

# Spondyloarthritis in over 16s: diagnosis and management

Information for the public

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## Spondyloarthritis: the care you should expect

This information explains the care that NICE has said works best for people who are 16 and older who have or may have spondyloarthritis (a type of inflammatory arthritis). It will help you, your family and carers know what to expect from health and care services.

### *Why is this important for you?*

NICE aims to help people get the best care no matter who they are or where they live. This NICE advice aims to help healthcare professionals recognise the symptoms of spondyloarthritis, especially symptoms in the back such as pain and stiffness, which may be mistaken for other types of low back pain. This is important so people get the right diagnosis and treatment without delay. For more information, see [where can I find out more?](#)

Your healthcare team should know what NICE has said. Talk to a member of your team if you don't think you are getting the care NICE has said you should have.

## What is spondyloarthritis?

### *Types of arthritis*

There are many types of arthritis and spondyloarthritis is one of them.

The most common type of arthritis is osteoarthritis, which is a normal part of ageing. Joints become damaged over time because of the way they move. People sometimes call it 'wear and tear'.

Spondyloarthritis and rheumatoid arthritis are types of inflammatory arthritis. This happens when the body's immune system – which is meant to keep us well by fighting infection – starts to cause inflammation in the joints and the area around them, causing damage. Why this happens is not fully understood, but research shows that it can run in families. Spondyloarthritis is a fairly new term; you might also see it called ankylosing spondylitis, psoriatic arthritis or reactive arthritis.

## *Spondyloarthritis*

There are 2 main types of spondyloarthritis:

- Axial spondyloarthritis, which mainly causes pain and stiffness in the back.
- Peripheral spondyloarthritis, which mainly causes pain, stiffness and swelling in the hands, feet, arms and legs.

Some people may experience both types of problems.

Other conditions increase a person's risk of developing spondyloarthritis. These include:

- an itchy, scaly skin condition called psoriasis
- inflammatory bowel disease (Crohn's disease and ulcerative colitis)
- certain infections, such as some stomach bugs or sexually transmitted infections (STIs)
- a painful eye condition called uveitis.

Spondyloarthritis is more common in people who have a gene called HLA-B27.

## **If your symptoms are mostly in your back (axial)**

### *What your GP will look for*

If you have low back pain and you go to see your GP, he or she will want to know more about your symptoms to find out if you could have axial spondyloarthritis.

They will want to know how old you were when the pain began and how long it has been going on for. They should also ask if you have any of the following

- low back pain that started before the age of 35 years
- waking during the second half of the night because of symptoms
- buttock pain
- symptoms that get better when you move around
- symptoms that get better with non-steroidal anti-inflammatory drugs (also known as NSAIDs; for example, ibuprofen)
- a close relative (parent, brother, sister, son or daughter) with spondyloarthritis
- any other type of arthritis
- pain or swelling in your joints that was not caused by an injury
- psoriasis.

### *Will I see a specialist?*

Doctors who specialise in treating arthritis and related problems are called rheumatologists. Your GP should refer you to a rheumatologist if:

- your back pain started when you were under the age of 45 **and**
- the pain has lasted for longer than 3 months **and**
- you have 4 or more symptoms from the list above (what your GP will look for).

If you have 3 symptoms from the list, you should have a blood test to see if you have the HLA-B27 gene. If the test shows you have the gene, you should be referred to a rheumatologist.

## If your symptoms are mostly in your hands, feet, arms and legs (peripheral)

### *What your GP will look for*

Your GP will want to know about symptoms in other parts of your body to find out if you could have peripheral spondyloarthritis. They will ask about signs and symptoms, and about your family and medical history, including:

- pain or swelling in your joints that wasn't caused by an injury
- back pain
- uveitis
- psoriasis
- infections, such as some stomach bugs or sexually transmitted infections (STIs)
- inflammatory bowel disease (Crohn's disease and ulcerative colitis)
- a close relative with spondyloarthritis or psoriasis.

### *Will I see a specialist?*

Doctors who specialise in treating arthritis and related problems are called rheumatologists. Your GP should refer you to a rheumatologist if you have pain and swelling in your joints, and your GP thinks you could have peripheral spondyloarthritis.

### **Problems with your eyes**

If a doctor thinks that you have uveitis, you should be referred to see an eye specialist (called an ophthalmologist) straightaway. The eye specialist should see you on the same day that you are referred.

### **What tests might I have?**

When you see a specialist, they may offer you an X-ray of your back and pelvis, and X-rays of any other parts of your body where you have symptoms. They may also offer you other scans and tests such as an MRI, an ultrasound or a blood test. These are to check for inflammation or infection and to look for the HLA-B27 gene.

## Coping with your symptoms

### Medicines

Early treatment of spondyloarthritis is important to relieve pain and reduce joint damage. Some medicines control the disease itself, and some help to ease symptoms. Your healthcare team will help you to find the best treatments for you.

Your healthcare team will talk with you about medicines you can try, based on your symptoms, needs, and any other medical conditions that need to be taken into account. See table 1 for different types of medicines and how they work.

**Table 1 Spondyloarthritis medicines and how they work**

Type of medicine	How the medicine helps
Non-steroidal anti-inflammatory drugs (NSAIDs)	Reduces inflammation and relieves pain
Biologics	Slows down your immune system's attack on your joints and spine
Disease-modifying anti-rheumatic drugs (DMARDs)	Slows down your immune system's attack on your joints
Steroid injections or tablets	Reduces inflammation

For all types of spondyloarthritis, if the medicine you try doesn't work, you should be offered a different one.

### Axial spondyloarthritis

If you have axial spondyloarthritis, you should be offered a non-steroidal anti-inflammatory drugs (NSAID).

If after 2 to 4 weeks the NSAID you try doesn't give enough pain relief, you should be offered a different NSAID to try instead.

Your specialist should discuss other medicines to try if NSAIDs haven't helped or they are not right for you, for example, if they cause problems with your stomach or other medical conditions.

Other medicines for axial spondyloarthritis are biologics, which include 'anti-TNF' medicines. In spondyloarthritis, a protein called tumour necrosis factor (TNF) is over-produced in the body. This causes inflammation and damage to bones, cartilage and tissue. Anti-TNF medicines block the action of TNF and can reduce inflammation.

## Peripheral spondyloarthritis

Depending on the extent and severity of your symptoms, your specialist may offer you a medicine called a disease-modifying anti-rheumatic drug (DMARD), steroid injections or tablets, an NSAID, or a combination of these medicines to help manage your condition.

## *Physiotherapy*

If your symptoms are mostly in your back (axial) you should be referred to a specialist physiotherapist.

A physiotherapist is a medically trained person who can help you with your joints, muscles and movement. They should help you to create an exercise plan that can ease symptoms such as stiffness and pain. The exercise plan should include:

- stretching, strengthening, and exercises to help your posture
- deep breathing
- exercises to move and stretch the different parts of your back and neck
- aerobic exercise (exercise that makes you breathe harder than normal, for example, walking, swimming and cycling).

Your healthcare team may also discuss exercise with a physiotherapist in a warm-water pool. This is called hydrotherapy.

## *Help with everyday activities*

If your symptoms make it hard for you to do everyday activities – such as cooking, dressing, cleaning and doing your job – you may be referred to specialist therapist. The therapist can assess your needs and help you to cope with your symptoms. For example, you might see an occupational therapist if you struggle with tasks around the house or at work, or you might see a podiatrist for help with foot problems.

If you see a therapist, they should find out about what you need, give you advice about equipment that might help, and arrange reviews to make sure that the therapy is still meeting your needs.

## Surgery

Some people with spondyloarthritis get problems with their back that cause it to become hunched or bent (called kyphosis). You should only be referred to a spinal surgeon if the postural problem is severe or if it is likely that you have broken a bone in your back.

## Coping with flares

Some people have times when their symptoms get worse. These are called flares or flare-ups. They can be treated by your GP or your specialist, depending on your needs.

You'll be given information about flares and what sort of symptoms you might get.

You may also have a flare management plan that includes what to do if you get a flare, for example:

- where to get care during a flare, including who to contact (for example, a specialist rheumatology nurse)
- what you can do to help your symptoms (such as information about stretching, exercises and how to protect your joints)
- coping with pain and tiredness
- what medicines you can take
- coping with the effect on your home and work life.

## Follow-up checks

If you have spondyloarthritis, your healthcare team should work together to make sure that your condition and medicines are monitored, and that you get specialist help when you need it, for example, to manage flares, symptoms or other health problems.

If you have axial spondyloarthritis, you might need a check-up every 2 years to look for signs of osteoporosis. This is a condition that weakens bones, making them fragile and more likely to break. Your healthcare team can give you more information.

If you have a fall or hurt yourself, you should seek medical advice, particularly if you are in pain.

## Making decisions together

You should be part of all decisions about your care so you can discuss and agree which treatments are likely to suit you best. Your healthcare team, which may include healthcare professionals such as consultant rheumatologists and other specialists, GPs, specialist nurses, physiotherapists or other therapists and pharmacists, should involve you by:

- talking and listening to you so that they understand what matters to you
- giving you all the information you need so that you can make your mind up
- explaining if they think something that is mentioned here won't work for you and why, and discussing other options you could try instead
- giving you details for someone in your healthcare team that you can contact if you have any questions.

There is more information about how you should be involved in your care on our [website](#).

## Information and advice

You should get explanations and information about spondyloarthritis. Information should be relevant to your needs and condition, verbal and written, and available whenever you need it.

You might also have questions for your healthcare team.

### *Questions you might want to ask*

- What is spondyloarthritis?
- What are the different types? What are their symptoms?
- How will I be diagnosed?
- Will my condition get better or worse?
- What symptoms might I get? How can I cope with them?
- What can I do to help myself?



- What treatments (medicines and other treatments) are available?
- What are the long-term risks of taking my medicines? What are their side effects?
- Is there ongoing research that might help me in the future?
- Which healthcare professionals will I see, and where are they based? How do I get in touch with them?
- Am I at a greater risk of getting other medical problems?
- Where can I find more support in my area, online and nationally?

## Where can I find out more?

- [Arthritis Action](#), 0203 781 7120
- [Arthritis Care](#), 0808 800 4050
- [Arthritis Research UK](#)
- [National Ankylosing Spondylitis Society \(NASS\)](#), 0208 741 1515
- [Psoriasis Association](#), 01604 251 620
- [Psoriasis and Psoriatic Arthritis Alliance \(PAPAA\)](#), 01923 672837

You can also go to [NHS Choices](#) for more information on [spondyloarthritis \(ankylosing spondylitis\)](#).

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

You may also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS.

## What are NICE guidelines?

NICE gives advice to staff working in health and social care. Our guidelines help them to give the best care to people with different conditions and needs. We wrote this guideline with people who have been affected by spondyloarthritis and staff who support them. All the decisions are based on the best research available. You can read the [guideline](#) written for people who work in health and care services.

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### *Accreditation*

