INTRODUCTION

A multi-step decision-making process

Your child’s care team has raised the possibility of spinal fusion for your child’s neuromuscular scoliosis, and now you (and your child, if they are able) are considering whether to proceed. There are many factors to consider, as a family and with your child’s surgeon and team. This worksheet will take you through a process to help you make a decision that works with your care goals.

You may find it helpful to complete some of the steps 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 others. Feel free to use this tool to guide your conversations with providers.

Take your time with this decision. It could take weeks, or even months, to go through the process. You may learn new things at certain points that make you want to re-think your prior ideas. That’s okay. The goal is to feel that you have done the best you can for your child.
Understanding how scoliosis affects your child

Spinal fusion is a procedure designed to connect two or more vertebrae in the spine, so that they can heal as a single unit. 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.

Record your answers as they apply to your child.

- Scoliosis is causing my child pain
- Scoliosis is causing my child difficulty with positioning (e.g., with sitting)
- Scoliosis is affecting my child’s balance and/or coordination
- Scoliosis is causing my child difficulty with breathing
- Scoliosis is causing my child to have difficulty cleaning him/herself (e.g., toileting and bathing)
- Scoliosis is interfering with activities my child wants to participate in:

  ____________________________________________________________

- 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?

  ____________________________________________________________

  ____________________________________________________________

  ____________________________________________________________
Identifying your hopes and concerns for your child

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:

- **Reason to consider surgery**
  
  *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.*

- **Hopes for that reason**
  
  *Our real hope is that John can sit again in his wheelchair without any pain or discomfort.*

- **Concerns for that reason**
  
  *Our concern is that unless we do something soon, he will have more pain and discomfort.*

**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 …*
Exploring the treatment options

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.

Questions for the Medical Providers

What options have been suggested to you, and what are you considering?

- 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

You can ask your child’s surgeon and other care team members how each option you are considering is likely to affect your child’s quality of life. Some suggested questions:

- Will the scoliosis get better or worse, or stay the same?
- What will happen with pain?
- What will happen with positioning?
- What sort of movement restrictions can we expect?
- What will happen with breathing?
- What will happen to my child’s overall health?
- How will the outcome affect other aspects of my child’s life, such as eating, sleeping, other symptoms?
- What restrictions will my child have after surgery and how long will these last?
- When will my child be ready to resume some of their customary activities (e.g., go back to school)?
- Is it possible that my child will have to undergo spine surgery more than once (e.g., if your child is still growing)?
- How could my child’s care needs change following the treatment?
- What equipment adaptations/changes will I need to make (e.g., wheelchair)?
- If we decide that the risks outweigh the benefits of spinal surgery for our child, what can we do to optimize their comfort?
**Understanding perioperative 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 team to learn what risk factors your child may have that could affect their health and safety as they undergo and/or recover from 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:

- Does your child have any of these conditions? Use this list of health problems as a guide to discuss risk factors for your child’s health and safety.
  - Apnea
  - Constipation
  - Underweight
  - Epilepsy
  - Behavioral problem
  - Aspiration
  - Heart problem
  - Problem with immune system
  - Kidney or urinary tract problem
  - Other problem
  - Difficulty with communicating
  - Fragile bones (osteopenia)
  - Problem with endocrine system
  - Pressure ulcer or other skin problem

**Questions for the Medical Providers**

Does your child’s care team feel that any of the above might present a risk? Why? Here are some questions to ask as they 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:

(continued)
**STEP 5**

**Working towards a decision**

Using your notes from above, record the risk 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.

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At this point, you may want to involve others in your decision-making process. In addition to your child’s surgeon, who would you like to discuss the surgery with? Who can help you in making this decision? You can check more than one.

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

Now, ask yourself the following questions to assess 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  If yes, what option do you think is best for your child and why?
  ☐ No  If no, what questions do you still have that would help you make a 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?
  ☐ Yes  ☐ No
STEP 6

Sharing your thoughts and considerations with your child

This step is up to your discretion as the caregiver of your child and the person who knows them 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 your decision, why you have made it, and the outcome you are hoping for. Your child’s nurse, social worker or another member of your palliative care team can be helpful in preparing for the conversation, and you can even ask them to be present to help you answer questions and concerns.

CONCLUSION

One (or two) steps at a time

The most important part of making decisions on your child’s behalf is feeling comfortable that you understand the options, along with the potential benefits—and risks. When you do, the path hopefully becomes more clear. If you have questions or concerns, be sure to ask. Your child’s team wants to help.
# Deciding on and preparing for surgery

Use this sheet to keep track of 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.

This 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.

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