

Syndromic scoliosis

Cause

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. Some syndromes in which scoliosis is likely to occur are connective tissue disorders (Marfan's and Ehlers-Danlos syndrome), trisomy 21, Prada-Willi, Retts syndrome and Beale's syndrome.

Diagnosis

Most patients are diagnosed with a syndrome in their early years. The medical staff involved in their care will be aware that scoliosis may occur. The patient will therefore be checked regularly for signs of curvature in their spine.

Treatment

Depending on the child's age and underlying condition the treatment may be similar to treatment offered for idiopathic scoliosis. Some syndromes might mean a patient is not mobile. In these cases, seating aids may be used to allow the child to sit more comfortably in their chair. Surgery may also be offered to allow the child to sit more comfortably.

Monitoring

In some cases no treatment will be needed and the child will simply be checked regularly by a scoliosis

specialist, usually every 6 months or a year. During times when the child is growing more slowly, monitoring may be up to every 2 years.

Casting

Young children with syndromic scoliosis may benefit from having a spinal cast (sometimes called a plaster jacket). This cast helps to guide the growing spine and may improve the shape of the spine as it grows, or may stop the curve getting worse. Casts start from the underarms and cover the whole of the trunk (upper half of the body also known as the torso).

The cast is made of light materials (fibreglass or plaster-of-Paris). It cannot be removed but is changed regularly as the child grows and the shape of the back starts to change. Casts need to be done in a special way. They have a hole in the chest or stomach area so that the lungs and trunk can expand and the child can eat and breathe properly.

In children under 2 years old, the cast will be changed every 2-3 months with the aim of making the spine straight.

Many parents find it easier for their child to wear a cast because it avoids the problem of getting the child to wear a brace each day. However, a removable brace may still be needed after this treatment.

Bracing

If the curve is getting bigger, and the child is still growing, the specialist may want to put the child in a brace.

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A brace does not usually reduce the size of the curve. The aim of bracing is to stop the curve getting bigger too quickly. Slowing down progression lets the child keep growing for longer before a more permanent treatment, such as surgery, is needed. Braces are usually worn 20 hours per day. They can be taken off for bathing, sports, and a break in the morning and evening. As the child grows, new braces will need to be made.

Surgery

If casts and braces don't stop a curve getting bigger the child may need an operation. The most common type of operation for children under the age of 10 is to attach growing rods to the child's spine.

Growing rods help to guide the spine as it grows so that the curve does not get too much bigger. The rods are usually attached to the spine above and below the curve. They can reduce it by up to half the size when first fitted. The child then returns to hospital every 4 to 6 months for the rods to be made longer to keep up with their growth.

The rods might be lengthened by a short operation (small cut, usually just an overnight stay in hospital). There is also a type of rod that can be lengthened without this surgery. These rods are called magnetic rods. They are lengthened by a magnet. The lengthening is quick and painless. With magnetic rods no surgery is needed to lengthen the rods and the child is awake as it is done, usually in the outpatient clinic

Some children will have to wear a brace to protect the rods. When the child becomes older and the spine has grown, the doctor will remove the rods. At this stage, usually the patient will have a final spinal operation called a spinal fusion. In some cases

surgery will not be possible because of other health conditions caused by the syndrome.

Prognosis

For someone who has scoliosis due to a syndrome, the aim of surgery would be to control the curve in a safe and comfortable position to allow for the patient's other health needs.

Some neurological conditions mean there are changes and complications as the person gets older. This means the spinal curve might change or a further curvature could develop, even if surgery has been successful.

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