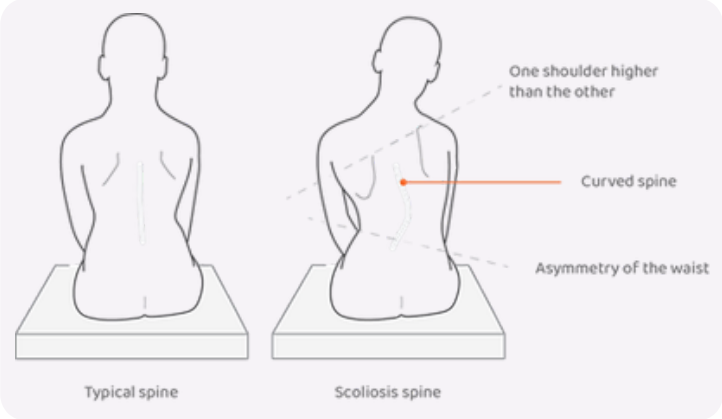
Considering Spine Fusion Surgery for a Child with Neuromuscular Scoliosis

Your child's care team has talked with you about spinal fusion surgery as one possible treatment for scoliosis caused by a neuromuscular condition (described below). This guide explains neuromuscular scoliosis, treatment options, and the possible benefits and risks of surgery to help your family make an informed decision. There is no single "right" choice. The best decision is the one that fits your child's health needs, comfort, and quality of life.

What is Neuromuscular Scoliosis?

Scoliosis is an abnormal curving of the spine. It is a three-dimensional condition, meaning the spine curves side-to side and also twists.

In neuromuscular scoliosis, the scoliosis is secondary to (or as a result of) a primary "neuromuscular" condition that impacts the nervous and/or muscular systems (e.g., brain, spinal cord, nerves, muscles). This may include cerebral palsy, spinal muscular atrophy, spina bifida, muscular dystrophy, arthrogryposis, or a number of other conditions. Because some muscles don't work as well together, it's difficult for the spine to stay upright as a person grows.

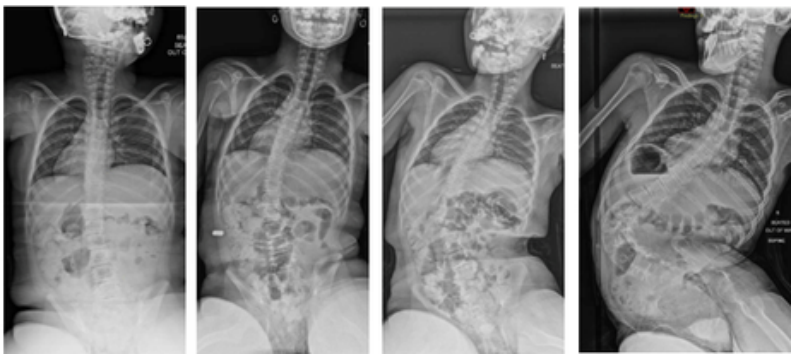


Compared with other types of scoliosis, neuromuscular scoliosis curves are more likely to be C-shaped, to involve pelvic tilt (uneven waist, elevated hips), and to continue progressing even after growth is complete—especially in individuals who do not walk independently or need support for sitting.

Figure 1. The image to the left shows the three common signs of scoliosis: one shoulder higher than the other, a curved spine, and asymmetry of the waist, meaning the two sides of the waist don't match in shape or size.

How Do We Measure and Monitor Scoliosis?

The size of a scoliosis curve is measured on X-ray using the Cobb angle, which is the angle made by the two most tilted vertebrae at the top and bottom of the curve. This measurement helps the care team monitor progression over time. Less than 10° means that there is no scoliosis.



Mild (10-20°) | Moderate (20-45°) | Severe (~45-90°) | Very Severe (>90°)

Figure 2. Repeated X-rays over time, like the ones to the right, are used to determine whether the curve is stable or progressing. Curves of about 50° or greater are often when surgery might first be recommended.

What Scoliosis May Mean for Your Child

As neuromuscular scoliosis progresses, your child and you may notice:

- Increased difficulty with sitting without tipping or leaning
- Increased difficulty with finding a comfortable position
- Increased pelvic obliquity (one hip higher than the other when sitting or uneven waist crease)
- Increased pressure on the skin with risk of pressure injuries
- More effort required for daily care activities (transfers, bathing, dressing)
- Increased discomfort or pain
- Increased difficulty with breathing or digesting food with very large curves

Not everyone experiences all of these challenges, and progression varies from person to person.

Treatment Options

Non-surgical Care

Non-surgical treatments focus on comfort, support, and maintaining function – they do not stop the curve from getting bigger or make the curve straighter. These include:

- Physical therapy for positioning, stretching, and comfort. Many people find that physical therapy helps them maintain or even improve physical abilities; however, there is no evidence that this will prevent the curve from getting bigger or make the curve straighter.
- Bracing to help support sitting up straight and maintain balance while sitting. Bracing does not stop the curve from getting bigger in neuromuscular scoliosis; bracing may make it difficult to practice mobility skills and physical activity. If chosen, bracing is often a long-term commitment because curve progression can continue beyond skeletal maturity.
- Custom seating systems or wheelchair adjustments can offer support; however, similar to physical therapy and bracing, these adjustments will not prevent curves from getting bigger.
- Skin care and pressure relief strategies to prevent or treat pressure injuries.
- Respiratory support when needed.
- Medications for pain or muscle tone management.

These approaches avoid the risks associated with surgery but do not prevent curves from getting bigger or make the curve straighter. For some children — especially those with very high surgical risk due to serious health conditions or a shorter life expectancy — a comfort-focused, non-surgical approach may best align with your family goals.

Surgical Care: Spinal Fusion

In individuals with neuromuscular scoliosis, untreated curves will continue progressing throughout life. The larger the curve, the greater the likelihood of continued curve progression and for it to have a negative impact on the child's health and quality of life. The goal of surgery is not to cure the underlying condition, but to address the challenges above by stabilizing the spine, improving balance, and slowing or stopping further progression.

Spinal fusion is the most common surgical treatment for neuromuscular scoliosis. It involves joining two or more vertebrae so they heal into one solid unit. The screws hold onto the bones of the curve and then metal rods link the screws to move the bones into a "straighter" position and stabilize the spine while fusion occurs.

The two types of fusion are:

- Posterior fusion: Surgery performed through the back; this is the most common approach.
- Anterior fusion: Surgery performed through the chest or abdomen; less common and used only in selected cases in combination with a posterior fusion.

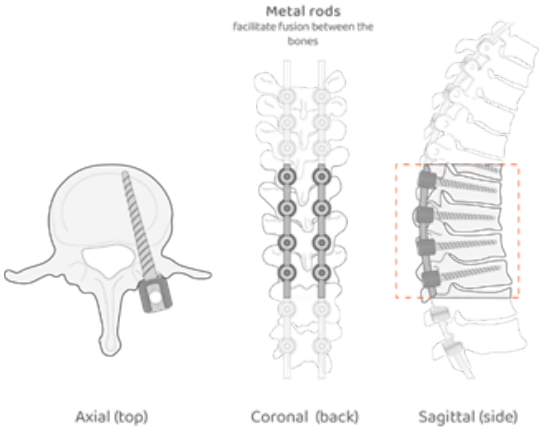


Figure 3 above shows how screws are placed during a posterior spinal fusion surgery.

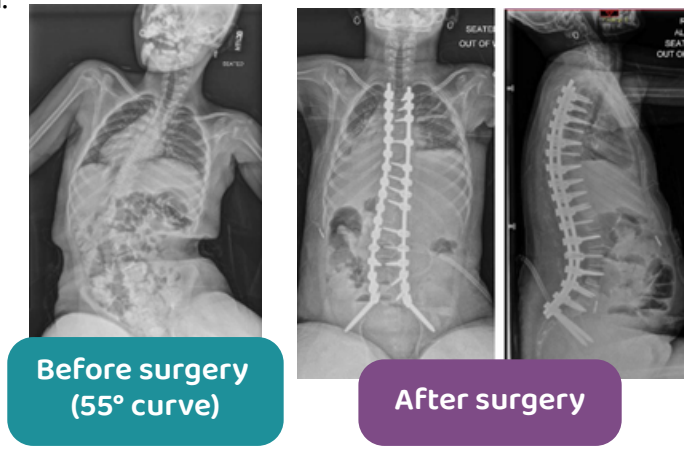


Figure 4 above shows X-rays from before (left image) and after (right two images) posterior spinal fusion surgery.

Potential Benefits and Risks of Spinal Fusion Surgery

Like any surgery, spinal fusion has both potential risks and benefits. Every child's risk is different and depends on their health, diagnosis, spine curve, and surgical plan. Potential benefits and risks can include:

Benefits

- Protect one's quality of life as their back condition changes over time
- Stop the curve from getting bigger
- Improve posture and sitting balance
- Make it easier to move, transfer, and position your child
- Improve comfort, especially if experiencing pain or discomfort before surgery
- Improve ability to do daily activities like eating, dressing, and bathing, and using communication devices
- Make breathing easier and support lung function
- Increase overall satisfaction with what your child is able to do
- Improve longevity and life span in some neuromuscular conditions

Risks

- Problems with wound healing or infection (which may need IV antibiotics or another surgery)
- Over time, the bones next to the surgery area may wear out, not heal as expected (pseudoarthrosis), or curve forward more than they should
- Issues with the hardware (screws or rods loosening, breaking, or causing discomfort) that may need repair
- Rare but serious nerve or spinal cord injury, including vision loss
- Ongoing or new back pain
- Blood clots (deep vein thrombosis, pulmonary embolism)
- Serious complications, such as death, are rare, but possible

General risks with any surgery may include:

- Blood loss that may require a blood transfusion
- Lung congestion or pneumonia
- Side effects from anesthesia (like nausea, sore throat, chills, headache or temporary confusion
- Slower return to normal diet and bowel habits
- Urinary tract infection

Thinking About the Decision

Preparing for spine surgery can feel overwhelming. Families can expect a few appointments to ensure your child is healthy and ready, along with labs, therapy planning, and supportive services to help everyone understand what to expect and feel more comfortable. The goal of this preparation is to address any health needs ahead of time, reduce stress, and set your child up for the safest surgery and smoothest recovery possible. Most patients are in the hospital for about 5 days and return to school within 4-6 weeks. After the initial recovery, care for your child is largely the same as care provided before surgery.

When you are considering spinal fusion surgery, it can help to think about a few key things:

- How comfortable your child is now and will be in the future
- How your child is able to participate in everyday activities now and how the spinal curve may affect those activities in the future
- Whether caring for your child is difficult now or may become more difficult over time
- Your hopes for your child's quality of life now and in the future
- Any worries you have about surgery and recovery
- Timing with school, family support, and other medical care

Take some time to think about why you're considering surgery and what you hope it will help with, as well as any concerns you may have. Reflect on the reasons you would consider a spinal fusion for your child, including your hopes and concerns related to that reason, in the table below:

Here are some sample questions you might ask your child's care team about the option of surgery:

- What changes do you expect in my child's spine in the future?
- What benefits might surgery offer for my child specifically?
- What risks of surgery are most important for us to understand?
- What will the hospital stay and recovery look like?
- How will pain, mobility, and equipment needs be managed afterward?
- If we wait or choose not to pursue surgery, what signs should we watch for?

Reasons to consider surgery	Hope	Concern
Example: My child has impaired lung health (challenges with breathing).	Surgery improves lung health	Surgery may not improve lung health. My child could experience complications from surgery.
Reason #1:		
Reason #2:		
Reason #3:		

Getting Ready to Choose a Treatment Option

Reflect on the questions below and circle the answer that best describes you:

Do you and your child understand the options available to treat neuromuscular scoliosis?	**Yes**	**No**
Are you clear about which benefits and risks matter to you?	**Yes**	**No**
Do you have enough information to make a decision?	**Yes**	**No**
Have you identified the best decision for your child's health needs, comfort, and quality of life?	**Yes**	**No**
Have you talked with your care team about any remaining questions or concerns?	**Yes**	**No**

What other questions or concerns do you have?

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Our Family's Decision

We know that this decision is important and often challenging. We encourage you to talk with your child's surgeon and other health care provider(s) such as your child's pediatrician, pulmonologist, physical medicine rehabilitation provider, etc. Talking with family members and others in the community can also be helpful in navigating these decisions. Take the time to thoughtfully consider what is the best decision for your unique situation and child right now. We recognize that this decision is not permanent - we can revisit this plan as things change. Your care team is here to support you, whatever decision you make.

For simplicity, throughout this tool we refer to "parent" and "child"; we acknowledge, however, that family structures and patient ages vary. "Parent" is used as a generic term that includes grandparents, relatives, and carers (caregivers) who are raising a child. "Child" is used as a generic term for a patient that includes all ages.

For more information: You may find it helpful to read Scoliosis: Congenital, Neuromuscular, Syndromic, and Other Nonidiopathic Types: Understanding and Managing the Condition: A Practical Guide for Families (Gillette Children's Healthcare Press, 2025). Scoliosis | Gillette Childrens Healthcare Press

This decision aid was developed by Gillette Children's and informed by an evidence-based literature search in addition to previously published shared decision-making resources, including The Nemours Foundation Neuromuscular Scoliosis Decision Aid and the Courageous Parents Network/Boston Children's Hospital Evaluating Spinal Fusion for Your Child with Neuromuscular Scoliosis Guide.