Considering Spinal Fusion Surgery in Children with Severe Scoliosis: A QI Guide for Families and Providers

> A Collaboration of BOSTON CHILDREN'S HOSPITAL and COURAGEOUS PARENTS NETWORK







## Introduction to the Guide and Videos

This is a tool to help families of children with severe scoliosis and providers work together to develop a clear roadmap for shared decision-making in the best interest of the particular child and family, as well as a rewarding experience for everyone involved.

It is the product of an interdisciplinary team of medical providers and parents at Boston Children's Hospital and Courageous Parents Network.

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## A Six-Step Guide

The tool includes a 6-Step Guide to help direct conversations between families and medical providers in making the decision. It is understood that these conversations and the process will take place over months.

- Step 1: Understanding how Scoliosis may affect your child.
- Step 2: Understanding your hopes and concerns long term.
- Step 3: Exploring surgical options.
- Step 4: Assessing the perioperative risk factors
- Step 5: Making the decision.
- Step 6: Discussing the decision with your child.

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#### Who is this for

Patients considering spinal fusion are typically very medically complex in differing ways: Their particular curves are potentially very different, may curve in different severities, have different effects on each child's overall functioning.

And then there is the child's age.

The underlying neurologic disease that is affecting the curvature of the spine is likely also affecting the other organ systems. There may be endocrine problems, cardiovascular or respiratory problems. All of those issues come into play when considering surgery.

We have to approach each child individually.

For surgery to be right and possible, everything must be in position. Watch Video

## **Current Indicators vs Future Possibilities**

Sometimes there is an **obvious indicator** that surgery is needed soon.

Sometimes there are other more immediate and pressing problems, such as seizures and reflux. In these instances, considering **surgery is** *in anticipation of* **problems on the horizon**.

## An Opportunity to Do It Better

For complex kids, in the absence of a coordinated process, there can be too many specialists operating in their respective domains and overwhelming the family with differing perspectives that do not encapsulate the child's *entire* physical system and well-being.

We can do better.



## Understanding How Scoliosis May Affect the Child



### Step 1: The Window of Opportunity

There is a window of best opportunity.

Too early, it's not obvious that something needs to be done; Too late, it gets much harder and less satisfactory.

Having a surgical date can be helpful as it provides a timeframe to ensure the child's optimal health for the surgery and prompts a comprehensive health assessment in which concurrent health issues can be revealed and which need to be addressed.

### Step 1: Obvious Indicators vs Anticipation

**Obvious Indicators vs Anticipating the Future** 

Again, Sometimes there is an obvious indicator that surgery is needed soon.

Sometimes there are other more immediate and pressing problems, such as seizures and reflux. In these instances, considering surgery is *in anticipation of* problems on the horizon.

## Step 1: Involving the Articulate Patient

#### Involving the articulate patient is a Must

- It is helpful when the child or young adult can express what physical limitations they are experiencing and why they are considering the surgery; for example young adults who are eager to live independently.
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- It is revealing to hear what their opinion is of their spine deformity and what they hope to make better. And sometimes you can help with that and sometimes you can't.

## Step 1: Projecting the Trajectory

Ideally the pediatrician and the specialists and the surgeons work with the family to project the short and long-term health trajectory for that child with or without the surgery. This includes discussions of survival and quality of life.

There are instances when life expectancy or a degenerative processes indicate that surgery doesn't make the best sense.

Another thing to consider is that the surgery is invasive and a painful and lengthy process. Some families perceive it as unacceptable for their child when the child cannot communicate his or her own wishes. This is a legitimate concern that we need to respect.

The imperative that medical providers feel to DO SOMETHING isn't always helpful to the family.

These are the times when it is most important for the medical team to be on board with the family's decision. There can be so many care providers with competing voices and it is not helpful for the family to keep revisiting their decision.



## Understanding Hopes and Concerns. Setting Expectations

# Step 2: Understanding hopes and concerns. Setting expectations

It's important to discuss where are we going if we don't do anything and what the physician's expectations are for what's going to happen in the future either with future growth or just with adulthood with the deformity.

Try to be honest about what our expectations are for function after the surgery. **Spinal fusion isn't a correction of the underlying problem**. It's a stabilization. This can bring up parents' underlying expectations about how surgery will impact symptoms: is it about pain, positioning, appearance, breathing, transport. And will the surgery alleviate the symptoms? For example, parents anticipate that transport will get easier but in fact it gets harder.

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# Step 2: How a palliative care consult and team can help

Palliative care is especially helpful in the perioperative space. These discussions about health trajectory, quality of life, hopes and concerns take time. But the existing health care system doesn't allow these conversations to occur. Palliative care as a specialty is about building rapport with families and supports these conversations and brings them back to the team.



## Exploring the Surgical Options

## Step 3: Exploring surgical options

For most children with a neuromuscular curve maintaining a sitting position becomes increasingly difficult as their curve worsens.

There are several ways to combat that in a short run: adaptive seating equipment; a body jacket or brace.

Surgery is the final option for children with bad curvature that equipment doesn't help: it partially straightens or straightens the spine; more importantly, it stabilizes the spine permanently so that it won't collapse over time.

Spinal straightening with instrumentation and spinal fusion arrests the growth of the spine. This is typically okay for a child who is 10 and older but it's not okay at a younger age. So some younger children are treated with expandable rods or expandable vectors.

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## Step 3: Positioning During Surgery

Parents can worry about how their child will be positioned during surgery and they appreciate the surgeon explaining how it is going to be done.

## Step 4

## Assessing Perioperative Risk Factors & Setting Post-Op Expectations

### Step 4: Assessing Periop Risk Factors

The preoperative period is about discovery and involves many different conversations over time. Everyone has their own piece that they're concerned about: the family members, the surgeon, the specialists, the anesthesiologist.

You can't do this in one office visit. The children are too complicated and the past medical history too complex. Recurrent office visits and phone calls bring it all together to inform how best to proceed.

It's also essentially impossible for a parent to absorb everything in one or two office visits. So medical providers should give them multiple sources of information and means to absorb it.

It's best not to force the decision but think of it as an educational process that will ultimately lead to the best decision.

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#### Step 4: Assessing Risk Factors

Medical providers shouldn't put the burden to prepare on the parents.

The process should also involve the people involved in the surgery as early as possible so they have time to prepare, including anesthesiology.

### Step 4: Considering Possible Side Effects

A mom reflects that she wishes her child's team had discussed possible side effects of surgery ahead of time -- to help them be prepared in the event they occurred (her son developed kidney stones a few months post- surgery) <u>Watch Video</u>

The stress of the surgery may affect symptoms after and health issues may look different on the other side of surgery. When the medical team takes the time to consider this, the family feels more prepared and not horribly surprised.

Parents should be encouraged to come with their list of questions for what it may look like: the path of questioning may illicit new and important <u>Watch Video</u>

#### Step 4: Comprehensive Health Assessment

Every child under consideration for surgery should have some a comprehensive health assessment – by one provider or multiple. The findings may indicate the need for more time or interventions before surgery.

- How healthy is the child?
- What is their health trajectory likely to be?
- What risks or health issues should be addressed ahead of surgery to optimize the health of the child?
- How controlled are the chronic health conditions; how severe are they are; how could they affect anesthesia?
- What medications are they on and how will they be delivered post-op? IV?
- What technologies are they dependent on and how will that work during and in post-op?
- Are the child's nutrition and hydration levels good for surgery and post-op?
- What is child's bone health?

This process takes time but builds confidence in family and medical team going into the surgery. **WATCH VIDEO** 

# Step 4: The Role of the Surgeon in Assessment

Surgeons understand that many different factors play into the child's readiness for surgery and surgical outcomes.

The better the pre-surgery assessment, the better the outcome.

What happens during the surgery itself also affects outcome:

- Blood loss
- Length of the surgery
- Child's inherent respiratory status (ability to manage coughs and secretions)

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#### Step 4: The Value of Communication

The value of communication and being transparent with the parents

Each specialist – surgeon, pulmonologist, nutritionist -- and the parents will have their own concerns: what are the health issues that can compromise this child's perio-health and safety? The more questions we're asking, the better.

Parents appreciate knowing the specialists are talking and conferring with each other.

Mom: "In my experience, increased communication has always led to better outcomes." <u>WATCH VIDEO</u>

### Step 4: Share Potential Post-Op Issues

Post-surgical complications to consider and share with families -so they feel prepared -- include:

- Prolonged pulmonary problems
- Deep wound Infection
- Exacerbation of an existing chronic condition
- Skin complications

The longer the child is in the hospital post-surgery, the more potential there is for things to go wrong. The goal is always to get the child back home as soon as possible.

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## Step 5

## Making the Decision



## Step 5: Decision Making and Uncertainty

It's important and ultimately helpful to be honest and transparent with the family about concerns.

e.g. "I'm concerned that the bone may be too soft to achieve satisfactory fixation."

There is so little scientific evidence and studies to pull from to ensure certainty. So much is left to clinical judgement to convey most accurate assessment of risk and benefit. <u>WATCH VIDEO</u>

It can be helpful to show families examples from previous surgeries and like situations. **WATCH VIDEO** 

### Step 5: Pros and Cons of Social Media

Social media can be a good source of peer-to-peer information for families as they seek insights. Of course, sometimes the information families receive from these sites can be wrong.

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Everyone needs to recognize that this is a very stressful decision for parents.

## Step 5: Projecting Short- and Long-Term Trajectory

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#### The imperative that medical providers feel to DO SOMETHING isn't always helpful to the family.

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#### Step 5: NO is always an Option

There are circumstances in which the physicians decide that surgery is not the right option: the child's condition is too fragile.

There are situations in which the family decides it is just not a good idea. In these instances, it is important that the medical team support the family in their decision and not abandon them.

In those instances when the family is deciding No but there may be long term complications from increasing curvature over time, it is important to help the family anticipate these complications and be clear that they are making an active decision in saying NO, but not abandon them. **WATCH VIDEO** 



## Discussing the Surgery with the Child

#### Step 6: To Share or Not to Share with Child

To share with the child or not to share

Some children are so developmentally or chronologically young that parents may elect not to involve or tell them about the surgery ahead of time. Families know their child best, including what they can handle.

Keep in mind: a sudden delay in the surgery can be very upsetting for children who were prepared.

<u>WATCH VIDEO</u> -- A mom shares how she communicated with her nonverbal son about the surgery during the decision-making process.

## Post-Op Considerations In-Hospital and the Transition Home

### Post-Op Considerations: In-Hospital

There is so much to attend to in Post-OP, especially in the ICU

- Meds, including dosage
- Equipment

Things can be overlooked or not reinstated in a timely manner.

In Post-Op, the parent knows best. How the patient does often depends on how vigilant the parent is. Encourage parents to be vigilant advocates.

Parents are critical players in how well the recovery time goes and should be encouraged to be vigilant advocates for their child. Mom/Dad – if you see something, say something. If you have a question, ask it.

Parents bring so much with them. They can share who their child is, how they communicate, preferences, meds, equipment.

This vigilance is especially important at points of transition. WATCH VIDEO

### Post-Op Considerations: In-Hospital

**Some families will need extra support from the hospital**. In these instances, the inpatient providers need to be extra vigilant themselves.

- Extra time to review the med list outside of rounds
- Doing more of a chart biopsy
- Bring in extra services available in the hospital
  - interpretative services
  - chaplaincy
  - -child-life
  - palliative care

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#### Post-Op Consideration: Remember

It's important to remember – and for parents to remind providers – that these children really do have rich lives outside the hospital.

They aren't just patient X with Y problem. They have a rich home life.

#### Post-Op Considerations: Discharge Home

Setting expectations that the recovery time is long and involved

"The crudeness of hospital discharge of the level of health you need to achieve is nowhere near where you need to be to fully recover from the operation."

This is likely the largest surgery the child will undergo. These children have complex conditions and the surgery may aggravate many of the underlying issues. It can take months for the children to get back to baseline, if that is even possible.

It is important to tell parents ahead of time that the after-care is going to be intense. This is especially true for families whose children have not had previous major surgery. <u>WATCH VIDEO</u>

### Post-Op Considerations: Discharge Home

Things to talk about:

- Time to return to baseline
- Availability of nursing
- Durable medical equipment
- Return to school
- Return to outpatient providers
- Possibility of re-admission due to comorbid conditions

### Post-Op Considerations: A Mother Reflects

Mom talks about the length of recovery and how things are now.

One thing to note for parents is that the child is going to be harder to transfer.

It's hard to know if the surgery, the spine, has had an effect on co-existing conditions.

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