

A Framework for Sharing Decision-Making with Your Child’s Clinicians



Based on “How Do You ‘Share’ Decision Making?” presentation by Kate Nelson, MD, PhD for the Courageous Parents Network “In the Room” webinar series, June 2023.

Learning Objectives

After reviewing this Guide you will be able to:

- Recognize your preferred ways, or styles, of making decisions
- Identify common clinician communication styles as you work together to make decisions
- Respond to style differences and resolve issues caused by mismatch

Introduction

Over the course of your child’s illness you will be prompted to consider some very difficult questions regarding clinical issues and your goals of care. Optimally, your child’s clinicians will lead you through these questions over time—although sometimes you will need to make relatively quick decisions. Through these continuing conversations, you and the clinicians can work together to talk about options for managing the issues, and together make decisions that work for your child and family. This process is commonly referred to as *shared decision-making*.

Why Decision-Making May Feel Complicated and Daunting

With medical complexity there are multiple clinical issues to navigate, and primary caregivers (parents) may be working with more than one clinician, or team of clinicians. If there is uncertainty about the source of any issue—or as you need specialists for any reason—there may be differences of opinion about how an issue is affecting the child’s overall health, and about how to proceed.

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In any decision-making, each of the participants will understand and respond to what is occurring in their own way. Each will bring their own experience and communication style. And, each conversation will likely produce many perspectives, interactions and reactions. Understanding different styles will help you identify what is occurring in the conversation, and help you feel more confident and effective in advocating for your child and family.

Principles of Shared Decision-Making

- Sometimes there is only one option that is likely to achieve the outcome you hope for. At these times decisions really can't be shared.
- In many cases there are several potential options to consider, and different families will make different choices.
- Sometimes there is no clear path to the hoped-for outcome. In this case moving forward depends on your goals for your child and family.
- In most cases you can ask for time to decide, even if it's only five minutes. However, sometimes there aren't even five minutes. In this case you probably need to defer to and trust the clinicians.

Your Decision-Making Style

We all share decision-making authority with others, most especially with other family members and some work colleagues. However, shared decision-making in a medical context may be very new to you. Many decisions we make are important, but ones regarding your child's health will likely feel much more critical. And they are more critical, because the responsibility that loving parents feel is complete and total.

As you work with clinicians, you and they might find it helpful for you to reflect on how you have made decisions in the past. Providing examples is a good way to begin the relationship. You, and perhaps the clinicians working with you, may discover patterns in how you prefer to receive and process information. Your child's primary clinician (pediatrician or family practice clinician), who knows you and your family, may be a helpful source of feedback as you try to sort this out.

Here are some common patterns to consider. Some people find that one or a combination of these fits their primary way of making important decisions.

- **Planning:** Some people prefer to focus on the most important decision today—one day at a time. Others think through full decision trees—today, tomorrow, next year, five years from now. Some people fall in between, and sometimes their preference changes depending on the circumstances.

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- **Information-seeking:** Some people appreciate a summary of the most important points from one trusted clinician. Others like to gather details from a range of sources, from independent research to multiple clinicians. Many people have a preference but may change their approach depending on the situation.
- **Intuition:** Some people believe in their ability to sense what needs to be done, with or without input. Most, however, will find that even if they have a strong “gut” sense of what to do, exploring the decision and its potential consequences is a useful double-check.

Clinician Communication Styles

So, there is your decision-making style, and then there is the style that the clinician typically uses. Both have an impact on the decision-making experience. Some common communication styles will work better for you than others, depending on how you tend to process information and make decisions. Or one style may work well under certain circumstances but not others. Unfortunately, you may not be in a position to change clinicians based on their style—and you may not wish to. With this knowledge you can help guide important conversations and get the information and support you need from your child’s clinicians. Here are some common clinician communication styles.

- **Curator:** The clinician has considered the options and makes a recommendation for the “best” choice to follow.
- **Teacher:** The clinician tries to give all the relevant data and to explain all the possible options so that caregivers can make their own choice.
- **Guide:** The clinician explores the family’s preferences and makes a recommendation that is directly related to the family’s values.

When Styles Collide: Some Ways to Resolve a Mismatch

Communication Style	The Experience (What You Observe or Feel)	Possible Responses
Clinician as Curator	Clinician is advocating for a particular path, and you aren’t quite sure.	<i>I appreciate that you are giving me a recommendation. Let me make certain that this recommendation reflects what’s important to my family.</i>

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Communication Style	The Experience (What You Observe or Feel)	Possible Responses
Clinician as Curator (cont.)	Clinician is advocating for a particular path, and you are worried that they are not working with certain information that you have about your child (for example, a drug reaction).	<i>I am concerned because I know [this] about my child. I want to make certain that this recommendation takes that information into consideration.</i>
	Clinician is advocating for a path that you just don't like.	<i>It sounds like there is only one way to move forward. I am struggling with that. Can you help me understand why you don't think there are reasonable alternatives?</i>
		<i>What would have to be different for {another option} to be a reasonable choice? Are there ways for us to achieve that?</i>
Clinician as Teacher	Clinician is offering a lot of choices. You feel overwhelmed, need different information, or simply want a recommendation.	<i>I hear that there are a lot of options. What would be helpful is for me to tell you what's important to me, and for you to tell me which of these options best matches to that.</i>
		<i>Why would a family choose Option A over Option B, or B over A?</i>

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Communication Style	The Experience (What You Observe or Feel)	Possible Responses
		<p>Can you describe a situation that is like ours, and how the family made their decision?</p>
<p>Any Style (Possibly Guide)</p>	<p>You believe that the clinician has a goal that is different from yours.</p>	<p><i>It sounds like [this] is your goal for my child. But I am more interested in making certain that [this] happens. How does this information affect your recommendation?</i></p>
<p>Any Style(s)</p>	<p>Suggestions from different clinicians seem to be in conflict.</p>	<p><i>We are getting what seems like conflicting information from different specialists. Can we have a team meeting to discuss the options? This would help me understand how the recommendations together may affect my whole child.</i></p>
	<p>You feel the need to get advice from another source, but you are unsure of how to have the conversation with your clinician.</p>	<p><i>I appreciate your input and all the time we have spent on this. I'm not yet certain what is the best way forward for our family.</i></p> <p><i>Would it be possible for us to take some time to think about this [and talk to other members of our team] [and talk to another specialist in this field]?</i></p>

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About the Second Opinion Option

Seeking input from other trusted clinicians on your team, or from clinicians from another team or even from another medical center, can be a crucial part of the decision-making process. Sometimes it is helpful to mention your plan to get additional opinions, and that can be a part of a request for more time to consider the recommendations you have received. Other times it feels awkward to be that direct, particularly if the conversation has been challenging. In those moments, it may be more comfortable to defer the discussion to another time—if time is available to do so.

Most important: try to keep in mind that decision-making is a shared process. You are your child's advocate, responsible for and empowered to do what is your family's best interest. The clinician is also trying to help your child. It is best for everyone if you can talk, together, about how to get the information you need to move forward with respect and appreciation for everyone involved.

Conclusion

Decisions and Regret

With any path or option that you choose, it is helpful to remember that in most cases your choices may inform your child's illness journey, but they do not always determine the outcome. As you reflect on your decisions, try not to judge them based on the specific outcome you may get. There are no crystal balls or other ways of predicting what outcome would have occurred with a different choice. The more you believe that you are making the best decisions you can with the information you have, the more self-compassion and the fewer moments of regret you are likely to feel.