Considerations and Decision Making Guide
for Spinal Fusion in Children with Neuromuscular Scoliosis

Introduction

You (and your child if they are able) are considering a decision about spinal fusion for neuromuscular scoliosis for your child. There are many things to consider with your child and your child’s surgeon and healthcare team. This guide will take you through steps to help you make the best decision for your child.

Steps to Consider

Step 1: Understand How Scoliosis Affects Your Child
Step 2: Understand Hopes and Concerns For Your Child With Scoliosis
Step 3: Explore Scoliosis Treatment Options
Step 4: Assess Peri-Operative Risk Factors That Pertain to Your Child
Step 5: Work Toward Making a Decision About Spinal Fusion
Step 6: Discuss Your Thoughts and Considerations with Your Child (when appropriate)

Take your time as you go through the steps. It could take weeks or sometimes months to go through all of them. You may learn new things in one step that make you want to re-think a prior one. That’s okay. The goal is to make the best decision for your child.

You may find it helpful to complete some of the steps (e.g., 1 and 2) on your own and then identify members of your child’s care team (e.g. your child’s doctors, aides, teacher) who can help you work through the other ones. Feel free to use this tool to guide your conversations with providers.
Step 1: Understand How Scoliosis Affects Your Child

There are several reasons why spinal fusion may be considered for a child with scoliosis. The main ones are listed below. Think about these reasons (and any others that apply to your child) in terms of how they affect your child’s health and wellbeing.

Reasons to Consider Spinal Fusion for Neuromuscular Scoliosis

Which of these reasons apply to your child?

☐ Scoliosis is causing my child pain

☐ Scoliosis is causing my child difficulty with positioning (e.g., with sitting)

☐ Scoliosis is causing my child poor balance and/or poor coordination

☐ Scoliosis is causing my child difficulty with breathing

☐ Scoliosis is causing my child to have difficulty cleaning him/herself (e.g., toilet and bathing)

☐ Other reason(s) ______________________

For each of these, describe how the reason(s) you selected currently affect your child’s health, wellbeing, and quality of life.

* e.g., The difficulty my child has sitting in her chair affects her quality of life in this way:

If you selected more than one reason, which one(s) affect your child the most?
Step 2: Understand Hopes and Concerns for Your Child With Scoliosis

Think more about each of the reasons you are considering spinal fusion for your child. It can be helpful to write down the hopes and concerns you have for each of them.

This can be a difficult task. Here’s an example that might be helpful as you think through it:

<table>
<thead>
<tr>
<th>Reason for surgery</th>
<th>My son John has difficulty sitting in his wheelchair because of his scoliosis. He’s having so much discomfort and pain that he can’t relax in school or at home.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hopes for that reason</td>
<td>Our real hope is that John can sit again in his wheelchair without any pain or discomfort.</td>
</tr>
<tr>
<td>Concerns for that reason</td>
<td>Our concern is if the scoliosis gets worse, he will have more pain and discomfort unless we do something about it soon.</td>
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</tbody>
</table>

Reason #1:

Our HOPES are that ….

Our CONCERNS are that ….

Reason #2:

Our HOPES are that ….

Our CONCERNS are that ….

Other reasons:

Our HOPES are that ….

Our CONCERNS are that ….
Step 3: Explore the Options to Treat Your Child’s Scoliosis

You are not expected to make this decision by yourself. Your child’s surgeon and other clinicians are there to help you explore all the options for treating your child’s scoliosis. It is possible and natural that your thinking and responses to the questions below may change as you work through this decision-making process with your child’s care team.

Beside your child’s surgeon, who else would you like to discuss the surgery with? Who may help you in making this decision? You can check more than one.

- Primary care physician: ____________
- Medical specialist(s): ____________
- Therapist: ____________
- Home care provider: ____________
- Family of another child with scoliosis who has had spinal fusion surgery: ____________
- Palliative care clinician: ____________
- Aide: ____________
- Teacher: ____________
- Others: ____________

Things to Consider

Which option(s) are you considering for your child?

- Full correction of the scoliosis with spinal fusion
- Partial correction of the scoliosis with spinal fusion
- Placement of growth or magnetic rods
- No spinal fusion/rods placement

For the surgical options available to your child, talk with the medical providers about these questions.

- Will the scoliosis get better or worse?
☐ What will happen with pain?

☐ What will happen with positioning?

☐ What sort of movement restrictions can we expect?

☐ What will happen with breathing?

☐ How will it affect other aspects of my child’s life such as eating, sleeping, other symptoms?

Now think about what your child’s life might be like after each surgical option.

☐ Is it possible that my child will have to undergo spine surgery more than once? (e.g., if your child is still growing)

☐ How long will my child need to stay in the hospital?

☐ How could my child’s care needs change following the treatment?

☐ What restrictions will my child have after surgery and how long will these last?

☐ What equipment adaptations/changes will I need to make? (e.g., wheel chair)
☐ When will my child be ready to go back to school?

☐ What will happen to my child’s overall health and quality of life?

☐ If we decide that the risks outweigh the benefits of spinal surgery for our child, what can we do to optimize comfort?
Step 4: Assess Peri-Operative Risk Factors That Pertain to Your Child

Keeping your child safe and stable during and after surgery is a top priority for everyone.

It’s important to work with your child’s healthcare team to learn what risk factors your child may have that could affect their health and safety when undergoing spinal fusion surgery.

List the things about your child’s health that worry YOU the most about undergoing spinal surgery?

Ask your child’s care team what are the things about your child’s health that worry THEM about the surgery. List them here:

Use this list of health problems as a guide to discuss risk factors of your child’s health and safety. Does your child have any of these conditions?

- □ Apnea
- □ Aspiration
- □ Epilepsy
- □ Constipation
- □ Heart problem
- □ Fragile bones (osteopenia)
- □ Underweight
- □ Problem with immune system
- □ Problem with endocrine system
- □ Kidney or urinary tract problem
- □ Pressure ulcer or other skin problem
- □ Behavioral problem
- □ Difficulty with communicating
- □ Other problem:
Does your child’s care team feel that any of the above might be a problem for surgery? Why?

To learn more about these risk factors, work with your child’s healthcare providers to answer the questions below that apply to your child.

How might my child’s risk factors affect...

- safety with anesthesia?
- blood loss during the operation?
- length of stay in the hospital after the operation?
- chance of having a post-operative complication?
- other?
Step 5: Work Towards Making a Decision About Spinal Fusion.

Now that you have finished Steps 1-4, write down the risks and benefits that you identified for each option you are considering. Again, these options may include full correction with spinal fusion, partial correction with spinal fusion, placement of growth or magnetic rods, or no spinal fusion or rods placement. Completing this chart will help you better see the potential impact of the options for your child.

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Risks</th>
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<tbody>
<tr>
<td>Option A: ___________________</td>
<td></td>
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<tr>
<td>Option B: ___________________</td>
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<td>Option C: ___________________</td>
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Now, ask yourself the following questions to understand how ready you are to make a decision.

How well do you understand the reasons for treating your child’s scoliosis?
- □ Very well
- □ Somewhat well
- □ Not well

How well do you understand the options for treating your child’s scoliosis?
- □ Very well. The options are clear to me.
- □ Somewhat well. There are things that are still unclear.
- □ Not well. The options are not clear to me.

How well do you understand the risks and benefits of each treatment option?
- □ Very well
- □ Somewhat well
- □ Not well

How ready are you to make a decision on how to treat your child’s scoliosis?
- □ Ready: My mind is made up.
- □ Not ready: I need more time or more information to make the decision.

Do you have a preference for any one option?
- □ Yes
- □ No

If yes, then what option do you think is best for your child and why?
If not, what questions do you still have that would help you make the decision?

What team members may be able to assist with providing the information you need to make a decision?

Would you like to speak with another parent or family who has gone through spinal fusion surgery?

Are you prepared to convey your preferred surgical option to your child’s medical team?

☐ Yes
☐ No
Step 6: Share Your Thoughts and Considerations with Your Child.

This step is completely optional and up to your discretion as the caregiver of your child and the person who knows him or her best. Depending on how much of this information your child is able to comprehend and what is appropriate for them to understand, you may or may not want to explain which options you are considering for your child, why, and the outcome you are hoping for.
Use this page to keep track of the things that you and your child’s healthcare team will work on to help make a decision for surgery and/or to prepare your child for surgery.

These things may include appointments, referrals, lab/radiographic testing, diagnostic tests, care planning, etc. Write down what needs to be done, who is doing them, and when they need to be completed.

<table>
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<tr>
<th>DATE</th>
<th>ACTIVITY</th>
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<tbody>
<tr>
<td>June 1</td>
<td>Talked to the neurologist about risks associated with surgery.</td>
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