



Understanding Ankylosing Spondylitis



Contents

Introduction 3

What is ankylosing spondylitis? 4

Symptoms of ankylosing spondylitis 5

What causes ankylosing spondylitis? 8

The role of genes and family history 10

Environmental factors 10

Treatment options 12

Medication 13

Living with ankylosing spondylitis 16

Psychological effects 16

Living better with ankylosing spondylitis 17

Resources 20

Introduction

Up to 2% of Australians live with ankylosing spondylitis¹ – an inflammatory condition which predominantly affects the spine.

Ankylosing spondylitis is a complex disease with an unknown cause. Scientists are still researching the role of the immune system in the development of ankylosing spondylitis.

As with any long-term condition, it is important that you work with your doctor to find the treatment that works for you.

This booklet has been prepared to help you:

- understand your condition and the different treatments available
- work with your healthcare team to reduce symptoms
- identify ways to assist you in managing your ankylosing spondylitis and living a full and balanced life.

Remember that the information provided in this booklet is general in nature and not intended to replace professional medical advice. If you have any further questions about your condition or treatment, please contact your healthcare professional.

We hope you will find this booklet useful in your journey with ankylosing spondylitis.

1. Taking control of your Ankylosing Spondylitis. Arthritis Australia booklet (updated June 2013). Available at: http://www.arthritisaustralia.com.au/images/stories/documents/booklets/2016/ArthAust_AnkylSpond_screen.pdf Accessed: August 2016.

What is ankylosing spondylitis?

Ankylosing spondylitis is a form of arthritis that mainly affects the spine. Ankylosing spondylitis affects up to 2% of Australians,¹ and is about three times more common in men than in women.² The most common age of onset of symptoms is between 15 and 40 years old.¹

Ankylosing spondylitis causes inflammation of the spinal joints and this can lead to severe, chronic pain and discomfort, starting generally in the lower back. In the most advanced cases, disease progression can lead to new bone formation on the spine, causing it to fuse in a fixed, immobile position. That's where the name comes from – ankylosis means fusion and spondylitis means inflammation of the spine. However, not everyone will experience the most serious complications or develop spinal fusion.

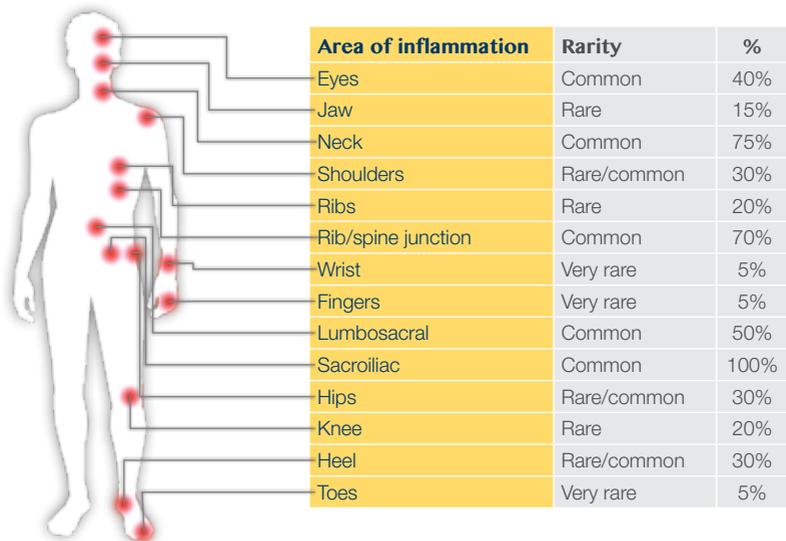
While ankylosing spondylitis is a chronic condition (meaning it can last for many years), people may experience periods of intense disease activity (known as flares) and periods of no symptoms at all (known as remission).

1. Taking control of your Ankylosing Spondylitis. Arthritis Australia booklet (updated June 2013). Available at: http://www.arthritisaustralia.com.au/images/stories/documents/booklets/2016/ArthAust_AnkySpond_screen.pdf Accessed: August 2016.
2. Arthritis Australia Empowered website: Ankylosing Spondylitis. Available at: <http://empowered.org.au/ankylosing-spondylitis/> Accessed: August 2016.

Symptoms of ankylosing spondylitis

The symptoms of ankylosing spondylitis vary from person to person. Some people experience only intermittent back pain and discomfort while others develop the most serious complication of spinal fusion. As well as affecting the joints of the spine, ankylosing spondylitis can cause inflammation, pain and stiffness in other areas of the body such as the shoulders, hips, ribs, heels and small joints of the hands and feet (Figure 1). In some cases the eyes are affected and, less often, the lungs and heart.

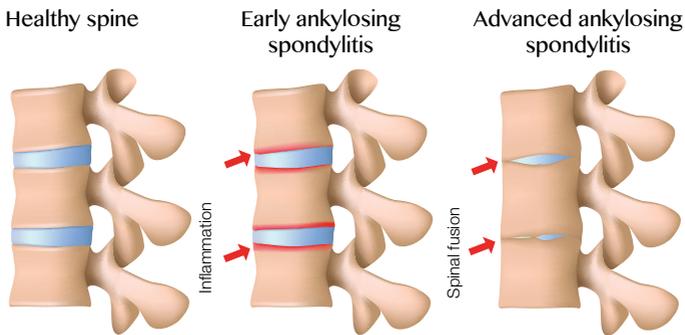
Figure 1: Areas of inflammation in ankylosing spondylitis



Adapted from: Spondylitis Association of America - Possibly complications of spondylitis. Accessed: September 2016. Available at: <http://www.spondylitis.org/About-Spondylitis/Possible-Complications-Of-Spondylitis>

How does ankylosing spondylitis affect the joints?

People with ankylosing spondylitis often develop painful and stiff joints. The intense periods of joint inflammation develop gradually until the pain becomes persistent on both sides of the body. Those with chronic, severe inflammation of the spine may develop complete bony fusion of the spine. Once fused, there is no longer any pain in the spine, but there is a complete loss of spine mobility. These areas of fused spine are also quite brittle, increasing the possibility of fracture.



Adapted from: Spondylitis Association of America - Possible complications of spondylitis.
Accessed: September 2016. Available at: <http://www.spondylitis.org/About-Spondylitis/Possible-Complications-Of-Spondylitis>

The most common symptoms of ankylosing spondylitis

- Pain and stiffness in the back, buttocks and neck. This is often worse after rest (e.g. early in the morning) and relieved with exercise.
- Pain in tendons (which connect muscles to bone) and ligaments (which connect bones to each other) often felt at the front of the chest, back of the heel or underneath the foot.



How does ankylosing spondylitis affect other parts of the body?

Ankylosing spondylitis is defined as a systemic autoimmune disease.

- Systemic means that it can affect the entire body, though it is most common in the joints. It can affect the eyes, and occasionally the heart and lungs.
- Autoimmune refers to the condition being due to an overactive immune response, where the immune system attacks its own body tissues.

About 30% of people with ankylosing spondylitis will experience inflammation of the eye (known as iritis or uveitis).¹ Signs of iritis or uveitis include painful, watery eyes, blurred vision and sensitivity to bright light.

Many people with ankylosing spondylitis also experience bowel inflammation, which may be associated with Crohn's disease or ulcerative colitis. In addition, ankylosing spondylitis can lead to fatigue, anaemia, loss of appetite and a low-grade fever.

1. Arthritis Australia Empowered website: Ankylosing Spondylitis. Available at: <http://empowered.org.au/ankylosing-spondylitis/> Accessed: August 2016.

What causes ankylosing spondylitis?



Ankylosing spondylitis is an autoimmune disease, meaning that the immune system attacks its own body tissues. While the exact cause of ankylosing spondylitis is currently unknown, the end result is an immune system that promotes joint inflammation.

In these areas of inflammation, immune cells (lymphocytes) are activated producing chemical messengers (called cytokines).

8

Lymphocytes are types of white blood cells that are involved in recognising and responding to infection and inflammation.

Cytokines are chemical messengers released from lymphocytes that regulate the body's response to disease and infection. Some cytokines reduce inflammation while others interact with the immune system to promote inflammation.

Conditions such as ankylosing spondylitis, rheumatoid arthritis, psoriatic arthritis, psoriasis, Crohn's disease and ulcerative colitis are associated with an overproduction of lymphocytes and cytokines that promote inflammation. This can cause tissue damage.

One of these cytokines is a protein called tumour necrosis factor alpha (TNF- α). TNF- α plays a central role in orchestrating an immune response against infection and tissue damage, which results in inflammation. The immune system is then counter-balanced by other cytokines that normalise the inflammatory response.

In conditions such as ankylosing spondylitis, the inflammatory response is magnified due to over-expression of TNF- α which, along with other inflammatory cytokines, is responsible for increasing inflammation of the tissue lining joints (called the synovium), resulting in the stiffness and swelling commonly associated with the disease. Scientists believe that inherited genes and environmental factors have a role in triggering the development and progression of ankylosing spondylitis.



The role of genes and family history

Research has shown that our genetic makeup has a key role in the onset of ankylosing spondylitis. Most people who have ankylosing spondylitis have a gene called *HLA-B27*.¹ This gene marker is found in almost nine in ten people with ankylosing spondylitis compared with only 8% of the general population.¹ Consequently, ankylosing spondylitis tends to run in families. In fact, close family members (such as a parent, child or brother or sister) of someone with ankylosing spondylitis have a one in five risk of developing the condition compared with the general population.²

A number of other genes have also been associated with ankylosing spondylitis and research into their role in the development of the disease is ongoing.

Environmental factors

A genetic tendency alone is not sufficient to develop ankylosing spondylitis – only about one in every eight people with the *HLA-B27* gene will go on to develop the disease.² It is thought that one or more additional environmental factors, such as infections, may trigger the condition in susceptible people, although the exact nature of these triggers is not yet known.

Key statistics

- The *HLA-B27* gene is found in almost nine in ten people with ankylosing spondylitis compared with only 8% of the general population.¹
- Most people with ankylosing spondylitis will experience their first symptoms between the ages of 15 and 40 years. It is less common for symptoms to first develop after the age of 45 years.¹
- Ankylosing spondylitis affects about 3 times as many men as women.²



1. Arthritis Australia Information Sheet: Ankylosing spondylitis. Available at: www.arthritisaustralia.com.au/images/stories/documents/info_sheets/2015/Condition%20specific/AnkylosingSpondylitis.pdf Accessed August 2016.
2. Taking control of your Ankylosing Spondylitis. Arthritis Australia booklet (updated June 2013). Available at: http://www.arthritisaustralia.com.au/images/stories/documents/booklets/2016/ArthAust_AnkySpond_screen.pdf Accessed: August 2016.

Treatment options

Ankylosing spondylitis is a chronic disease, which cannot be cured. However, there are many treatment options available that can ease the symptoms of ankylosing spondylitis and even slow its progression to limit joint damage and disability.



Your doctor will work with you to decide which treatments are most suitable for you. This will involve considering factors such as your disease activity and the types of joints involved, as well as your general health and lifestyle.

The optimal approach to managing ankylosing spondylitis usually involves a combination of medications, physical therapy and exercise. Medications decrease inflammation in the spine and other joints and organs, while physical therapy and exercise help improve posture, spine mobility and lung capacity. Education about the condition is also an important component of treatment. Working closely with your healthcare team is the best way to help ensure that you get the most out of your treatment plan.

Medication

Medications used to treat ankylosing spondylitis can be divided into two groups:

1. Those that help relieve symptoms and reduce inflammation (non-steroidal anti-inflammatory drugs [NSAIDs] and corticosteroids)
2. Those that can modify the disease or can achieve remission (disease-modifying anti-rheumatic drugs [DMARDs] and biologic agents).

All medications can have side effects and it is important to discuss the risks and benefits of any treatment with your doctor. Always speak with your doctor about any concerns you have about the medications you are prescribed, or if you experience any side effects.



Pain relievers and anti-inflammatories

Non-steroidal anti-inflammatory drugs (NSAIDs)

As the name suggests, NSAIDs reduce inflammation, which also reduces pain. NSAIDs are used to treat a very broad range of conditions.

Corticosteroids

Steroids are naturally produced by the body to be used in many normal body processes. Chemical corticosteroids alleviate joint pain, swelling and other symptoms of ankylosing spondylitis by blocking the production of substances (such as prostaglandins) that promote inflammation or trigger allergic responses. Possible side effects with longer term use may include weight gain, brittle bones and osteoporosis, glaucoma, cataract, increased risk of infection, high blood pressure, fragile skin and onset or worsening of type 2 diabetes. For this reason, corticosteroids are usually prescribed for a short period of time.



Disease modifiers

Disease-modifying anti-rheumatic drugs (DMARDs)

DMARDs are a group of unrelated drugs with different modes of action that collectively slow the progression of ankylosing spondylitis or even enable disease remission. DMARDs are known to modulate the immune system and hence reduce inflammation. Your doctor can advise you if these agents may be appropriate for you.

Biologics

Biologic response modifiers (biologics) work by targeting specific biological proteins involved in chronic inflammation. In ankylosing spondylitis, biologics such as anti-TNFs work by helping to reduce the excess TNF- α levels produced during the inflammation process. The biologic attaches to TNF- α and stops the activity that is driving the disease process.



Talk to your doctor about any concerns you have about the medications you are prescribed or if you experience any side effects.

Living with ankylosing spondylitis



The effects of ankylosing spondylitis are more than just physical. Living with ankylosing spondylitis can have an impact on your life socially, psychologically and even financially.

Psychological effects

Everyone responds differently to challenges. If you experience emotional reactions such as anger, frustration, helplessness or anxiety in relation to your ankylosing spondylitis, you are far from being alone.

If you feel depressed, it is important to talk to someone you trust, such as a family member, close friend or a healthcare professional. There are ways to help you manage the emotional challenges of living with ankylosing spondylitis. To find out more about depression and its symptoms, visit Beyond Blue: www.beyondblue.org.au



Living better with ankylosing spondylitis

Living with any long-term health condition is difficult. Taking medication can help your disease, but you need to take care of yourself too. There are things that you can do to help you cope more positively, beyond taking your medications as prescribed.



Things you can do for yourself

- Learn about your condition and take an active role in its management. A good place to start is by talking to your doctor and visiting the websites provided in the resources section of this booklet.
- Make time for physical activity. Physical activity is crucial in maintaining joint movement and muscle strength – it also has great mental health benefits such as relieving stress.
- Eat a healthy, well-balanced diet. While what you eat does not cause ankylosing spondylitis, it may affect the way you feel. A good diet and an active lifestyle will reduce the risk of gaining weight and will keep your joints in motion, which may assist in the management of your symptoms. Your doctor or a dietitian may be able to help you with individual dietary advice to suit your needs.

Don't smoke – cigarette smoking is associated with ankylosing spondylitis progression and severity. Quitting smoking can be a challenging but important step to help your ankylosing spondylitis. If you would like advice on how to quit smoking, you can talk to your doctor or other healthcare team members, call the Quitline on 13 78 48 or visit www.quitnow.gov.au

- Use assistive devices. Many devices are available to help people with ankylosing spondylitis manage their everyday activities. Occupational therapists are able to provide advice on how to reduce joint strain and pain. They can also suggest changes that can be made in your house or recommend an assistive device that would best help you.
- Apply heat to affected areas. Heat application can help ease pain, relax muscles and increase blood flow. It is particularly useful before exercise, but should not be used on joints that are already hot and swollen.
- Apply cold to affected areas. Cold treatments can help ease joints that are hot and swollen.
- Educate your friends and family about ankylosing spondylitis. This way they can better understand what you are going through and provide you with support if needed.
- If you are comfortable, talk to your employer about ankylosing spondylitis and discuss your abilities, noting any constraints or concerns you may have.
- Get in touch with other people living with ankylosing spondylitis. Feeling connected with others who are going through the same thing as you can make a huge difference. Consider joining a support group – a good place to start is by contacting Arthritis Australia: www.arthritisaustralia.com.au

Resources

Australian Rheumatology Association (ARA) **www.rheumatology.org.au**

An association that provides information for patients on the different treatments available for ankylosing spondylitis.

Arthritis Australia **www.arthritisaustralia.com.au**

A national not-for-profit organisation that provides information about ankylosing spondylitis and the support available. It promotes awareness of the challenges facing people with arthritis across the community, including leaders in business, industry and government.

Empowered – Arthritis Australia **<http://empowered.org.au>**

Bringing together people living with arthritis, their rheumatologists, general practitioners and allied health supporters to share knowledge on how to manage, survive and thrive with arthritis.

Always discuss any issues relating to your treatment with your doctor or a member of your healthcare team.

These websites are provided for your information only. The sites may contain content that the sponsor of this booklet does not endorse. The sponsor is not responsible for the validity of the information on these sites. Websites may contain or link to information that is not consistent with the way medicines are used in Australia.

©Janssen-Cilag Pty Ltd 2016. Janssen Cilag Pty Ltd, ABN 47 000 129 975. 1–5 Khartoum Road, Macquarie Park NSW 2113 Australia. Phone 1800 226 334

MKT-SIM-AU-0071 JANS1673/EMBC Date of preparation: October 2016