

A photograph of a woman from the back, with her arms raised and hands clasped behind her head. She is wearing large, heart-shaped earrings. The background is plain white.

Scoliosis

Know the Facts



Scoliosis

What is it?

Scoliosis is when the spine twists and curves to one side.

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.

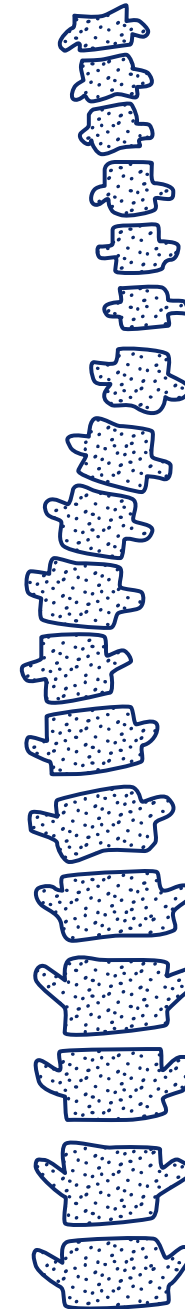
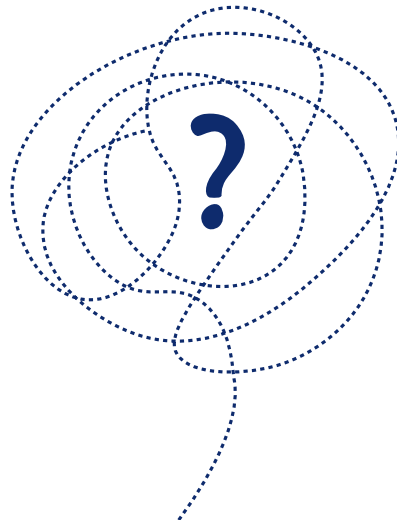
Scoliosis can happen at any age.

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 family member has scoliosis can be a shock. Many people have never heard of scoliosis and have little understanding of the effects it may have. It can leave people feeling isolated and overwhelmed.

We're here for you. We can help you to reduce feelings of isolation, worry, fear, and poor body image. We can also support you to access adequate care and information and provide advice for pain management.

Following the merger of Scoliosis Association UK (SAUK) and British Scoliosis Research Foundation (BSRF), we now also fund high-quality research into scoliosis and other spinal conditions, as well as providing advice and support.

Advice and Information

We offer a free and confidential helpline for those affected by scoliosis. Please call our helpline on:

020 8964 1166

Our website provides up-to-date and reliable information and advice about scoliosis and treatment options.

www.ssr.org.uk

We also run online support groups facilitated by a qualified counsellor for all ages. These provide the opportunity for those living with scoliosis to engage with others facing similar issues in a safe and supportive environment.

Finding a specialist

If you or a family member are diagnosed with scoliosis, it is important to see a specialist. We can provide a list of specialists near you.

Talking to others

Our community network allows us to bring those with scoliosis and their families together. Many have found the support and advice of others in the community to be a great comfort.

For more information on the various support services we provide, please e-mail us at **info@ssr.org.uk** or call **020 8964 1166**.

How you can help us

We receive no government funding so rely solely on donations and fundraising efforts. If you would like to support our work, please email **fundraising@ssr.org.uk** or call us on **020 4537 4139**.



www.ssr.org.uk

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Contacts

Who can be affected?

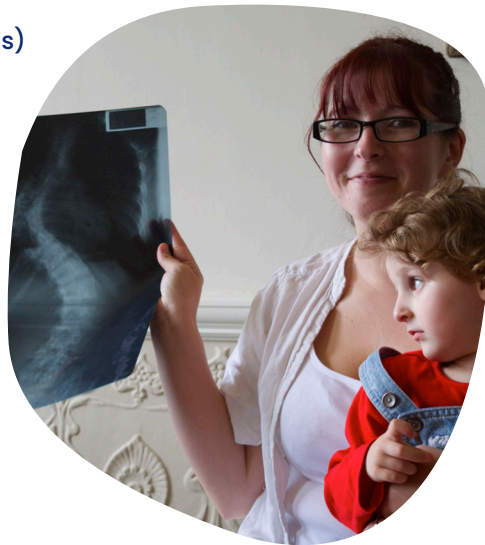
Babies and Children

(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.

Adolescents

(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.

Adults

(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.

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:

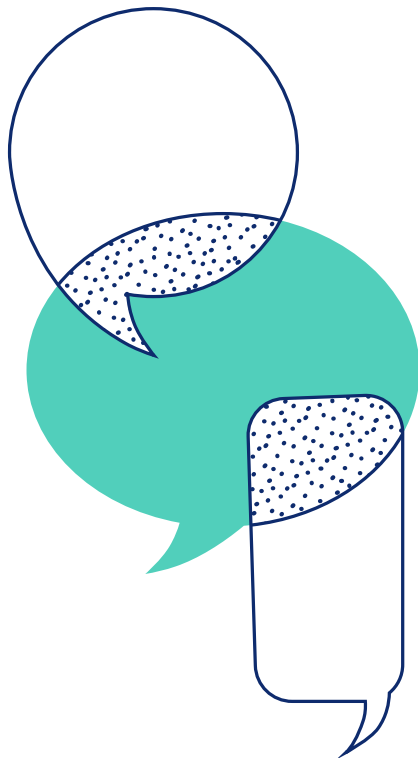
020 8964 1166 or **info@ssr.org.uk**

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, you will be examined, X-rays will be taken and you will be told the Cobb angle. 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:

0208964 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?

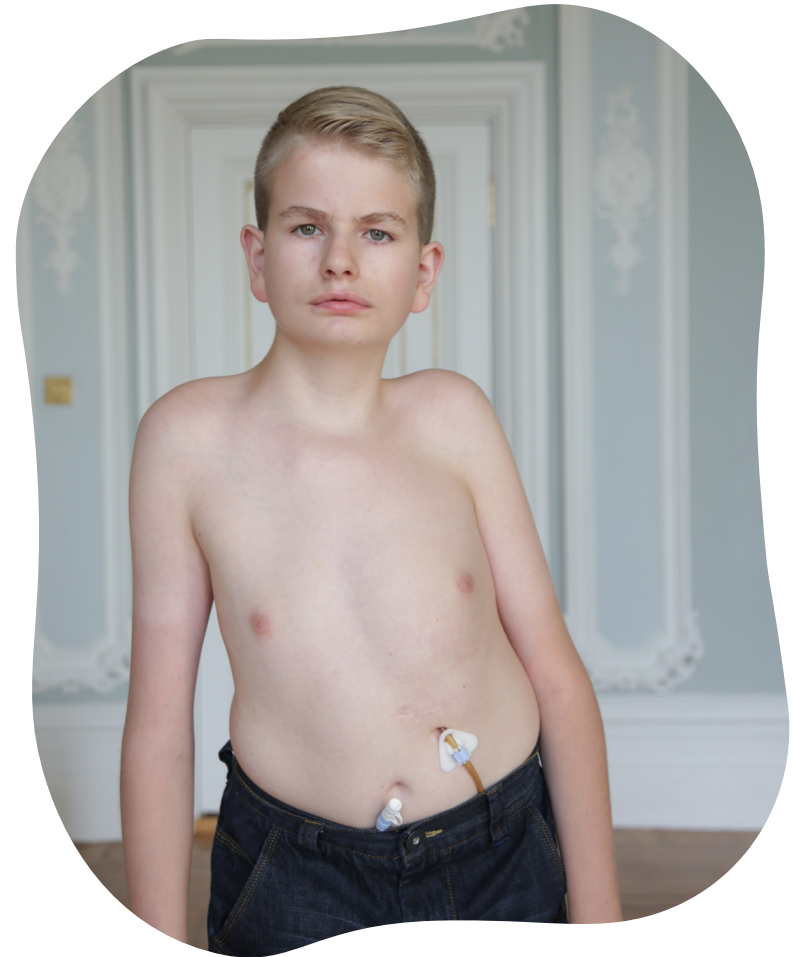
Recovery looks different for everyone. After the operation, patients will feel exhausted and have some pain, but this will be managed with medication. Eating, drinking and moving after surgery is an important part of the recovery process. The time spent in hospital is usually between 4 to 7 days. By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



If you still have further questions, please get in touch with us on:

020 8964 1166 or info@ssr.org.uk

The Myths

The Facts



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.



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



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



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



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



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



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



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



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: 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.



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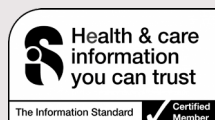
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