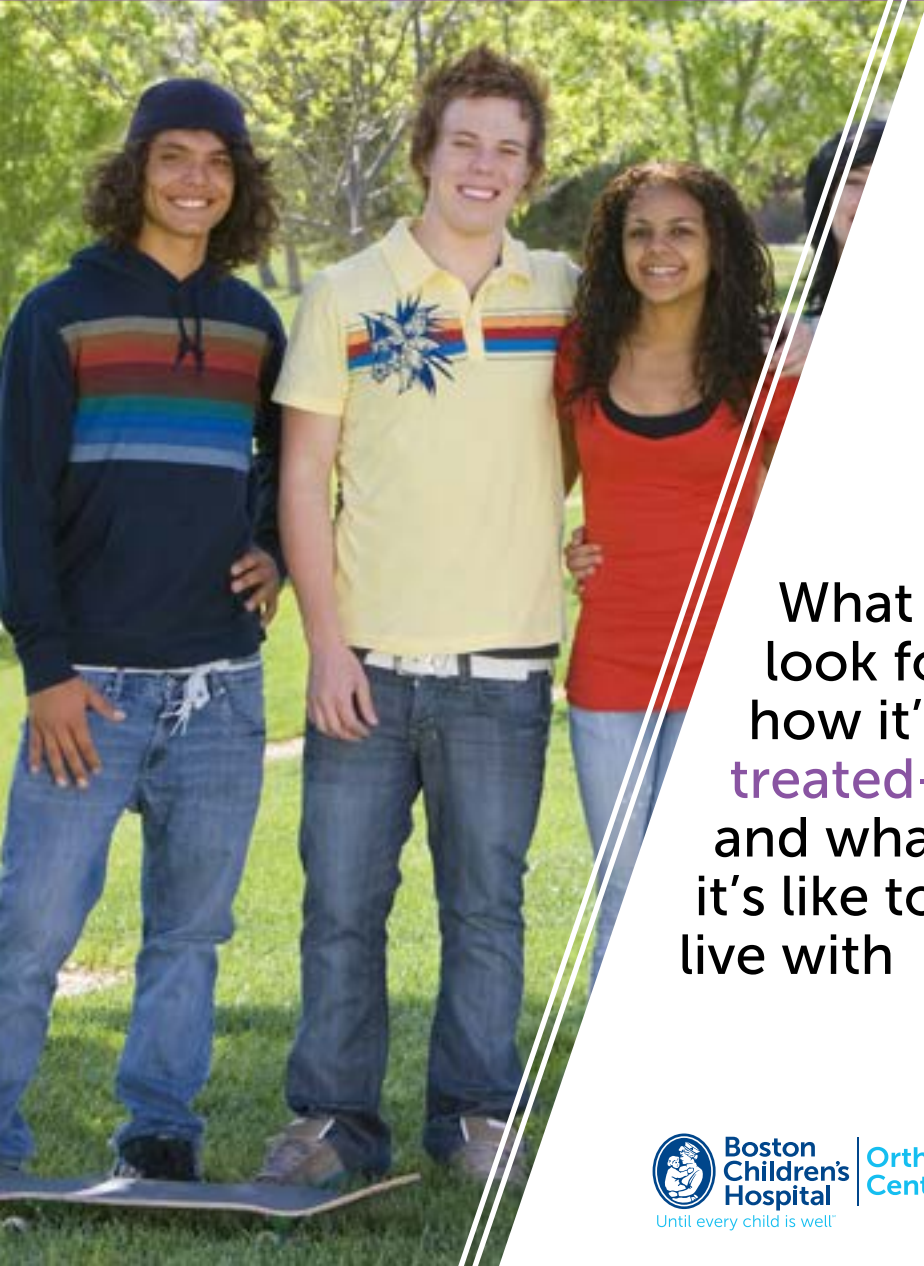


Patient and family guide to scoliosis

*Prepared by The Spinal Program at
Boston Children's Hospital's Orthopedic Center*



What to
look for,
how it's
treated—
and what
it's like to
live with



**Boston
Children's
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Until every child is well™

**Orthopedic
Center**



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Until every child is wellSM



1

What is scoliosis?

Scoliosis is a condition in which the spine has an abnormal side-to-side “S”- or “C”-shaped curvature.

In addition, the spine may also rotate or twist, pulling the ribs along with it to form a multidimensional curve. The Scoliosis Research Society defines scoliosis as a curvature of the spine measuring 10 degrees or greater on x-ray.

Most of the time, scoliosis is more of a cosmetic challenge than a health challenge, and children and teens may not

experience pain or other symptoms. In more severe cases, bones may twist in a way that puts the organs at risk. Usually when this happens, surgery is required.

Scoliosis occurs and is treated as three main types:

Idiopathic scoliosis is the most common form, with no definite cause. It mainly affects adolescent girls but

also appears in infants and juveniles.

Neuromuscular scoliosis is associated with a neuromuscular condition such as cerebral palsy, myopathy or spina bifida.

Congenital scoliosis, the least common form, is present at birth and is caused by a failure of the vertebrae to form normally.

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What is the anatomy of scoliosis?

The normal spine is strong and mobile.

While it varies in size and shape from person to person, the healthy spine has natural front-to-back curves that enable us to walk, balance, sit, stand and twist. When these natural front-to-back curves become too large, they can present a potential problem.

The scoliotic spine is rotated or twisted to form a multi-dimensional curve. Spinal curvature from scoliosis may occur on the right or left side of the spine, or on both sides in different sections. Both the mid (thoracic) and lower (lumbar) spine may be affected by scoliosis.



Normal spine viewed from the front (left) and side (right)

Scoliotic spine

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Who gets scoliosis?

Scoliosis is not rare and mainly affects girls, many of whom have mild forms of the condition and are never even aware of it.

Three to five children out of every 1,000 develop spinal curves that are considered large enough to require treatment.

Idiopathic scoliosis tends to run in families, although no definitive genetic link has been confirmed. Girls are more likely to have a curve that progresses.

Risk factors for developing idiopathic scoliosis include:

- » **Age:** Signs and symptoms of scoliosis may begin to manifest themselves with the onset of puberty, during the maximum growth spurt.
- » **Gender:** Girls are five to eight times more likely than boys to develop scoliosis that requires active treatment.

» **Heredity:** Idiopathic scoliosis tends to run in families.

In most cases, there is no definite cause or way to prevent the spine's failure to grow as straight as it should. Scoliosis is a spinal abnormality—it's neither a cause nor a result of poor posture or use of a backpack.

Visceria was treated for scoliosis as a pre-teen. As a teen, she's now back to sports and cheerleading.





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What are the signs and symptoms of scoliosis?

Because of the many possible combinations of curvatures, scoliosis can be very different in different people.

Screening will reveal common signs and symptoms of scoliosis, including:

- » uneven shoulder heights
- » head not centered with the rest of the body
- » one prominent shoulder blade
- » uneven hip heights or positions
- » when bending forward, the left and right sides of the back are asymmetrical
- » uneven shoulder blade heights or positions

To watch a video about scoliosis management at Boston Children's Hospital's Orthopedic Center, please visit bostonchildrens.org/scoliosis





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How is scoliosis diagnosed?

Sometimes curves are obvious, but other times they aren't immediately visible.

Since scoliosis curves often aren't painful and usually progress slowly, they can be overlooked until a child approaches puberty.

The Adams Forward Bend test is a common way to look for scoliosis. During this examination, the patient puts her hands together and bends forward while keeping the knees straight—making her spine visible and curves or unevenness more obvious. The clinician can observe any unevenness in the hips, ribs or shoulder or use a scoliometer to measure the degree of a curve. If a curve measures more than 5 to 7 degrees on the scoliometer, this may indicate scoliosis. The curve's overall impact will depend on the child's age and bone maturity.

During physical exams, the physician will be looking for and measuring abnormal contours that indicate scoliosis. Through physical exams and diagnostic testing, the doctor will determine the:

- » Shape of the curve ("S"- or "C"-shape; involvement of ribs and muscles)
- » Location of the curve (upper thoracic spine; lower lumbar spine; or both—thoracolumbar)
- » Direction of the curve (bend to left or right)
- » Angle of the curve in degrees (Cobb angle)

Once a condition is detected, doctors use medical and family history, physical exams and diagnostic tests to determine the nature and extent of the child or teen's scoliosis.

Commonly done:

X-rays (front and side)

Occasionally done:

Magnetic resonance imaging (MRI)

Rarely done:

- » Computerized tomography scan (CT or CAT scan)
- » Blood tests
- » Ultrasound (sonogram)
- » Bone scans
- » Bone density scans (dual-energy x-ray absorptiometry, DEXA, DXA)
- » Pulmonary function tests



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How is scoliosis treated?

Treatment for scoliosis depends on the nature and severity of the condition. Treatments can include:

Treatment without surgery

Simple observation and monitoring: Once an abnormal spinal curve has been detected, it's important to monitor it closely as the patient grows. In many cases, this may be the only treatment needed. The child's physician will determine the appropriate treatment plan and follow-up based on her x-rays and physical exams. Referral to an orthopedic specialist may be recommended.

Physical therapy: Physical therapy may address any pain and imbalance that can be associated with spinal abnormalities.

Bracing: If a patient's curve shows significant worsening or is already greater than 30 degrees, the physician may recommend a bracing program, in which a scoliosis brace

is custom-designed to suit a particular curve. The brace holds the spine in a straighter position while it grows, both to help correct the curve and prevent it from getting worse. This may help avoid the need for surgery. (See next section for more on bracing.)

Casting: In certain situations—as in some cases of early-onset (infantile) scoliosis—body casting is done to help straighten the spine.

Treatment with surgery

In more severe cases, surgery can help correct spinal problems.

Spinal fusion: The most common surgical procedure for treating spinal problems in adolescents is fusion and instrumentation combined to correct and solidify the curve.

For younger, growing children: Dual poste-

rior growing rods control spinal deformity while allowing spinal growth with periodic lengthening (for early-onset scoliosis).

Expansion thoracostomy/ VEPTR™ (titanium rib) is a procedure to control chest and spine deformity while permitting growth of both the chest and spine.

Vertebral stapling is a minimally-invasive surgical alternative to bracing for scoliosis in some circumstances.

Hemivertebra and wedge resections (for congenital scoliosis) is removal of the abnormal spine segment and reconstruction of the spine.

Spinal osteotomy is the controlled breaking or cutting and realigning of bone into a corrected position. It may be performed when there is significant deformity.



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A closer look at bracing

Scoliosis treatment depends on the curvature's location and degree of severity.

Slight curves (measuring less than 20 degrees) usually require no treatment but must be monitored carefully during growth.

If a patient's curve shows significant worsening or is already greater than 30 degrees and she is still growing, her doctor may recommend a bracing program.

A scoliosis brace is designed especially for each patient and her particular curve and may help avoid surgery. The patient will need to wear her brace for the prescribed daily time until she finishes growing. Most braces can be hidden beneath normal clothing, and the patient can continue to do all athletic activities.



The physician usually works with a team of professionals, such as orthotists and physical therapists, who will help each patient adjust to bracing treatment. An orthotist is a professional trained in the construction and fitting of the spinal brace. Construction of the individual customized brace includes measurement of the patient's body contour, manufacturing of the brace and final fitting of the brace to the patient. The process takes several visits to the orthotist and several weeks to complete.

The physical therapist (PT) will evaluate the patient's posture, muscle strength and flexibility. The PT will provide her with a home

exercise program designed specifically for her. This program helps to stretch and strengthen the child's muscles so that she is more comfortable in her brace.

A bracing program can be challenging, and the patient may need help in organizing her daily activities. In many cases, clinical staff will help the patient and her parents with their questions and appointments. Staff members will also teach the child how to care for herself and her brace, give her a schedule to follow and help her plan day-to-day activities.

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What's the long-term outlook for kids with scoliosis?

As a patient grows, an orthopedist will monitor her curve through frequent checkups.

No matter how old someone with scoliosis is, she can be encouraged to live normally and participate in sports or school activities. These will add greatly to her general health and sense of well-being.

The outlook for each person greatly depends on the nature and severity of her scoliosis and her age. Since older teens have already completed the majority of growth, their bones probably won't evolve as much as a

younger child's would. Early diagnosis and early treatment can improve the outlook for many forms of scoliosis—and most children and teens diagnosed with scoliosis can look forward to normal, active lives.



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Chloe's mantra: Embrace the brace

By: *Chloe Conway*, guest blogger. Reprinted with permission from *Thriving*.

Scoliosis is and always will be a struggle for me, but I will not let it stop me from doing anything. I have learned to love my spine. It defines who I am, and I am a stronger person because of my brace—emotionally, mentally and physically.

In August 2012, I discovered I was crooked. My cross-country coach noticed that I ran tilted, with one shoulder much higher than the other. When I saw the doctor, he told me I had scoliosis. My 18-degree "S"-curve increased to 24 degrees in December 2012. By April 2013, I learned that my upper thoracic curve and lower curve had increased to 32 and 25 degrees, respectively.

Running free

I knew that I would eventually need a brace, but when the doctor showed me that horrible piece of plastic, it was a whole dif-

ferent story. I turned into a statue.

When my brace was ready for me to wear, the orthotist who makes the braces showed me an assortment of patterns—Scooby-Doo, butterflies and rainbow—but I chose flesh-colored, the most inconspicuous of them all.

My brace stretches from over my hips, with the left side reaching down to my thigh, to the top of my rib bones in the front and above my shoulder blades in the back. When I first tried it on, I felt like I was strapped in a corset.

I was instructed to ease into my brace and wear it a couple of hours at a time. The first night I wore the brace, I felt like a turtle flipped on its shell. When I started to wear it at school, I wore it for three hours and then took it off in the nurse's office. In a few days, I became

frustrated with having to go to the nurse's office, so I wore it the entire day. My only break from the brace was showering and running.

When I run, I feel like I am released from a cage. I love the feeling of being free, but sometimes it feels foreign and weird to be without my brace.

Like any 15-year-old, clothes and fashion are very important, but when I first tried on my clothes with the brace, its entire outline was visible. At first, this upset me, but then I took it on as a fashion challenge. I rearranged, layered and accessorized my clothes until the shape of my brace was hardly noticeable.

Last summer, my mom and I started the "Chloe Project," my way of fighting scoliosis. To strengthen my muscles equally, my body must be neutral.



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Chloe's mantra continued

After talking it over with my orthopedic surgeon from Boston Children's Hospital Orthopedic Center, M. Timothy Hresko, MD, I started a new exercise program.

I swam every other day (my body was neutral in the water). I do Pilates once a week, as well as Schroth physical therapy, a German technique designed for scoliosis. There are postural and breathing exercises to help neutralize the curve of the spine and help "de-rotate" it. To perform the exercises, I had to know everything about the curves and twists of my spine, and it requires lots of concentration. But I do anything I can to fight back because I don't want to look back with regret for not attempting everything to fight scoliosis.

My support network

I am blessed to have the best family and friends to support me. Originally, I was afraid that my friends would think my brace is weird, but instead they seemed excited about it. One day, I had put my brace on the ground at cross-country practice, and one of my friends asked to try it on. I said "yes" and strapped her up. After her turn, every other girl on the team asked to try it on, and not one of them lasted more than 30 seconds in it.

At the beginning of my scoliosis journey, I thought I was all alone. Even with the most supportive family and friends, I felt that I had no one to relate to who would truly understand what I was going through. That is when I became a Curvy Girl.

Curvy Girls is an international support group

for girls with scoliosis. When I found out there was no New Hampshire (NH) Chapter, I created one. We meet once a month and talk about our braces, surgery, clothing, pain and anything to do with scoliosis. There are plenty of tears, but also lots of laughter. Wearing my brace for the correct amount of hours is tough, but starting Curvy Girls NH and meeting other girls with scoliosis has helped all of us.

I would not change a thing because without my scoliosis, I would not have met so many wonderful and inspiring girls who have become my friends. I hope to help other girls "embrace the brace" like me. Although I do not know how many years I will wear my brace, or if I will have to have spinal surgery, I am ready to face whatever comes my way and not back down.



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Glossary of helpful terms

Adams Forward Bend test: a screening tool for scoliosis.

Adolescent scoliosis: a classification of idiopathic scoliosis representing the vast majority of cases—mostly occurring in girls 10 to 18; many cases of this kind of scoliosis don't require any kind of treatment.

Brace, bracing (spinal orthosis): If a curve significantly worsens or is already greater than 30 degrees, a physician may recommend a bracing program, in which a brace is designed specifically for a particular curve. The brace holds the spine in a straighter position, while the child or teen grows, in order to partly correct the curve or prevent it from increasing.

Casting: an option for holding the spine in a straighter position while growing. This is used in

specific situations, as in some cases of early-onset (infantile) idiopathic scoliosis.

Cobb angle: an angular measurement on x-ray to evaluate the degree and severity of scoliosis curves.

Congenital scoliosis: The spine forms and develops between three and six weeks after conception. Congenital scoliosis results from abnormal *in utero* spinal development, where a vertebra either doesn't form at all or only forms partially, or there is a lack of separation of the vertebrae.

Diagnosis: identifying disease or injury through examination, testing and observation.

Dual posterior growing rods: Devices affixed to the spine for early-onset scoliosis. These control spinal deformity while allowing spinal growth with periodic lengthening.

Idiopathic scoliosis: the most common form of scoliosis. "Idiopathic" simply means that there's no known cause. Nothing a parent or child did caused the problem, and there's nothing anyone could have done to prevent it.

Infantile idiopathic scoliosis (one of several types of early-onset scoliosis): a classification of idiopathic scoliosis representing about 5 percent of cases. The only type of scoliosis occurring more often in boys from birth to 3 years, it often resolves on its own, but can sometimes be serious.

Instrumentation: the metal rods, hooks, screws and wires implanted during spinal fusion surgery to correct the spinal curve and secure the spine in position while the fusion heals and becomes solid.



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Glossary of helpful terms continued

Juvenile scoliosis: a classification of idiopathic scoliosis representing about 10 percent of cases—occurring in children ages 3 to 9 years.

Neuromuscular: affecting, or characteristic of, both neural (nerve) and muscular tissue.

Neuromuscular scoliosis: scoliosis that's associated with disorders of the nerve or muscular systems like cerebral palsy, spina bifida, muscular dystrophy or spinal cord injury.

Orthopedics: the medical specialty concerned with diagnosing, treating, rehabilitating and preventing disorders and injuries to the spine, skeletal system and associated muscles, joints and ligaments.

Orthopedic surgeon, orthopedist: a physician specializing in surgical and non-surgical treatment of the spine, skeletal system and associated muscles, joints and ligaments.

Orthotics: the science of designing and fitting of devices such as braces to treat orthopedic conditions.

Physical therapy: a rehabilitative health specialty that uses therapeutic exercises and equipment to help patients improve or regain muscle strength, mobility and other physical capabilities.

Progression, curve progression: worsening of a scoliosis curve.

Scoliometer: a surface measurement device for evaluating the angle of trunk rotation (ATR or scoliometer angle, which is different from the Cobb angle measured on x-ray).

Scoliosis: a spinal condition in which the spine, in addition to the normal front-to-back curvature, has an abnormal side-to-side "S"- or "C"-shaped curvature. The spine may also be rotated or twisted, pulling the ribs along with it. Scoliosis occurs in three main types: idiopathic (no definite cause), neuromuscular (associated with neuromuscular diseases) and congenital (present at birth).

Spinal cord: a nerve bundle within the vertebral column that extends down from the brain stem. It conducts signals in both directions between the brain and extremities, and allows for bodily motion and sensation.

Spinal abnormality (spinal problem): a condition in which the spine is abnormal. It may be that the spine's structure has developed abnormally—for example, congenital scoliosis or congenital kyphosis (a forward curve in the upper spine). Some conditions are the result of nerve or muscle (neuromuscular) diseases or injuries—for example, cerebral palsy. In some cases, there is no definite cause (idiopathic) for the spine's failure to develop normally.

Spinal fusion: usually a solid fusion (solidification) of the curved part of the spine, achieved by operating on the spine, adding

bone chips and allowing the vertebral bones and bone chips to slowly heal together to form a solid mass of bone called a fusion.

Spine (spinal column, vertebral column): the series of moving vertebrae forming the axis of the skeleton and protecting the spinal cord.

Spine curves, normal and abnormal: front-to-back and sideways curves of the spine.

- » All spines have normal front-to-back curves. Abnormal front-to-back curves can indicate "round back" (hyperkyphosis) or "swayback" (hyperlordosis).
- » Normal spines don't have much sideways curvature. An abnormal sideways "S"- or "C"-curve can indicate scoliosis.

VEPTR™ (titanium rib) procedure: an operation that expands the chest and

allows continued growth of the chest and spine. A curved metal rod fits the back of the chest and spine, helping the spine to become straighter and allowing the lungs to grow and fill with enough air to breathe. The device is made longer as the child grows. The procedure is used for some early-onset scoliosis, with the device attaching to the ribs, spine or both.

Vertebra, vertebrae: the individual bones that form the spinal column

Vertebral stapling: a newer surgical technique to modulate growth that may prevent the curve progression in children and adolescents with moderate scoliosis. A minimally invasive procedure, stapling may be an alternative to bracing for some children at risk for progression of their scoliosis and the prospect of spinal fusion in their future.

To learn more about
treatment for scoliosis at
Boston Children's Hospital,
call 617-355-6021 or visit
bostonchildrens.org/scoliosis



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