Spondyloarthritis JUST DIAGNOSED

- Ankylosing Spondylitis
- Enteropathic Arthritis
- Psoriatic Arthritis
- Reactive Arthritis
- Undifferentiated Spondyloarthritis
- Juvenile Spondyloarthritis
The Spondylitis Association of America (SAA) has produced this brochure to provide you, a newly diagnosed person, with practical information about ankylosing spondylitis (AS) and related diseases in the family of Spondyloarthritis (SpA).

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

Just Diagnosed...

Whether you have been newly diagnosed with spondyloarthritis, or if someone close to you has been newly diagnosed, 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 your 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.

It may have taken some time for a correct diagnosis to be made, but now you have a name for the cluster of symptoms that you have been experiencing. Being newly diagnosed with spondyloarthritis (SpA) can be a confusing experience. Though often there is a sense of relief associated with knowing the diagnosis, there can also be associated feelings of anger, shock, loss or frustration. These feelings are completely normal as you begin to learn about the condition and to adjust to it in your life.
What is Spondyloarthritis (SpA)?

The great numbers and types of rheumatic diseases present a challenge to patients and doctors. Among the more than 100 different types of rheumatic diseases, which are conditions that affect the joints and muscles, is a group of six diseases called spondyloarthritis (SpA). This unwieldy name describes a form of arthritis that occurs in the spine and other joints. It includes ankylosing spondylitis, reactive arthritis, psoriatic arthritis, enteropathic arthritis - which is arthritis associated with inflammatory bowel disease, undifferentiated SpA, and juvenile SpA.

While these conditions display a variety of signs and symptoms, they also share many of the same features, such as:

- A tendency toward inflammatory arthritis of the spine, sacroiliac and other joints of the body, typically knees, hips, and feet.
- A condition called enthesitis, in which inflammation develops where ligaments and tendons attach to the bone.
- A tendency to occur in more than one family member.
- The absence of obvious physical signs or testing markers that are found in other types of arthritis, such as subcutaneous nodules or lumps under the skin or a positive blood test for the rheumatoid factor.

Who is at Risk?

Most types of SpA begin around the ages of 20-45 but can occur earlier in teens and younger children. These conditions typically include spinal involvement, and many affected tend to have the gene that makes a protein called HLA-B27. (Though not everyone who has SpA will test positive for the protein). While it is not known exactly how HLA-B27 influences the development of SpA, recent findings suggest that having HLA-B27 allows for the persistence of certain types of bacteria in the human body that cause inflammation. How abnormal bone formation, arthritis, or enthesitis occur because of this inflammation is still largely unknown and is the subject of intense scientific investigation at the present time.
Along with a daily stretching and strengthening routine and good posture habits, your doctor will most likely prescribe medications. Your treatment will depend upon the type of SpA that you have, whether symptoms are more mild or severe, and which goals are most important. We now have medications that may help prevent damage to the spine and other joints. These medications have substantial costs as well as the potential for side effects. The choices for a patient may vary at different times during the course of the disease, and adjustments will need to be made.

**Advances in Treatment Options**

The newest medications on the SpA treatment landscape are the biologic drugs, such as the TNF and IL inhibitors.

These drugs block specific elements in the immune pathways that can produce arthritis, enthesitis, and often skin, eye, and bowel inflammation. These biologic agents have risks resulting from a suppressed immune system. In recent years, some of these agents have been shown to slow disease progression in addition to their demonstrated ability to be effective in treating joint pain and arthritis, as well as some of the skin, eye, and bowel aspects of spondyloarthritis. For many SpA patients, the discussion of disease management is going to be complicated based on the particular type of SpA as well as the tolerance and desires for the patient to accept potential side effects or risks from suppressing the immune system. For the newly diagnosed patient, there needs to be a clear understanding that the discussion of medication management will take place many times over the course of the disease, and not just once at diagnosis.

**Understanding Treatment/Taking an Active Role**

All forms of SpA are felt to be primarily chronic diseases but not all are always active; some may remit entirely after a period of time while others have a quite intermittent course. It would be very helpful to know which course each patient is going to take, yet we do not currently have this knowledge and this concept (called risk stratification) is under active investigation.

Although there is no cure, there is an extraordinary amount that can be done to help. In recent times, important advances have been made in understanding what triggers the condition, in diagnosing it much earlier, and in treating it much more effectively than in the past.

Once a diagnosis of SpA has been made – usually by a rheumatologist – your doctor will review with you some of the treatment options available. In general, three goals are typically discussed between the patient and their doctor: those goals are pain relief, maintaining function (including work-related activities), and prevention of joint damage and fusion. Every patient will have their own priority for these three goals, and discussions should take place as to which course of management will best achieve these goals.
Why is Exercise So Critical?

According to doctors and patients alike, exercise is effective in controlling pain. However, pain relief isn’t the only reason to exercise. Exercise can counteract some of the impacts of SpA, helping you maintain more of your mobility and flexibility. In fact, in no other type of arthritis is the combination of medication and exercise as important.

Medication alone will not maintain nor increase mobility, strength, and function. You need exercise for that.

Exercise has been shown to optimize physical and mental health in everybody. In addition to directly increasing strength, endurance, balance, and flexibility, some of the other physical benefits of exercise include improving cardiovascular endurance, reducing high blood pressure, increasing good cholesterol (HDL), maximizing bone density, helping weight management and possibly even enhancing response to medications. The mental health benefits of exercise include reducing stress, improving self-esteem, and improving productivity.

In addition to the general benefits of exercise noted above, individuals with spondyloarthritis can benefit from exercise in other ways. Regular exercise can help improve posture, stiffness, pain, fatigue, breathing capacity, and therefore overall function. Through these physical effects, people with spondyloarthritis also report that exercise increases their quality of life and decreases the burden they associate with their disease.

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. It is often difficult to exercise or participate in physical activity if pain persists due to active inflammation. A good treatment plan must include exercise/physical activity.

Recommendations for Different Types of Exercises

There are 4 main types of exercise:
- Range of Motion or Stretching
- Aerobic or Cardiovascular
- Strengthening
- Balance

An ideal exercise program will incorporate each of the types of exercise noted above. However, most of us have limited time to exercise, so please ask your physician and physical therapist to help you decide which of these types of exercises are most important for you.

Getting Ready for Exercise

Allow time to “warm up” prior to beginning your exercise sessions – this reduces the chances of injury and improves comfort and performance during exercise, and can include walking, gentle stretching, and/or using heat (i.e., warm shower or bath, or heating pad on “medium” for 10-15 minutes).
**Stretching Exercises**

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.

Keeping your head in line with your spine, raise your right arm forward as you raise your left leg backward to be level with the ground. Hold for 5 seconds. Return to all fours and change to raising your left arm and right leg.

**Make Exercise Work for You**

**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.
Medical Team

Several different types of professionals may be involved at one time or another in providing you with resources to manage your condition. After diagnosis and once treatment has begun, you may decide that seeing your rheumatologist once a year or so is enough and that your primary care physician can provide adequate care the rest of the time. You may also decide that you need to enlist additional professionals in your care.

These might include any one or a combination of the following:
- Rheumatologist
- Gastroenterologist
- Ophthalmologist
- Physical Therapist
- Psychologist
- Occupational Therapist

What is the Role of the Rheumatologist?

Rheumatologists are internists with additional specialized training and certification in treating rheumatic diseases (arthritis). There are more than 100 rheumatic diseases.

The role of the rheumatologist is to make a diagnosis and to recommend and, in most cases, initiate and monitor a course of treatment. 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 imparting not only medical information, but also techniques for preventing disability and appropriate coping mechanisms. Many important questions come up from time to time (reproductive health risks, familial and genetic risk for family members, for example) and the rheumatologist is responsible for initiating and addressing these issues.

With so much information being made available almost daily in the field of rheumatology, it would be nearly impossible for all rheumatologists to be well-versed on all the latest treatment approaches at all times. Hence, you will be better served if your physician has experience and even a special interest in spondyloarthritis. Frequently an ophthalmologist and gastroenterologist may become a member of the team depending on what kind of SpA you have or evolve into.

To help you, the SAA has developed a free booklet entitled SAA’s “Rheumatologist Directory: A Patient-to-Patient Recommended List.” 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.
What is the Role of Diet in SpA?

In recent years, many specialized diets have gained popularity among people with arthritis. To date, there have been small studies that have suggested that for some people an anti-inflammatory diet may play a role in managing their arthritis symptoms.

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 as 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. A registered dietician knowledgeable and experienced in working with arthritis patients can help you fine tune ideal nutrition for your particular needs.

Depression – When to Seek Help?

Most people learn to live with the inconsistencies of having a life-long disease with its ups and downs, but if your distress is starting to interfere with your functioning on a daily basis, or you are deeply unhappy and having difficulty coping with the disease, it might be time to reach out and seek help.

Potential signs of clinical depression include:

- Marked changes in sleeping patterns
- Ongoing fatigue and listlessness
- Changes in appetite-loss or over-eating
- Uncontrollable feelings of sadness, guilt, worthlessness or purposelessness
- Inability to concentrate
- Suicidal thoughts
- Problems with sexual function
Dealing with the Diagnosis

Because spondyloarthritis often presents in a young person in the prime of life, it can be a big blow to self-esteem and confidence.

It can generate tremendous fear for the future to have to deal with a painful condition, and to start visiting doctors and taking medications.

Fortunately, many people newly diagnosed with SpA will find that with appropriate medication, a commitment to physical exercise, and the support of a strong social network, their condition can be adequately controlled. In time, many discover that, while residual pain and discomfort may linger, the pain does come and go, and they can learn to accept and manage it as a new normal.

Remember that even for the most well-adjusted among us, having to deal with SpA can, at times, be a difficult process. That is why it is important to be gentle with, and easy on yourself. If you find yourself in an emotional rut, it can be helpful to consult with a psychologist or other mental health professional who is experienced in treating people who have a chronic illness. The more positive support you can bring into your life, the easier it will be to keep SpA from imposing needless limitations.

Looking to the Future

We do not want in any way to understate the impact that the news of this diagnosis can have, and we recognize the tremendous adjustments that have been made and are going to be made in time to come. However, it is well recognized that when a person takes control of any chronic illness, and has a positive perspective, self-esteem is more likely to be high and quality of life is improved to include hope and optimism for the future.

We wish you every success in designing and carrying out your program for optimal health, and trust that this pamphlet will serve as a beginning guide in that process.

There is reason to hope that new advances in research and treatment will lead to more effective control of the disease in the near future.

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

Special thanks to Michael Weisman, MD, FACP for updating this brochure in 2018.
The Spondylitis Association of America was the first, and remains the largest, resource in the U.S. for people affected by spondyloarthritis. For more than 35 years, SAA has dedicated all of its resources to funding medical research, education, advocacy, and supportive programs and services that directly benefit the spondylitis community.

By joining SAA you gain access to tools that will improve your own quality of life while also making a difference for the 2.7 million affected people throughout the nation. Join today and receive:

- **“Spondylitis Plus,”** our information-packed, advertising-free quarterly news magazine
- SAA’s Patient-to-Patient Recommended Rheumatologist Directory
- Access to exclusive Members-Only content on spondylitis.org
- A complimentary copy of our guidebook, **“Your Guide to Living with Ankylosing Spondylitis”**
- Discounts on SAA educational and awareness products, such as books, DVDs, and exclusive, limited edition SAA logo items
- The satisfaction of knowing that you are part of an extraordinary community of patients, friends, family, and healthcare professionals dedicated to finding the cure!

There are over 100 types of arthritis. At SAA, we focus on one – yours. So that no one has to face spondylitis alone.