Scoliosis Know the Facts

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Scoliosis

What is it?

Scoliosis is the abnormal twisting and curvature of the spine and can affect people of any age, from babies to adults.

It is not a disease. It simply means that in an otherwise healthy person, the spine is curved and twisted. It is not infectious or contagious. It does not develop because of anything a person did or did not do.

Scoliosis can happen at any age.

However, it most often begins in children between the ages of 10 and 15. In most cases, the cause of scoliosis is unknown. It can sometimes be attributed to a neuromuscular condition, such as muscular dystrophy or cerebral palsy and can also develop as part of a syndrome, such as Marfan syndrome. Scoliosis can affect a person's appearance.

When the spine bends to the side it can also twist.

The twisting can pull the ribcage out of place to form a bulge on the back, as well as other effects such as causing the shoulder blade to stick out. One hip can also be higher than the other.



How do I know if I have it?

There is a quick test to check for the possibility of scoliosis, known as the 'Adams Forward Bend'. The test can be taken with a doctor, parent or guardian present.

To take the test, the patient should bend forward from the waist with their legs and arms straightened. Once in position, a curve in the spine may be seen.

When viewed from the back, a clear bulge where the ribs are will be visible if scoliosis is present. Other common signs include: one shoulder blade sticking out more than the other, a tendency to lean to one side or an uneven waist or hips.

What happens next?

If you suspect that you or a family member may have scoliosis, speak to a doctor as soon as possible.

If scoliosis is diagnosed, it is important to see a scoliosis specialist. Please call or email us to find out where your nearest specialists are.



How can we help?

Finding out that you or a loved one has scoliosis can be a shock. Many people have never heard of the condition and may feel overwhelmed, anxious, or isolated. We're here to help you through it.

We support people with scoliosis by reducing feelings of isolation and worry, improving body image, helping manage pain, and ensuring access to reliable information and care. We also fund vital research into scoliosis and other spinal conditions.

Information

Our website offers up-to-date, trusted information about scoliosis and treatment options. Whether you're newly diagnosed or seeking specific advice, we're here to support you. www.ssr.org.uk

Helpline

We offer a free and confidential helpline for anyone affected by scoliosis—whether you're a patient, parent, or carer.

Call us on: 020 8964 1166

You can speak with someone who understands and can guide you to the right support and resources.

Find a Specialist

Seeing a scoliosis specialist is key to understanding your condition and exploring treatment options. We can help you find a qualified specialist near you.

Contact us via our website or helpline for details.

Online Support Groups

We run online support groups for all ages, facilitated by a qualified counsellor. These safe, supportive spaces allow people to connect with others living with scoliosis, share experiences, and feel less alone.

Join our community via the website to stay up to date with these sessions.

Patient Events

Every year, we organise events of up to 100 people in locations across the UK to discuss the issues faced by families and individuals affected by scoliosis. These provide the opportunity to hear from scoliosis specialists and treatment experts, and get answers to your questions. They are also a great opportunity for people to meet each other and share stories and information about their experiences with scoliosis.

Get Involved

We do not receive government funding, but there are many ways you can support us— whether by fundraising, making a donation, joining our community, or leaving a legacy. To get involved, email **fundraising@ssr.org.uk** or call us on **020 4537 4139**.

Types of scoliosis

Congenital or Early Onset Scoliosis

Scoliosis can develop before birth because the spine does not develop properly in the womb. The spine is made up of several small bones called vertebrae. Sometimes the vertebrae do not fully form. One or more might not form at all, which causes the spine to grow unevenly after a baby is born.

The condition can also develop in babies or children between birth and the age of 10, before puberty. This is called Early-Onset Scoliosis. Usually this is idiopathic, meaning there is no known cause. Children can also develop scoliosis as a result of a neuromuscular condition or as part of a syndrome, such as Marfan's syndrome.

If a curve is spotted in a baby or child, the curve's status should be monitored regularly by a scoliosis specialist. In some children, the curve will remain the same, but in some instances it can increase as they grow. This can happen quickly, so a



referral to a specialist should be made as soon as possible.

The earlier treatment is started for young children with scoliosis, the better the prognosis. This is because the spine can be guided into a better position as they grow.

Adolescent Idiopathic Scoliosis

Scoliosis is most commonly diagnosed between ages 10 and 15. Adolescent Idiopathic Scoliosis (AIS) affects more females than males, with around 5 out of 6 people with AIS being female. This type of scoliosis occurs while they are still growing.

If a teenager has scoliosis, it is important that your GP arranges a referral to a scoliosis specialist as soon as possible. At the first appointment, the patient will be examined by the specialist, X-rays will be taken and the Cobb angle will be determined. The Cobb angle is measured in degrees and will tell you the size of the curve.

The specialist will then discuss possible treatments options, such as bracing. For smaller curves, they will likely want to start by monitoring the curve regularly to see if it is increasing. For larger curves, it is likely that treatment will be recommended. It is important to remember that every case of scoliosis is different and there is no standard treatment, so seeking the advice of a specialist is vital.

Degenerative or De novo Scoliosis

Degenerative scoliosis occurs in adults and is categorised under two main types. Degenerative scoliosis is a type of scoliosis that may have started earlier on in life and worsened or become arthritic with age. De novo scoliosis begins after 40 and is thought to be caused by arthritis or a gradual deterioration of the spine. The difference between the two is that de novo scoliosis affects patients who have never had scoliosis in the past.

Degenerative scoliosis of both kinds can happen because the spine gets weaker with age. Often, the discs and facet joints in the vertebrae wear out, causing them to slip out of place. As a result, the spine curves to one side. Discs sit between the vertebrae and act as a cushion. Facet joints are small joints between each of the vertebrae, linking the bones together.

Degenerative curves may become larger over time. While surgery is sometimes an option for adults, it can be harder to forecast its success due to the natural aging of the body. However, treatments are available to help manage pain and improve mobility if surgery is not an option.

Neuromuscular Scoliosis

Neuromuscular scoliosis is a type of spinal curvature caused by underlying neurological or muscular conditions that affect the brain, spinal cord, nerves, or muscles. Common causes include muscular dystrophy, spinal muscular atrophy, cerebral palsy, spina bifida, and spinal cord trauma though not everyone with these conditions will develop scoliosis.

These conditions often weaken the muscles needed to support the spine, leading to abnormal curves such as scoliosis or kyphosis (a forward rounding of the back), or both. As the child arows and trunk muscles weaken, the spine may begin to collapse into a long, C-shaped curve. This progression tends to worsen during periods of rapid growth, particularly puberty. around

Early and ongoing medical monitoring is crucial. All individuals with neuromuscular scoliosis should be assessed by a scoliosis specialist, and children should be regularly monitored from a young age. Timely intervention helps ensure spinal curves do not become severe, supporting better health outcomes and quality of life. Syndromic scoliosis means that a sideways curve of the spine develops as part of a syndrome. A syndrome is a condition that is made up of lots of symptoms (signs) that appear together.

The syndrome condition causes the scoliosis to occur as a secondary disorder. Some syndromes where scoliosis is likely to happen are connective tissue disorders where weaknesses in the areas where this connective tissue is found, can occur. Syndromes such as Marfan's and Ehlers-Danlos syndrome, trisomy 21, Prada-Willi, Retts syndrome and Beale's syndrome are connective tissue disorders and can cause problems with eyes, lungs, joints and bones, including in the back.

Depending on the age of the patient, and the nature of their underlying condition, the treatment may be similar to that offered for adolescent idiopathic scoliosis

In some cases, no treatment will be needed and the patient will simply be checked regularly by a scoliosis specialist, in growing children this is usually every 6 months or a year. If the patient is growing more slowly, monitoring may happen every 2 years.

Syndromic Scoliosis

Scheuermann's Kyphosis

Scheuermann's kyphosis is a condition in which the front sections of the vertebrae, which are the small bones that make up the spine, grow more slowly than the back sections.

This difference in growth means the vertebrae grow into the shape of a wedge, when they should grow into the shape of a rectangle resulting in the bones developing a forward angle as it grows rather than stacking up in a straight line. This forward bend of the spine is called kyphosis.

Scheuermann's kyphosis usually appears in adolescents when they are around 10–16 years old. Patients with Scheuermann's kyphosis often have back pain, especially during the early teenage years.

Pain is also often the most noticeable symptom for adult patients but other signs are tightness of the chest (pectoral) muscles, hamstrings, which are the strong bands of tissue at the back of the thighs, and hip flexors, which are the inner hip muscles.

The curve caused by Scheuermann's kyphosis often



stays mild and usually patients will only need X-rays to check that it is not getting bigger. Treatment may be needed if the size and progression, or worsening, of the curve is observed. The patient's age, how much growing they have left to do, whether they are in pain, the effect of the curve on their appearance, and, in rare cases, the risk of cardiopulmonary (heart and lung) or neurological (nervous system) problems, are also taken into consideration when deciding the best course of treatment.

Frequently Asked Questions

Here are some common questions asked by callers to our Helpline. If you need further information or advice, please get in touch with us on:

020 8964 1166 or info@ssr.org.uk

Why has this happened?

In most cases, the cause of scoliosis is idiopathic, which means that there is no known cause. In some cases it does seem to run in families. Around a quarter of people with scoliosis have a close relative with a curvature of the spine.

I (or a family member) have been diagnosed with Scoliosis. What is going to happen now?

After diagnosis, make sure that you are seen by a scoliosis specialist. There are many scoliosis centres across the UK, which we can email to you. You will need to take their names to your GP, who will organise a referral.



You will then receive a letter in the post with your appointment date and time. At your first appointment, vou will be examined, X-rays will be taken and vou will be told the Cobb anale. The Cobb angle is measured in degrees and will tell you the size of the curve. The specialist will then talk to you about possible treatments options. It is important to remember that every case of scoliosis is different and there is no standard treatment. This is why consulting a specialist is essential.

I live in Scotland, what happens next?

If you live in Scotland, after you have been assessed by your GP, you will then be referred to the Scottish National Spine Service (SNSS) if they deem it necessary. For our list of specialists in Scotland, please contact us on:

020 8964 1166

or info@ssr.org.uk

Could I have prevented my Scoliosis?

Scoliosis can only be prevented when it is due to rickets or poliomyelitis. These conditions can be treated and are fortunately now very rare.

Scoliosis is not caused by bad posture, carrying a heavy backpack, or anything the child or parents did or did not do.

How can I encourage my child to wear their brace?

Encouraging a young person to wear a brace can be difficult. There will be times when it feels hot and uncomfortable and they may feel self-conscious and different from their friends.

We know that young people find it helpful to speak to others who have been through the bracing process. Our support groups and community network can facilitate these conversations. You could also ask their school to host an assembly to increase understanding of the condition.

How long does it take to recover from scoliosis surgery?

Recovery looks different for everyone. After the operation, patients will feel exhausted and have some pain, but this will be managed with medication. Eating, drinking and moving after surgery is an important part of the recovery process. The time spent in hospital is usually between 4 to 7 days. By this time, the patient should see some mobility returning and can gradually build up activity levels.

For children, teenagers and young adults, the general guideline for returning to education is around 6 weeks post-operation.

Specialists will advise on when activity and exercise can be resumed. Many patients will be able to carry out normal activities around six months after the operation. For some activities, such as contact sports, it will be longer - usually around nine months to a year after the operation.

Visit our website for further information on surgery:

ssr.org.uk





Contacts

The Myths



Myth: Having scoliosis means that a child or young person cannot undertake sport or exercise.



Myth: Playing sports will worsen scoliosis.



Myth: Having scoliosis means you will be unable to have children, a healthy pregnancy or a natural birth.



Myth: Scoliosis will always require surgery.



Myth: After surgery, you cannot take part in other physical activities such as horse riding, sky diving and contact sports.

The Facts



Fact: Having metalwork in the spine will not necessarily set off the detection system at airports.



Fact: Parents often don't notice their child's scoliosis for some time. Nobody is to blame for not spotting the curvature sooner.



Fact: Keeping active improves muscle strength in the spine. Specialists should advise on this.



Fact: After surgery, most patients will be able to resume daily activities relatively quickly. Specialists should advise on this.



Fact: Scoliosis cannot be prevented. In most cases it is idiopathic, meaning there is no known cause.



Fact: A scoliosis diagnosis does not necessarily result in surgery. Many patients will have their spine monitored regularly to make sure the curve is not increasing.



Fact: All scoliosis surgeries carry risks, but paralysis is extremely rare.



Fact: In some cases surgery is the only option for large curves at high risk of progression. 2-3% of the population will have scoliosis and 10% of them may require surgery. 50 degrees is the typical indicator for surgery because the curve is at a high risk of progressing into adulthood.



Fact: Scoliosis has no effect on conception. In most cases, there are no issues with pregnancy and labour.



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Scoliosis: Know the Facts Sixth Edition: 2025 Planned Date of Review: March 2026

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