A FAMILY OF RELATED DISEASES

- ANKYLOSING SPONDYLITIS
- ENTEROPATHIC ARTHRITIS
- PSORIATIC ARTHRITIS
- REACTIVE ARTHRITIS
- UNDIFFERENTIATED SPONDYLOARTHITIS
- JUVENILE SPONDYLOARTHITIS
The Spondylitis Association of America (SAA) has produced this brochure to provide practical information about ankylosing spondylitis in women and to help dispen the myth that AS is a “man’s disease.”

Many of the characteristics of AS in women are similar to those in men; however, there are differences. Some of these differences have been scientifically documented and are recorded in the medical literature, but others are not yet well understood. That said, there is hope that current studies being conducted in this area by dedicated researchers will soon be able to shed more light on these issues.

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

The Spondylitis Association of America acknowledges with great appreciation the expertise and guidance of its Medical and Scientific Advisory Board with regard to its programs and educational materials.

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ANKYLOSING SPONDYLITIS IN WOMEN

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, will 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 in the quest for optimal health.

AS is a rheumatic disease (arthritis) and is one condition among a group of related diseases called spondyloarthritis or spondylitis. Although AS primarily affects the spine, other parts of the body can be involved. That is why AS is called a systemic disease – meaning that it can affect the whole body.

All forms of spondyloarthritis (SpA), 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. In recent times, important advances have been made in understanding the condition and treating it much more effectively than in the past.

WHO GETS AS?

It has been estimated that at least 1.7 million people in the U.S. have AS. It appears to be more
common in men and less common in both genders in Americans of African descent. AS can occur as early as the teenage years, or as late as age 40 to 50, and more rarely in children, but it usually begins in people in their 20s and 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 Caucasian population, over 90% of patients with AS will have the HLA-B27 gene. This can be confusing to understand. What it really means is that HLA-B27 is a relatively common marker found in people who will never get AS, but that a high proportion of people with AS have the marker. Thus, identifying the marker is not, on its own, diagnostic.

While HLA-B27 does not by itself cause AS, most researchers believe that it plays a role in triggering the disease. One theory suggests that the presence of the gene in the human body may cause certain types of bacteria to thrive and to remain in the body a long time. This theory claims that the persistent presence of these bacteria may result in the type of inflammation that can lead to new bone formation; that is, bone formation where it would not normally exist. Another theory is that HLA-B27 may interact with other proteins and alter the body’s immune response. There is a great deal of work being conducted worldwide to explore these and other theories in regard to what causes AS. Many researchers believe that bacteria are an important component.

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Contrary to outdated beliefs, ankylosing spondylitis is NOT a so-called “man’s disease.” As of the printing of this brochure, the most recent information suggests that the male-to-female ratio of people who have AS is beginning to be more realistically documented, and now stands at 2:1. It is also now known that AS can be just as severe in women and children as it is in men.

**HOW DOES AS IMPACT WOMEN?**

In general, it takes longer for a woman to be diagnosed with AS than it does for a man. It has been suggested in recent studies that AS can initially affect different parts of the body in women (neck, peripheral joints) than in men (low back, spine). In addition, one might speculate that the
primary reason for a delayed diagnosis in women may be that oftentimes doctors are not *looking for*, and so do not find, AS in women. Thus, we hope that via wide dissemination of this brochure and additional outreach efforts, we will start to bring about change in this regard.

The average age of mean onset, 23 years, does not differ significantly between the sexes, but spinal fusion (ankylosis) may progress more slowly in women than in men. According to recent studies, women tend to be worse off than men when it comes to pain and the need for drug therapy. A reduction in pain after the fusing of the vertebrae is experienced by some people, perhaps as a result of

**HOW IS AS DIFFERENT IN WOMEN AND IN MEN?**

The average age of mean onset, 23 years, does not differ significantly between the sexes, but spinal fusion (ankylosis) may progress more slowly in women than in men. According to recent studies, women tend to be worse off than men when it comes to pain and the need for drug therapy. A reduction in pain after the fusing of the vertebrae is experienced by some people, perhaps as a result of
less inflammation in the region of the spine. Therefore, the slower and relatively incomplete progression of spinal fusion in women can mean that it takes considerably longer for pain to decrease as a result of spinal fusion.

Research studies suggest that early symptoms in women with AS often include peripheral arthritis, acute anterior uveitis, psoriasis, and inflammatory bowel disease.

Women may have more frequent family histories of AS in first-degree relatives, i.e., their parents and siblings. And among patients with longstanding AS, it is the men that appear to have more severe changes on X-ray examinations.

INTERVENTIONS AND TREATMENT

Along with exercise and good posture habits, nonsteroidal anti-inflammatory drugs (NSAIDs) are the cornerstone of treatment and work well for up to 50% of people with AS. If NSAIDs are not capable of reducing your symptoms sufficiently for you to be able to function properly in your everyday life, your doctor may suggest that you try a biologic medication, such as a TNF inhibitor. These drugs can be remarkably effective in treating moderate to severe AS, although not everyone needs them or will benefit from them.

To find out more about treatments for AS, we invite you to read our pamphlet What Is Ankylosing Spondylitis, or visit our website at www.spondylitis.org.
According to doctors and patients alike, exercise is amazingly effective in controlling pain. However, pain relief isn’t the only reason to exercise. The arthritis associated with AS and related conditions may try to rob you of mobility and flexibility. Exercise is the antidote to this, counteracting the creeping control that the disease can impose on your life. With exercise a person is empowered, has less stiffness, more flexibility, better quality of sleep, weight control, a healthier heart, and an improved sense of well-being. We are not suggesting that you get up and train for a marathon, just that you will feel better if you start a daily strengthening and stretching routine. Remember that it is your doctor’s job to help control the pain, inflammation, and stiffness so that you can maintain a healthy exercise program that will lead to better pain control for most people. Therefore, it is important not to minimize your pain when seeking treatment from your physician.

We invite you to read our pamphlet, The Role of Exercise in Spondyloarthritis, for more detailed information in regard to how regular exercise can help you.

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MAKE EXERCISE WORK FOR YOU

TIP

MORNING STRETCH. If you are typically stiff 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.
EXERCISES

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, forwards for 20 seconds and sideways for 20 seconds.

STRETCHING EXERCISES

*Only work within the limits of comfort*

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

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

3. Keeping your head up, raise your right arm forwards as you raise your left leg backwards as high as possible. Hold for five seconds. Return to all fours and change to raising your left arm and right leg.
EXERCISES

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.

**1. Stretch up as tall as possible without lifting your heels. Hold this position. Raise your right arm forwards and upwards while keeping your elbow straight, your upper arm close to your ear, and your thumb towards 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 activity can help prevent postural deformity from developing into a forward stooped position. It will not prevent the fusing of the vertebrae which often occurs in more advanced AS, but should fusing occur, this activity will increase the likelihood that 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.
There are several aspects of this disease only now becoming more widely appreciated in the medical community that have major implications for its treatment. As happens so often, this has occurred following the application of advanced technology, in this case Magnetic Resonance Imaging (MRI). This technology has enabled us to better understand why patients with AS have a more fragile skeleton despite the overgrowth of bone that is so typical of this disease. This, in turn, has led to the introduction of additional therapeutic approaches for the disease.

Why do patients with AS have a more fragile skeleton? It is of some considerable interest that this was first noted almost a century ago when post-mortem analysis of spines was the only available approach to conducting research in this disease. Several pathologists remarked on the fact that cutting through the bones of patients with AS was like cutting through putty — the knife met no resistance whatsoever. These observations were largely forgotten and/or ignored until the modern era of advanced radiological imaging techniques and molecular immunology.

The introduction of MRI showed several interesting findings that readily helped to show just how different AS is from rheumatoid arthritis (RA). Although AS patients understand that, like RA, this is an inflammatory disease of the joints, what is not well appreciated is that the major site of inflammation is in the bone next to the joint. We call this an osteitis, which means inflammation in...
bone. Very often, MRIs from AS patients show minimal inflammation in the joint but striking inflammation in the bone next to the joint. This is different from RA, where inflammation within the joint is the major feature of the disease. In addition, what is essentially unique for AS is that this inflammation in bone is also typically seen where ligaments and tendons attach to the bone.

A classic example would be the Achilles tendon attachment to the heel bone. Examples have been seen where the entire heel bone is inflamed. These patients often receive cortisone injections around the Achilles tendon with little benefit. This is not surprising since the major source of pain and inflammation is actually within the heel bone. Another example is the shoulder. This is a problem that is not well recognized by medical practitioners and often dismissed as “bursitis” or “tendonitis.” These patients also have inflammation within the bone where the shoulder tendons attach to the
point of the shoulder. Cortisone injections around the tendon are unlikely to be of benefit for many patients because the major site of inflammation is within the bone. These same features are observed on MRIs in the spines of patients with AS. The major site of inflammation is within the bone of the vertebrae.

If this local inflammation in the vertebrae is not checked, it will ultimately cause severe loss of bone mineral, resulting in fragile bones. But there is also a second way in which patients with AS can get fragile bones.

We now know that severe inflammation — wherever it exists — causes the release of certain chemicals into the blood that activate cells in bone that can literally dissolve bone mineral. These cells are called osteoclasts. They are normally present in bone but are only activated periodically when bone undergoes re-modeling in response to the stresses of various activities, e.g., sports. These cells secrete acid, which dissolves bone very efficiently. It is therefore understandable that the body keeps these cells under tight control — most effectively by secreting sex hormones, which typically shut these cells down. This is why menopause is a precarious period for the bones of women. The rapid decrease in sex hormone production results in the activation of osteoclasts — as if they are emerging from a period of hibernation. Women then become at high risk for osteoporosis. Long-standing inflammation also causes persistent activation of osteoclasts.

**HOW DOES THIS OCCUR?**

Inflammation, whether it occurs in the joints, the intestine, or the lungs, causes the release of a
variety of molecules into the blood. Some of these cause an elevation of body temperature, others cause fatigue, and still others cause persistent activation of osteoclasts. This is why RA is a major risk factor for osteoporosis and fractures of the spine, even though the inflammation of RA does not occur within the spine other than the neck. Similarly, chronic inflammation of the bowel — colitis — also results in osteoporosis and an increased risk for fractures of the spine and hips. AS patients also release these same molecules into the blood that cause activation of the osteoclasts. So AS patients suffer from a double-whammy when it comes to the development of fragile bones. They have inflammation locally within the bones of the spine but also release molecules into the blood that cause activation of osteoclasts. This is one of the reasons why patients with AS are at much higher risk of developing fractures of the spine. To make matters worse, fusion in the spine makes it rigid and inflexible, making it more likely to fracture if subjected to any significant impact.

IS THERE ANYTHING THAT CAN BE DONE ABOUT THIS?

The answer is — a great deal. First, patients must make sure that they stay active, not only to preserve strength and flexibility but also to preserve bone mineral. The cells that make bone mineral — osteoblasts — love weight-bearing exercise. But they can only make bone effectively if they are supplied with the proper nutrients. This means plenty of calcium, about 1500mg per day. A good rule of thumb is that a good helping of a dairy product, e.g., yogurt, cheese, a tall glass of
skimmed milk, amounts to 300mg of elemental calcium a day, as does one tablet of extra-strength Tums. Beware of expensive calcium preparations that often fail to deliver on the required amount of elemental calcium. Read the label and make sure you know how much elemental calcium is in the product, because this is what really counts, and not the total grams of each tablet (which is what is often on the front label). Good nutrition also means 800 units of vitamin D per day. It is surprising how many patients with AS are vitamin D deficient — about 20% according to the experts. Americans are not great milk drinkers, and if you are amongst them, then over-the-counter supplementation is important.

IS THERE A WAY OF TESTING WHETHER YOU ARE ALREADY AT INCREASED RISK OF HAVING A SPINAL FRACTURE?

This is normally done by having a bone density test — often confused with a bone scan. Bone density testing is widely available, and according to many rheumatologists, everyone who has had AS for at least 10 years should have this done. If a fracture has already occurred, a bone density test should be done regardless of how long the AS has been present. This is the same approach to the assessment of osteoporosis for women of post-menopausal age. Is such screening currently being done for patients with AS? A recent survey of British rheumatologists showed that only a minority of AS patients had received bone density tests, and it is likely that the figures in North America would not be very different. Osteoporosis in AS patients is clearly not a well-recognized problem and requires more vigorous intervention.

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Several agents have now been shown to be effective for the treatment of osteoporosis. These include agents belonging to a general class of drugs called bisphosphonates. They have been shown to be effective in most forms of osteoporosis and to be equally beneficial in men and women.

AS patients have many reasons to seek out the best preventative care, and osteoporosis is a readily preventable complication of AS.

AS typically starts in both men and women around the mid-20s, just when they are making plans for life, which may include having a family. Not surprisingly, people with AS often have concerns and questions about having children. Women may feel insecure about going through pregnancy with a chronic disease and drug treatment. Men may worry about any harmful effect on their fertility from drug treatment they receive. Future parents often are concerned about possible inheritance of AS.

Fortunately, AS does not impair fertility in women or in men. A large international study of
reproductive performance in Caucasian AS patients found on average 2.4 children per woman; not dissimilar from the number of offspring in the unaffected population. Among drugs used to treat AS, it is recognized that sulfasalazine can impair the maturation of sperm cells and therefore impair fertility in men. The sperm alterations recover in an average of 2.5 months after discontinuation of sulfasalazine. Azoospermia (meaning few or no sperm cells) occurs only rarely during therapy with methotrexate and is reversible after discontinuation of the drug. Neither of these drugs impairs fertility in women, though it's important to note that methotrexate is strongly contraindicated in pregnancy, as it has caused birth defects and death in unborn babies. Women who are planning to become pregnant and taking methotrexate are advised to stop the medication before trying to conceive. Finally, some women experience delayed ovulation when taking nonsteroidal anti-inflammatory drugs.

PREGNANCY AND AS

Several studies have investigated the effects of pregnancy on the course and severity of AS. These studies suggest that, in contrast to rheumatoid arthritis, pregnancy does not improve the symptoms of AS. For the most part, disease activity is not substantially altered during pregnancy. According to researchers, the typical pattern has shown to demonstrate active disease during the first and early second trimester, sometimes

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accompanied by a disease flare around week 20 of the pregnancy, causing an increase in pain, stiffness, and nocturnal pain. During this period, a sudden swelling has occasionally been documented to occur in the knee or ankle joints. In some patients, pain at the site where ligaments and tendons attach to bone and feeling of tightness in the chest have been reported; uveitis has also shown to be more active during this period. For the group as a whole, research studies suggest that disease activity decreases again in the third trimester.

**COURSE OF PREGNANCY AND DELIVERY**

There is no reason to believe that AS has any harmful effect on the course of pregnancy or on fetal well-being. The rates of miscarriage, stillbirth, and infants that are small for their gestational age are within normal limits of healthy women. As a rule, pregnancies conclude at term with the delivery of live, healthy children of normal birth weight.

**PREGNANCY AND DISEASE ACTIVITY POSTPARTUM**

50 to 80% of women with AS experience more severe symptoms 4 to 12 weeks after delivery. As a rule, disease activity returns to a pre-pregnancy pattern during the year following delivery.

**WHAT ARE THE CHANCES OF MY CHILDREN INHERITING AS?**

If you have AS, the likelihood of passing it on to your children is relatively low. In general, there is approximately a 50% chance that the child of one
HLA-B27+ parent will inherit the gene, but only a small percentage of those will develop AS.

DRUG TREATMENTS DURING PREGNANCY AND LACTATION

Patients with AS frequently have active disease at some stage of pregnancy. Hence, many people find it more helpful to plan ahead and talk to their doctor about these issues prior to getting pregnant. It is commonly thought that it is preferable not to use any medication during pregnancy. Your doctor can advise you and be in a position to explain your options to you, since he or she is familiar with both your medical history, and which drugs may be safe for you during this time.

ADDRESSING AFFORDABILITY OF CARE

The rapid and steady growth in healthcare costs has had a disproportionate effect on women because of statistically lower incomes and greater need for health care services throughout their lives. In recent years, policymakers and employers have begun to embrace consumer-driven health care models such as high deductible health plans coupled with tax-protected accounts. There are concerns, however, that as a result of this trend, the high-out-of-pocket liability in consumer-driven arrangements could deter lower income and chronically ill people from getting health services.

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that they need. Today, due to the high cost of some of the newer therapies for people with AS, access to medication is an issue. If you or a loved one cannot afford your AS medicines, it is important to know that there are numerous programs that provide these medicines at low or no cost. Your doctor will need to be involved should you decide to pursue medication via this route. *We invite you to visit the SAA website for more information or call our helpful toll-free line at 800-777-8189 for someone to assist you.*

**WOMEN AND SUPPORT SYSTEMS**

Women’s health is often intimately connected to their roles as mothers, partners, and daughters. Women are often the main providers for their children’s health and well-being, and are usually the critical link to their health care system. Some women manage their partner’s health needs, and more than one in ten women are taking care of an aging or chronically ill relative, often a parent. Research tells us that women who have a solid support system do better than those who do not.

Spondylitis Educational Support Groups can become an important part of a woman’s support network. Since we know that taking an active role in managing your condition, backed by a sound knowledge base, will have a positive influence on its outcome, a support group that focuses on education about spondylitis, as well as emotional peer support for those living with a chronic illness, can be tremendously empowering. Groups provide members with current information and education about how to manage their disease; the opportunity to hear from speakers who are educated about
spondylitis; literature and materials about these diseases; confidential, non-judgmental interaction with others; and understanding and assurance that you are not alone in your experience. These groups afford women the opportunity to meet other people who are living with spondylitis and to learn how other women are managing their disease.

Women involved with these groups often find that they receive the benefit of practical, every-day information they don’t always receive at the physician’s office.

*Is there a group near you? Find our support groups, and more ways of connecting with others at www.spondylitis.org/community.*

**LOOKING TO THE FUTURE**

It is important to emphasize that the majority of people with AS do well and are generally satisfied with their care. If your AS is not being treated, or you are unhappy with your treatment, it is important that you do something about it. Speak with your physician. Don’t downplay how you really feel, and explore ways to change your care.

The future looks promising for people with AS. We have learned much about the causes of the disease, and new treatments have been introduced that appear to not only reduce the symptoms, but may even slow down its progression. It is important to remember that much can be done to help, and more importantly, much that women, just like you, can do to help themselves.

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How do I become a member?
It’s easy. Call toll free 800-777-8189 to speak with our friendly staff or join online at www.spondylitis.org

Benefits of Membership

The Spondylitis Association of America provides the largest and most comprehensive library of resources in the U.S. for people affected by spondylitis. Since 1983, SAA has been dedicated to funding medical research and other programs that directly benefit the spondylitis community.

By joining SAA you can access the tools that will improve your quality of life while helping hundreds of thousands of people throughout the nation to do the same. Join today and receive:

• A subscription to Spondylitis Plus, the only multi-issue, advertising-free news magazine dedicated to the spondylitis patient.
• Access to exclusive content on 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 members, advocates, and healthcare professionals who are all dedicated to preventing this disease in future generations.

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!