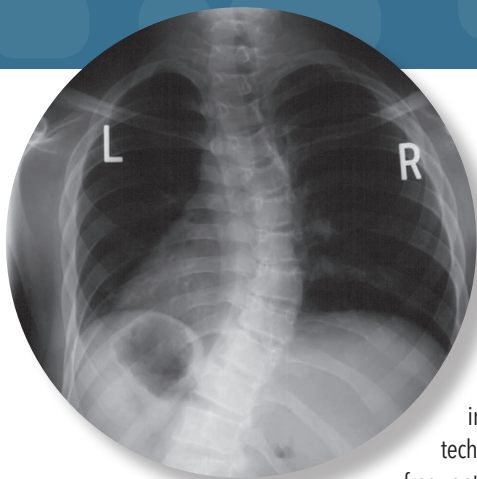


A woman with long blonde hair, seen from behind, is wearing a white sleeveless dress. She is holding a large, vibrant rainbow flag aloft with both hands above her head. The background is a bright green field under a clear sky. The image is framed by blue decorative borders at the top and bottom with abstract circular patterns.

Scoliosis: An Owner's Manual

What you need
to know about
Adolescent
Idiopathic
Scoliosis.



HOW IS AIS DIAGNOSED?

The spine is made up of a number of bones (or vertebrae) stacked on top of one another. When seen from the back, the spine bones should be stacked in a straight line. For reasons that are not understood, the vertebrae can sometimes be stacked in a curved or a rotated position, so that they resemble a "C" or an "S". This leads to the condition called scoliosis. Because it occurs most commonly in teenagers and because the cause is unknown (the technical word is 'idiopathic'), this condition is most frequently referred to as Adolescent Idiopathic Scoliosis or AIS.

Although the exact cause of AIS is not known, it has been clearly shown that it is not caused by anything that the parents or child did or didn't do while growing up. Diet, exercise, poor posture or carrying a backpack do not cause scoliosis. However, they can have an important effect on children with scoliosis.

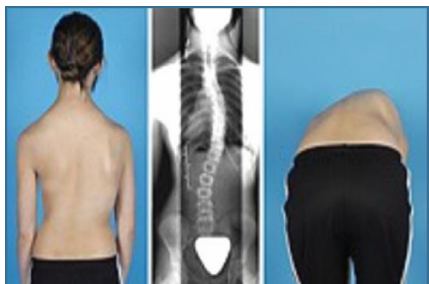


Image 1. The visual identifiers of potential scoliosis.

Of the approximately 2-2.5% of adolescents with scoliosis, the curve will worsen in about 10%. Though it is unclear why, scoliosis occurs equally across gender but progresses 8 times more in girls than in boys. This is why many specialists recommend that girls especially, but in fact all children, be screened frequently during growth.

What you need to know about Adolescent Idiopathic Scoliosis

Although most AIS cases are found on screening or at doctor's examinations, many cases are actually seen by the child or the parents during sporting events or while in swimsuits. Scoliosis does not generally cause pain in younger people, so it may not be diagnosed until the curve is visibly noticeable. However, there are often subtle signs of asymmetry which can be detected in screening even small curves. The child's ribs, waist or shoulders may be uneven, one arm may hang lower than the other or farther away from the body, or one shoulder blade may protrude. One frequently overlooked sign is that the hips may be uneven with one side appearing higher or sticking out more.

When the child bends forward, the back may seem even more uneven with one side raised up, and there may be more obvious curvature. The examiner may measure how much asymmetry there is in the ribs or the back with a device called a Scoliometer, which is just like a carpenter's level.

HOW COMMON IS AIS?

Scoliosis affects an estimated 7 million people in the United States. While scoliosis may develop in infancy or early childhood, the most common age for it to occur is early puberty, with most cases first detected between the ages of 9 and 13. The condition is related to growth and if it is going to get worse, it will mainly do so when the child is growing most rapidly.

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A small air bubble in a fluid filled chamber will not stay level as the device tilts, and that will give a measurement of the amount of prominence. It is important to remember that even though the Scoliometer can give a degree measurement, it does not give the amount of actual curvature or scoliosis that the child has.

If there is a significant alignment problem on the screening exam, the physician may take an x-ray of the back – a picture of the bones in the spine which can be measured to see how much curve there is. The curve is measured using a technique called the Cobb Angle (CA), which determines the angle in which the bones sit with respect to each other. If the angle on the x-ray is more than 10° then the curve is considered a true scoliosis. Scoliosis is considered mild from 10-25°, moderate from 25-40° and severe when over 40° by Cobb angle measurement.

SHOULD I TAKE MY CHILD TO A SPECIALIST?

According to the Scoliosis Research Society, the Cobb angle, physician observation and age of the child should determine whether a patient requires observation or treatment under the guidance of a specialist, such as a pediatric orthopedic surgeon. In general, it is recommended that any curve that seems to be progressing or that is about 20°, should be referred to a specialist. In fact, a whole medical team may be involved in treating a child's scoliosis depending on the recommended course of treatment. The team might include the pediatric provider, physiotherapist (PT), orthotist for bracing, and/or a mental health professional, as well as the spine specialist. Parents, teachers, coaches, friends and other family members may be important supports for the child as well.

WHAT IS THE PROGNOSIS FOR AIS?

Once a child is diagnosed with AIS, the most natural questions is "What is going to happen with the curve?" Because the behavior (or prognosis) of scoliosis is uncertain, the diagnosis may raise far more questions than can be answered.

Treatment decisions are based on the progression of the curve over time. Since scoliosis may get worse during times of rapid growth, the child's skeletal maturity is determined. This takes into consideration the child's age, signs of maturity such as facial and body hair or breast development, whether a girl has started having periods, and x-ray signs such as the shape and development of the bones and whether certain growth areas are still open in the hand (Bone Age) or the pelvis (Risser sign). The combination of the amount of curve, the age at the time it is detected and prediction of growth and maturity, have classically been used to determine the prognosis of a curve.



Image 2. The Scoliometer in clinical practice.

Reference: Izatt et al. *Scoliosis* 2012 7:14 doi: 10.1186/1748-7161-7-14

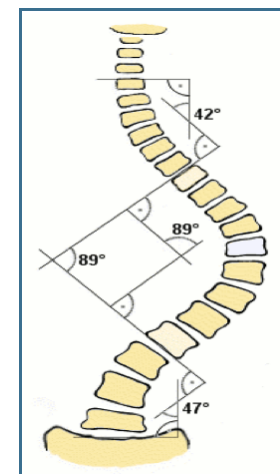


Image 3. Illustration of Cobb Angle measurements.



Another tool for determining the prognosis is to test for genes which are known to be associated with progression of the curve. This is done by a technique called the ScolioScore™ Test, which analyzes a child's saliva for 53 genetic markers associated with spinal curve progression in AIS patients. The test must be ordered by a doctor and is administered in the doctor's office.

Each ScolioScore (between 1 and 200) is unique to the child's genetic make-up and informs a physician about the likelihood that the child's curve will either not progress (low score, 1-50) or will progress to require treatment (high score, 181-200). Knowing a child's risk of progression allows clinicians to personalize the patient's treatment plan. For those with a low risk of progression, there may be fewer office visits and x-rays reducing cost and radiation exposure. For high risk children, the specialist may be able to be more aggressive with braces and exercises which may decrease the risk of needing surgery. The ScolioScore Test is indicated for self-reported Caucasian (North American, South American, European, Eastern European, Middle Eastern) children with AIS who are aged 9 years to skeletal maturity and have a mild curve (Cobb angle 10-25°).

WHAT ARE THE GOALS OF TREATING AIS?

In addition to treating the physical spinal curve, specialists are concerned with the overall well-being of the patient.

Common treatment goals include:

- Aesthetic look of the spine
- Quality of life now and future
- Psychological well-being
- Avoidance or reduction of disability
- Diminished back pain
- Improved breathing and other organ functions
- Improved scoliosis Cobb angles
- Avoidance of progression and need for further treatment into adulthood

WHAT ARE THE TREATMENT OPTIONS FOR AIS?

In general, Cobb angle curves less than 20° require observation about twice a year. The physician may obtain x-rays to make sure that the scoliosis is not progressing. A curve that is between 25° and 40° may require intervention either with physical therapy exercise and/or bracing, as prescribed by a scoliosis specialist. Surgical treatment is generally reserved for the most severe cases, those with Cobb angles over 50°.

Despite improvements in our understanding of the possible progression of AIS, debate continues regarding the most appropriate treatments for AIS.



METHODS TO CONSIDER:

Observation

Mild curves (less than 20°) are monitored by physicians every six to twelve months. During these appointments, the spinal curve will be analyzed and x-rays may be taken to determine if there is progression of spinal curvature.

Scoliosis-Specific Exercises

Though research continues, many specialists believe scoliosis-specific exercises (SSE) in tandem with bracing may benefit patients. Self-directed exercise programs focus on active self-correction and postural control, spinal stability, aerobic functioning, strength training and development of a positive body image. There are several different SSE methods available. A physician can advise which exercise program may best benefit each individual patient. For further information refer to www.sosort.org.

Bracing

Mid-range curves (25° and 40°) are commonly fitted with a body brace. The body brace is meant to support the spine and prevent progression. There are many types of braces, and the specialist will determine which type is best, the hours per day the patient should wear the brace, and its duration of use. A brace is usually worn until growth stops or the scoliosis stabilizes, usually around two years. Recent studies have shown the effectiveness of bracing in stopping progression of curves, but there is still controversy amongst experts regarding which children ultimately will benefit from bracing.

Alternative Interventions

Parents may seek different treatment approaches within the field of complementary and alternative medicine (CAM), even in conjunction with orthopaedic treatments. These options may include osteopathy-manual interventions, chiropractic adjustments, and flexible postural stabilizers. Although these treatments have definite merits, their effectiveness at stopping progression of scoliosis has not been proven in the medical literature.

Surgical Treatment

Most providers recommend surgery (spinal fusion) when curves progress to greater than 50°, although that may vary depending on the individual patient situation. Other factors, such as pain and other symptoms, the risk of late progression and the trunk balance and appearance may also factor into the decision-making process. The goals of surgical treatment are to achieve curve correction and prevent curve progression. This is generally achieved by placing metal implants onto the spine which are then attached to rods to correct the spine curvature and hold it in the corrected position. Bone graft is placed around the devices, so that the corrected spine will be a stable solid construct. This is called spinal fusion or the knitting of the spine elements together. The surgery and healing process are complex and may take as long as six to twelve months for full recovery.



WHAT ARE THE TYPICAL OUTCOMES FOLLOWING TREATMENT FOR AIS?

GENERAL CONSIDERATIONS

Any case of AIS, even a small curve, has been shown to have a risk of increased pain into adulthood. As with any back problem, children with AIS must learn to be very careful with their backs. Backpacks should be carefully weighted and carried with the straps tight so that the bag does hang down to the lower back. The child should consider alternatives to a standard backpack, like a rolling bag or a messenger bag carried over the shoulder and on the hip.

Athletics are very important to children with AIS. The child should stay as fit and active as possible and maintain her or his ideal body weight as discussed with the pediatrician. Some sports, like dance or yoga may need to be modified so that the individual can fully participate. It is also very important to stretch the back before and after sports and other strenuous activities.

A child with AIS must be very careful with her or his diet. Nourishing high-protein foods will help support the muscle frame. Calcium intake is vital, since the mineral can only be incorporated into the bones until around 25 years old and weakness of the bones in a curved spine can have a significant impact later in life. The child's pediatrician or a nutritionist can be very helpful in personalizing the proper diet.

BRACING RESULTS

A recently published study in the *New England Journal of Medicine* evaluated the effectiveness of bracing, as compared with observation, in preventing progression of a curve to 50° or more (a common indication for surgery). The study concluded that in children considered to be at high risk for curve progression, bracing can effectively slow progression over time, assuming bracing compliance. In general, other studies show that brace wearing does not seem to decrease an adolescent's quality of life.

SURGICAL RESULTS

Most patients are very satisfied with the outcome of their surgeries, especially into early adulthood. According to some post-spine fusion studies, AIS patients consistently demonstrated improved quality of life scores, including improved function, improved self-image and decreased pain from preoperative values. Other studies have more mixed results.

Some reports have shown that individuals may have significant rates of back pain long after spinal fusion. Activity levels, fitness and nutritional circumstances seem to improve the overall function later in life.



WHAT KIND OF SUPPORT WILL A CHILD WITH AIS NEED?

Adolescents diagnosed with AIS may experience stress and anxiety about what the condition means for them and how they will cope with the possible treatments. A recent study found that adolescents with progressive AIS report lower self-image and worse quality of life than children without scoliosis. Of course, the effectiveness of the treatments, particularly bracing, is very much related to the adolescent's physical, emotional and social well-being. Parents need to be understanding of the challenges their child will face as they are being treated for AIS.

Scoliosis specialists should strive for optimal AIS care by working together with the patient and family to provide an individualized patient centered treatment plan. Overall, the decision parents and adolescents must make regarding non-operative and/or surgical treatment should be based on the individual patient's disease characteristics, curve type, risk factors for progression, personal needs and expectations.

GLOSSARY

Asymmetry refers to two halves not being identical on both sides of a central line. In the case of AIS, asymmetry refers to the back and shoulders being unevenly set compared to the spine, which is curving.

Cobb Angle is a measurement of a curved spine that is used to diagnose scoliosis. Lines are drawn on an X-ray of the spine to form an angle. The physician measures the angle to determine the ° (degree size) of the curve.

Idiopathic is having a disease/condition of unknown cause.

Scoliosis is an abnormal or asymmetric curving of the spine, usually in a "C" or "S" shape.

WANT TO LEARN MORE? For more information.

Curvy Girls Scoliosis Support Groups:
www.curvygirlsscoliosis.com

National Scoliosis Foundation:
www.scoliosis.org

National Institutes of Health:
www.nlm.nih.gov

ScoliScore™:
www.ScoliScore.com

Scoliosis Research Society:
www.srs.org

SOSORT:
www.sosort.mobi



This educational information was brought to you Transgenomic, makers of ScoliScore™, the first clinically validated and highly accurate prognostic test for AIS curve progression www.scoliscore.com.

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