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Questions and Answers about Ankylosing Spondylitis

This booklet contains general information about ankylosing spondylitis (AS). It describes what ankylosing spondylitis is, its causes, and treatment options. Highlights of current research are also included. At the end is a list of key words to help you understand the terms used in this booklet. If you have further questions, you may wish to discuss them with your health care provider.

What Is Ankylosing Spondylitis?

Ankylosing spondylitis is a form of progressive arthritis due to chronic inflammation of the joints in the spine. Its name comes from the Greek words "*ankylos,*" meaning stiffening of a joint, and "*spondylo,*" meaning vertebra. Spondylitis refers to inflammation of the spine or one or more of the adjacent structures of the vertebrae.

Ankylosing spondylitis belongs to a group of disorders called seronegative spondyloarthropathies. Seronegative means an individual has tested negative for an autoantibody called rheumatoid factor. The spondyloarthropathies are a family of similar diseases that usually cause joint and spine inflammation. Other well-established syndromes in this group include psoriatic arthritis, the arthritis of inflammatory bowel disease, chronic reactive arthritis, and enthesitis-related idiopathic juvenile arthritis.

Although these disorders have similarities, they also have features that distinguish them from one another. The hallmark of ankylosing spondylitis is "sacroiliitis," or inflammation of the sacroiliac (SI) joints, where the spine joins the pelvis.

In some people, ankylosing spondylitis can affect joints outside of the spine, like the shoulders, ribs, hips, knees, and feet. It can also affect entheses, which are sites where the tendons and ligaments attach to the bones. It is possible that it can affect other organs, such as the eyes, bowel, and—more rarely—the

heart and lungs.

Although many people with ankylosing spondylitis have mild episodes of back pain that come and go, others have severe, ongoing pain accompanied by loss of flexibility of the spine. In the most severe cases, long-term inflammation leads to calcification that causes two or more bones of the spine to fuse. Fusion can also stiffen the rib cage, resulting in restricted lung capacity and function.

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Who Has Ankylosing Spondylitis?

Ankylosing spondylitis typically begins in adolescents and young adults, but affects people for the rest of their lives. Men are more likely to develop ankylosing spondylitis than are women.

What Causes Ankylosing Spondylitis?

The cause of ankylosing spondylitis is unknown, but it is likely that both genes and factors in the environment play a role. The main gene associated with susceptibility to ankylosing spondylitis is called HLA-B27. But while most people with ankylosing spondylitis have this genetic marker, only a small percentage of people with the gene develop

the disease.

How Is Ankylosing Spondylitis Diagnosed?

A diagnosis of ankylosing spondylitis is based largely on the findings of a medical history and physical exam. Radiologic tests and lab tests may be used to help confirm a diagnosis, but both have some limitations.

Medical History

The medical history involves answering questions, such as the following:

- How long have you had pain?
- Where specifically is the pain in your back or neck? Are other joints affected?
- Is back pain better with exercise and worse after inactivity, such as when you first get up in the morning?
- Do you have other problems, such as eye problems or fatigue?
- Does anyone in your family have back problems or arthritis?
- Have you recently suffered from a gastrointestinal illness?
- Do you have any skin rashes such as psoriasis?

From your answers to these questions, your doctor can begin to get an idea of the diagnosis.

Physical Exam

During the physical exam, the doctor will look for signs and symptoms that are consistent with ankylosing spondylitis. These include pain along the spine and/or in the pelvis, sacroiliac joints, heels, and chest. Your doctor may ask you to move and bend in different directions to check the flexibility of your spine and to breathe deeply to check for any problems with chest expansion, which could be caused by inflammation in the joints where the ribs attach to the spine.

Radiologic Tests

X ray and magnetic resonance imaging (MRI) may be used in making or confirming a diagnosis of ankylosing spondylitis, but these tests have limitations. X rays may show changes in the spine and sacroiliac joints that

indicate ankylosing spondylitis; however, it may take years of inflammation to cause damage that is visible on x rays. MRI may allow for earlier diagnosis, because it can show damage to soft tissues and bone before it can be seen on an x ray. However, MRI is very expensive. Both tests may also be used to monitor the progression of ankylosing spondylitis.

Lab Tests

The main blood test for ankylosing spondylitis is one to check for the HLA-B27 gene, which is present in the majority of Caucasians with ankylosing spondylitis. However, this test also has limitations. The gene is found in much lower percentages of African Americans with ankylosing spondylitis and in ankylosing spondylitis patients from some Mediterranean countries. Also, the gene is found in many people who do not have ankylosing spondylitis, and will never get it. Still, when the gene is found in people who have symptoms of ankylosing spondylitis and/or x-ray evidence of ankylosing spondylitis, this finding helps support the ankylosing spondylitis diagnosis.

What Type of Doctor Diagnoses and Treats Ankylosing Spondylitis?

The diagnosis of ankylosing spondylitis is often made by a rheumatologist, a doctor specially trained to diagnose and treat arthritis and related conditions of the musculoskeletal system. However, because ankylosing spondylitis can affect different parts of the body, a person with the disorder may need to see several different types of doctors for treatment. In addition to a rheumatologist, there are many different specialists who treat ankylosing spondylitis. These may include:

- An **ophthalmologist,** who treats eye disease.
- A **gastroenterologist,** who treats bowel disease.
- A **physiatrist,** a medical doctor who specializes in physical medicine and rehabilitation.
- A **physical therapist** or **rehabilitation specialist,** who supervises stretching and exercise regimens.

Often, it is helpful to the doctors and the patient for one doctor to manage the complete treatment plan.

Can Ankylosing Spondylitis Be Cured?

There is no cure for ankylosing spondylitis, but some treatments relieve symptoms of the disorder and may possibly prevent its progression. In most cases, treatment involves a combination of medication, exercise, and self-help measures. In some cases, surgery may be used to repair some of the joint damage caused by the disease.

What Medications Are Used to Treat Ankylosing Spondylitis?

Several classes of medications are used to treat ankylosing spondylitis. Because there are many medication options, it's important to work with your doctor to find the safest and most effective treatment plan for you. A treatment plan for ankylosing spondylitis will likely include one or more of the following:

Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)

These drugs relieve pain and inflammation, and are commonly used to treat ankylosing spondylitis. Aspirin, ibuprofen, and naproxen are examples of NSAIDs.[1] All NSAIDs work similarly by blocking substances called prostaglandins that contribute to inflammation and pain. However, each NSAID is a different chemical, and each has a slightly different effect on the body.

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[1] Warning: NSAIDs can cause stomach irritation or, less often, they can affect kidney function. The longer a person uses NSAIDs, the more likely he or she is to have side effects, ranging from mild to serious. Many other drugs cannot be taken when a patient is being treated with NSAIDs, because NSAIDs alter the way the body uses or eliminates these other drugs. Check with your health care provider or pharmacist before you take NSAIDs. Also, NSAIDs sometimes are associated with serious gastrointestinal problems, including ulcers, bleeding, and perforation of the stomach or intestine. People over age 65 and those with any history of ulcers or gastrointestinal bleeding should use NSAIDs with caution.

Some NSAIDs are available over the counter, but more than a dozen others, including a subclass called COX-2 inhibitors, are available only with a prescription.

All NSAIDs can have significant side effects, and for unknown reasons, some people seem to respond better to one NSAID than another. Anyone taking NSAIDs regularly should be monitored by a doctor.

Corticosteroids

These strong inflammation-fighting drugs are similar to the cortisone made by our bodies. If NSAIDs alone do not control inflammation in people with ankylosing spondylitis, doctors may inject corticosteroids directly into the affected joints to bring quick, but temporary relief. Injections may be given to the sacroiliac joint, hip joint, or knee joint, but are not given in the spine.

Disease-Modifying Antirheumatic Drugs (DMARDs)

These drugs work in different ways to control the disease process of ankylosing spondylitis. The most commonly used DMARDs for ankylosing spondylitis are sulfasalazine and methotrexate.

Biologic Agents

Members of this relatively new class of medications are genetically engineered to block proteins involved in the body's inflammatory response. Four biologics —adalimumab, etanercept, golimumab, and infliximab—are approved by the Food and Drug Administration (FDA) for treating ankylosing spondylitis. All four work by suppressing a protein called tumor necrosis factor-alpha (TNF-α), and are often effective for relieving symptoms when NSAIDs or other treatments are not. These drugs are taken by intravenous infusion or injection.

Will Diet and Exercise Help?

A healthy diet and exercise are good for everyone, but may be especially helpful if you have ankylosing spondylitis.

Although there is no specific diet for people with ankylosing spondylitis, maintaining a healthy weight is important for reducing stress on painful joints. In people with rheumatoid arthritis, another inflammatory joint disease, a diet high in omega-3 fatty acids (found in coldwater fish, flax seeds, and walnuts) has been shown to help in reducing joint inflammation. Although the usefulness of omega-3 fatty acids is not as well studied in

people with ankylosing spondylitis, there is some evidence that omega-3 supplements could reduce disease activity in people with ankylosing spondylitis.

Exercise and stretching, when done carefully and increased gradually, may help painful, stiff joints.

- **Strengthening exercises,** performed with weights or done by tightening muscles without moving the joints, build the muscles around painful joints to better support them. Exercises that don't require joint movement can be done even when your joints are painful and inflamed.
- **Range-of-motion exercises** improve movement and flexibility and reduce stiffness in the affected joint. If the spine is painful and/or inflamed, exercises to stretch and extend the back can be helpful in preventing long-term disability.

Many people with ankylosing spondylitis find it helpful to exercise in water.

Before beginning an exercise program, it's important to speak with a health professional who can recommend appropriate exercises.

When Might Surgery Be Necessary, and How Can It Help?

If ankylosing spondylitis causes severe joint damage that makes it difficult to do your daily activities, total joint replacement may be an option. This involves removing the damaged joint and replacing it with a prosthesis made of metals, plastics, and/or ceramic materials. The most commonly replaced joints are the knee and hip.

In very rare cases, a procedure called osteotomy may be used to straighten a spine that has fused into a curved-forward position. This surgery involves cutting through the spine so that it can be realigned to a more vertical position. After the bones are realigned, hardware may be implanted to hold them in their new position while the spine heals.

Surgery to straighten the spine can only be done by a surgeon with significant experience in the procedure. Many doctors and surgeons consider the procedure high risk. This procedure is done more commonly in Europe than in the United States.

What Are Some Things I Can Do to Help Myself?

Aside from seeing your doctor regularly and following your prescribed treatment plan, staying active is probably the best thing you can do for ankylosing spondylitis. Regular exercise can help relieve pain, improve posture, and maintain flexibility. Before beginning an exercise program, speak with your doctor or physical therapist about designing a program that's right for you.

Another important thing you can do for yourself is to practice good posture. A good test for posture is to check yourself in a mirror. First, stand with a full-length mirror to your side and, if possible, turn your head to look at your profile. Next, imagine you have dropped a weighted string from the top of your head to the soles of your feet. Where does the string fall? If your posture is good, it should pass through your earlobe, the front of your shoulder, the center of your hip, behind your kneecap, and in front of your anklebone. If you are not standing that way already, practice holding your body that way in front of a mirror until you know well how it feels. Practicing good posture can help you avoid some of the complications that can occur with ankylosing spondylitis.

What Is the Prognosis for People With Ankylosing Spondylitis?

The course of ankylosing spondylitis varies from person to person. Some people will have only mild episodes of back pain that come and go, while others will have chronic severe back pain. In almost all cases, the condition is characterized by acute, painful episodes and remissions, or periods of time where the pain lessens.

In the sacroiliac joints and spine, inflammation can cause pain and stiffness. Over time, bony outgrowths called syndesmophytes can develop that cause the vertebrae to grow together, or fuse. Fusion can also stiffen the rib cage, resulting in restricted lung capacity and restricted lung function.

A number of factors are associated with an ankylosing spondylitis prognosis. One study found that among people who had ankylosing spondylitis for at least 20 years, those who had physically demanding jobs, other health problems, or smoked had greater functional

limitations from their disease. People with higher levels of education and a history of ankylosing spondylitis in the family tended to have less severe limitations from their disease.

A recent study supported by the NIAMS found that the likelihood of having severe joint damage increased with age at disease onset, and that men were twice as likely as women to be in that group. The study also found that current smokers were more than four times as likely to have severe damage as nonsmokers, and that having a genetic marker called DRB1*0801 seemed to protect against severe spine damage.

What Research Is Being Conducted on Ankylosing Spondylitis?

In addition to the studies mentioned above, research has focused on finding the additional genes involved in the development of ankylosing spondylitis. In 2007, a large comprehensive genome-wide association scan led to the discovery of the genes ARTS1 and IL23R, which is bringing the scientific community closer to understanding ankylosing spondylitis. In addition, a 2010 study reported four genetic regions associated with ankylosing spondylitis risk, two of which encode for proteins that may play a role in ankylosing spondylitis susceptibility.

The IL23R gene plays a role in the immune system's response to infection. ERAP1 (previously known as ARTS1) is involved in processing proteins in the cell into small "chunks" that can be seen—and fought—by the body's immune system. Researchers believe the discovery could eventually lead to an understanding of the pathways that are involved in ankylosing spondylitis, and ways for doctors to inhibit or strengthen those pathways to better treat ankylosing spondylitis. In the near future, the finding could lead to a blood test to predict ankylosing spondylitis risk or aid in early diagnosis.

Researchers are also investigating a small DNA marker that makes it easier and less expensive to screen for the HLA-B27 gene. This marker may also provide insights into how ERAP1 and HLA-B27 interact, contributing to the development of ankylosing spondylitis.

Scientists are also developing methods to quantify the progression of spinal fusion in patients with the disorder and are examining whether some of the newer drug therapies can

stop its progression. In the meantime, medication treatment and exercise are important for relieving the symptoms and enabling people to live well with the disorder.

Information on research is available from the following resources:

- **NIH Clinical Research Trials and You** helps people learn more about clinical trials, why they matter, and how to participate. Visitors to the website will find information about the basics of participating in a clinical trial, first-hand stories from actual clinical trial volunteers, explanations from researchers, and links to how to search for a trial or enroll in a research-matching program.
- **ClinicalTrials.gov** offers up-to-date information for locating federally and privately supported clinical trials for a wide range of diseases and conditions.
- **NIH RePORTER** is an electronic tool that allows users to search a repository of both intramural and extramural NIH-funded research projects from the past 25 years and access publications (since 1985) and patents resulting from NIH funding.
- **PubMed** is a free service of the U.S. National Library of Medicine that lets you search millions of journal citations and abstracts in the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and preclinical sciences.

Where Can People Find More Information About Ankylosing Spondylitis?

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
Information Clearinghouse
National Institutes of Health

1 AMS Circle
Bethesda, MD 20892-0001
Phone: 301-495-4484
Toll Free: 877-22-NIAMS (877-226-4267)
TTY: 301-565-2966
Fax: 301-718-6366
Email: NIAMSinfo@mail.nih.gov
Website: http://www.niams.nih.gov

Other Resources

American College of Rheumatology

Website: http://www.rheumatology.org

Arthritis Foundation (AF)

Website: http://www.arthritis.org

Spondylitis Association of America (SAA)

Website: http://www.spondylitis.org

For additional contact information, visit the NIAMS website or call the NIAMS Information Clearinghouse.

Key Words

Biologics. A relatively new class of medications that are genetically engineered to block a protein involved in the body's inflammatory response. Four biologics are approved by the FDA for treating ankylosing spondylitis. They work by blocking a protein called tumor necrosis factor-alpha (TNF-α) that helps drive inflammation.

Calcification. A process in which tissue becomes hardened as a result of calcium deposits. In ankylosing spondylitis, calcification in tissues around the spine can lead to loss of flexibility and forward curvature.

Corticosteroids. Powerful anti-inflammatory hormones made naturally in the body or manmade for use as medicine. In people with ankylosing spondylitis, corticosteroids may be injected to temporarily reduce inflammation and relieve pain.

COX-2 inhibitors. A relatively new class of nonsteroidal anti-inflammatory drugs (NSAIDs) that are formulated to relieve pain and inflammation. Currently, there is just one COX-2 inhibitor on the market: celecoxib.

Gastroenterologist. A medical doctor who specializes in diagnosing and treating diseases of the digestive tract.

Ligaments. Tough bands of connective tissue that attach bones to each other, providing stability.

Magnetic resonance imaging (MRI). A procedure that provides high-resolution computerized images of internal body tissues. MRI uses a strong magnet that passes a force through the body to create these images.

Nonsteroidal anti-inflammatory drugs (NSAIDs). A class of medications available

over the counter or with a prescription that ease pain and inflammation. Commonly used NSAIDs include aspirin, ibuprofen, and naproxen sodium.

Ophthalmologist. A medical doctor specializing in diagnosing and treating diseases of the eye.

Omega-3 fatty acids. A type of fatty acid found in fish and fish oils. Omega-3s have proven beneficial for decreasing inflammation and reducing the risk of cardiovascular disease in some people.

Osteotomy. A surgical procedure that involves cutting a bone to shorten it, lengthen it, or realign it. In rare cases, the bones of the spine may be cut and realigned to help straighten a spine that has fused in a curved-forward position due to ankylosing spondylitis.

Physiatrist. A medical doctor who specializes in nonsurgical treatment for injuries and illnesses that affect movement. Also called rehabilitation physician or rehabilitation medicine specialist.

Rheumatologist. A medical doctor who specializes in arthritis and other diseases of the bones, joints, and muscles.

Syndesmophyte. A bony growth attached to a ligament. Syndesmophytes between adjacent vertebrae in ankylosing spondylitis can cause the vertebrae to grow together, or fuse.

Tendons. Tough, fibrous cords that connect muscles to bones.

X ray. A procedure in which low-level radiation is passed through the body to produce a picture called a radiograph. X rays showing damage to the sacroiliac joints are used to help diagnose ankylosing spondylitis.

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The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases

(NIAMS), a part of the U.S. Department of Health and Human Services' National Institutes of Health (NIH), is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases. The NIAMS Information Clearinghouse is a public service sponsored by the NIAMS that provides health information and information sources. Additional information can be found on the NIAMS website at www.niams.nih.gov. Information on bone and its disorders can be obtained from the NIH Osteoporosis and Related Bone Diseases ~ National Resource Center by calling toll free at 800–624–BONE (2663) or by visiting its website at www.bones.nih.gov.

For Your Information

This publication contains information about medications used to treat the health condition discussed here. When this publication was developed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact

U.S. Food and Drug Administration

Toll Free: 888–INFO–FDA (888–463–6332)
Website: http://www.fda.gov

For additional information on specific medications, visit Drugs@FDA at www.accessdata.fda.gov/scripts/cder/drugsatfda. Drugs@FDA is a searchable catalog of FDA-approved drug products.

For updates and questions about statistics, please contact

Centers for Disease Control and Prevention's National Center for Health Statistics

Website: http://www.cdc.gov/nchs

Additional copies of this publication are available from:

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