Shared Decision-Making Considerations

Introduction

When you are facing a difficult medical decision for your child, it can be hard to know what questions to ask or how to organize your thoughts. This guide helps you reflect on the information you've received, identify what matters most to your family, and prepare for conversations with your child's healthcare team.

The questions included here may be relevant to the medical decisions you are making for your child, but not every question will apply to every situation. You don't need to answer them all. Instead, use the questions that feel most relevant to your child's situation and resonate with your family's circumstances.

They can help you:

- Better understand your child's medical situation and treatment options.
- Clarify your family's goals, values, hopes, and concerns.
- Prepare questions for your healthcare team.
- Think through how today's decision may affect your child and family over time.

Shared decision-making is a partnership between families and clinicians. Your expertise about your child and your family's priorities is just as important as your medical team's clinical expertise. Together, you can make decisions that are informed, thoughtful, and centered on what matters most.

Short-Term Considerations:

What do we need to know right now?

- [ ] What problem are we trying to solve, and how urgent is this decision?
- [ ] What are our options, including choosing to wait or not pursue treatment?
- [ ] What are the benefits, risks, and burdens of each option in the short term?
- [ ] How will each option affect my child's comfort, symptoms, and quality of life right now?
- [ ] What symptoms or changes should we monitor, and when should we seek medical attention?
- [ ] Where can we go to find more information that will help us think about this decision? Should we seek another opinion or additional expertise?

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Medium-Term Considerations:

How will this affect our family over the coming weeks and months?

- [ ] How will this decision affect my child's daily life, development, and ability to participate in meaningful activities?
- [ ] How will this decision impact our family's routines, caregiving responsibilities, emotional well-being, and financial resources?
- [ ] What support,services, or equipment will our family need if we move forward with this plan?
- [ ] How does this decision align with our goals, hopes, and priorities for our child and family?
- [ ] How will this plan be communicated and coordinated across our child's healthcare team, school, therapists, and home caregivers?
- [ ] Are there other families with similar experiences who could help us better understand what to expect?

Long-Term Considerations:

How might this decision shape the future?

- [ ] What are the possible long-term outcomes if we choose this option, or decide not to?
- [ ] Will this decision preserve future choices, or limit options later?
- [ ] Is this decision reversible, and under what circumstances could we change course?
- [ ] How might my child's condition change over time, and what signs should prompt us to revisit this decision?
- [ ] Looking back months or years from now, what decision is most consistent with our values and what matters most to our family?
- [ ] What important questions haven't we asked that other families often wish they had considered?

Next Steps:

Putting Your Questions Into Action

After reviewing the questions in this guide, you may have a better understanding of what matters most to your child and family, or you may have identified areas where you need more information.

You do not need to have all the answers before talking with your child's healthcare team. Shared decision-making is an ongoing conversation, and your questions, concerns, and priorities are an important part of that process.

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1. Identify What Matters Most
Before your next conversation with your child's healthcare team:

- Choose two or three questions from this guide that feel most relevant to your child's current medical decision.
- Consider what you understand, what remains unclear, and what matters most to your child and family.
- Write down any concerns you would like to discuss.

2. Start the Conversation
You can use the following language during an appointment or in a message to your child's healthcare team.

During an appointment:

> *"We've been thinking about the decisions we're facing for our child and have some questions we'd like to talk through. We want to better understand our options and how they might affect our child's comfort, quality of life, and our family. Could we take some time to discuss what matters most to us and how that fits into the care plan?"*

Through a patient portal message:

> *"Hello, we're considering some medical decisions for our child and have been reflecting on our options and priorities as a family. We have a few questions we'd appreciate discussing with the care team. Would it be possible to schedule time to talk through the options, potential outcomes, and how they align with our goals for our child? Thank you for helping us navigate these decisions."*

3. Make a Plan Together
Before ending the conversation, consider asking:

> *"What are our next steps, who should we contact if we have more questions, and when should we revisit this decision?"*

Remember, your family's goals and priorities may change over time. You can return to these questions whenever a new decision arises or your child's needs change.

Related Resources:



Family Meeting: Being Prepared



Framework for Sharing Decision-Making with Your Child's Clinicians



Goals of Care

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