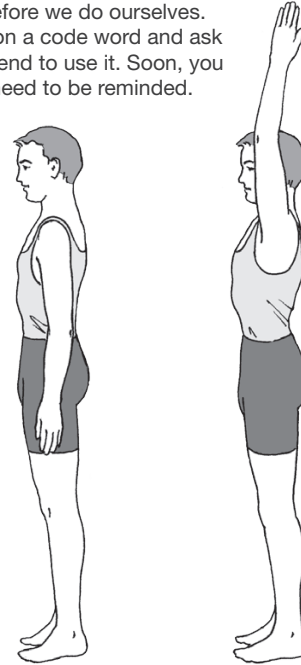


Keeping your head up, raise your right arm forward as you raise your left leg backward as high as possible. Hold for 5 seconds. Return to all fours and change to raising your left arm and right leg.

Exercise and Posture

Only work within the limits of comfort

Give someone close to you permission to nag. Often those around us notice bad habits, such as slouching, long before we do ourselves. Agree on a code word and ask your friend to use it. Soon, you won't need to be reminded.



Stretch up as tall as possible without lifting your heels. Hold this position. Raise your right arm forward and upward while keeping your elbow straight, your upper arm close to your ear, and your thumb toward the wall. Lower and repeat with opposite arm.

Daily Posture Exercise

Only work within the limits of comfort

Prone lying (laying on your stomach). Experts believe that this single activity alone can prevent postural deformity from developing into a forward stooped position. It will not prevent the fusing of the vertebrae, which can occur later in severe forms of AS, but should fusing occur, this activity can help with ensuring an erect position is maintained. Make it part of your daily routine. The best time to do the prone lying down might be after a warm bath in the evening when your muscles are warm and relaxed. Consistency is key.

Surgical Options

In some people, when the arthritis associated with AS is severe, it can cause destruction of the joint cartilage. When this occurs, particularly in the knees and hips, surgical joint replacement with artificial joint components can be effective in alleviating pain and restoring function to the severely damaged joint. It should be noted, however, that surgery is rarely used in the management of spondylitis, and that the decision to undergo a surgical procedure should be mutually agreed upon by the doctor and patient. In more rare, severe cases, AS can be associated with severe flexion deformity (severe downward curvature) of the spine, particularly in the neck. Surgical correction (lumbar osteotomy) is possible, though this procedure is considered risky, and should only be attempted by surgeons who have extensive experience with this procedure in people with AS.

What Is the Role of the Rheumatologist?

Rheumatologists are doctors with additional specialized training in treating rheumatic diseases (arthritis). There are more than 100 rheumatic diseases. Some examples include ankylosing spondylitis, rheumatoid arthritis, and lupus.

The role of the rheumatologist is to make a diagnosis and to facilitate the management and monitoring of the patient's disease. Toward this aim, the rheumatologist advocates for the patient. He or she educates the patient, the family, and the community. The rheumatologist takes an active role in teaching not only medical information, but also techniques for preventing disability and appropriate coping mechanisms.



To help you, the SAA has developed a free booklet entitled *Member-to-Member Recommended Rheumatologists Directory*. The booklet is a listing of board-certified rheumatologists who have either been recommended by other patients or who have demonstrated a special interest in SpA and have asked to be included in the directory. E-mail us at info@spondylitis.org to request a free copy of the directory.

What Is the Role of Diet in AS?

In recent years, many specialized diets have gained popularity among people with arthritis.

Foods affect everyone differently. If you think that you are affected either negatively or positively by certain foods, try keeping a food diary for a while to keep track of results. If you plan to do this, it might be helpful to also remember that in SpA, just like in many other forms of inflammatory arthritis, the symptoms can come and go without an apparent explanation. This situation can make it difficult to track such patterns over a short period of time. Make sure to talk to your doctor about an appropriate, well-balanced diet.

Seeking Support

Connecting with others who understand and can relate to our struggles is a universal human desire. We seek out people who have been through what we have, often simply to tell our stories and hear them say “me too!” or “I know what that’s like.” To know that we’re not alone in managing disease and that someone else understands can provide a source of strength and help with coping.

The Spondylitis Association of America’s Connections Program provides a number of ways you can connect with others who understand. Support groups, social networking, message boards, seminars, webinars, and more are ways you can seek support and information about ankylosing spondylitis. For more information, visit SAA’s website at www.spondylitis.org/connect.



Outlook for the Future

Discoveries in the past few years have yielded numerous genetic clues to further understand ankylosing spondylitis. As new genetic factors associated with AS are discovered, there is potential for new diagnostic tests as well as treatment approaches.

Benefits of Membership

The Spondylitis Association of America was the first, and remains the largest, resource in the U.S. for people affected by spondylitis. For more than 20 years, the SAA has dedicated all of its resources to funding programs and research that directly benefit the spondylitis community.

By joining the SAA, you can gain valuable knowledge while helping hundreds of thousands of people throughout the nation. **Join today and receive:**

- A subscription to *Spondylitis Plus*, the only national magazine dedicated to your unique needs
- SAA's *Member-to-Member Recommended Rheumatologists Directory*
- Access to the "Members Only" section of www.spondylitis.org
- A complimentary copy of our guidebook, *Your Guide to Living with Ankylosing Spondylitis*
- The satisfaction of knowing that you are part of an extraordinary community of patients, friends, family, and health professionals who are all dedicated to advancing our knowledge and expanding treatment options for spondylitis

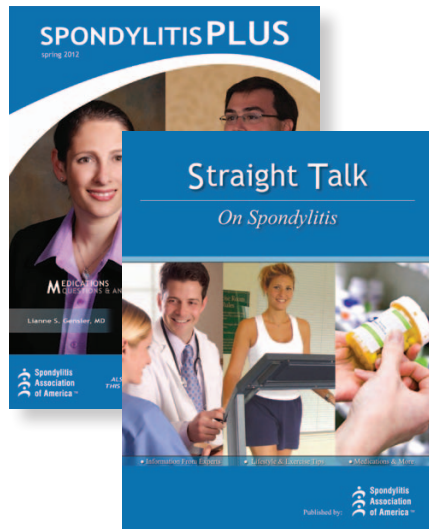


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The Spondylitis Association of America acknowledges with great appreciation the expertise and guidance of the Medical and Scientific Advisory Board with regard to its programs and educational materials, and thanks AbbVie Inc. for its support in the creation of this educational brochure.



How do I become a member?

It's easy. Call toll-free
at **1-800-777-8189**
to speak with our friendly
staff or join online at
www.spondylitis.org

Your membership support makes you a partner
in the national force to fight AS and related
diseases, and ensures that no one has to face
these diseases alone. Thank you!



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