

Sharing Decision-Making with Families



Learning Objectives

After reviewing this Guide you will be able to:

- Work with caregivers to identify their preferred decision-making styles and preferences
- Consider your common communication style(s) and how to adapt based on families' needs
- Respond to families' concerns about decision-making and fear of regret

The Family Experience

Courageous Parents Network research reveals that parents of children with serious illness want to do the best they can for their child. To them, this means that they are effectively advocating for their child—in effect, making decisions that are consistent with matters most to them as a family (sometimes referred to by clinicians as goals and values).

Of course, all parents want to protect, provide and help their children thrive. This is an especially poignant aspiration for those who are faced with difficult, complex decisions to make on behalf of their child living with a serious medical condition. In particular, it is common for parents to worry about their choices for their child, fearing that they will later experience regret for the decisions they have made.

Parents and caregivers rely on their child's medical team for medical expertise and to provide them with information and recommendations. They want to engage in these conversations in open, positive and productive ways. This process of working together to talk about options for managing medical issues and making choices is commonly referred to as shared decision-making.

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Principles of Shared Decision-Making

The Courageous Parents Network Guide [“A Framework for Sharing Decision-Making with Your Child’s Clinicians.”](#) co-authored with Kate Nelson, MD, offers caregivers these principles:

- 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. The medical team makes the singular recommendation
- 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 the family’s goals for their child and family, to be explored in conversation with their child’s medical team
- 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

The Centrality of Respect

A sense of mutual respect is central to shared decision-making. The family has a unique perspective—expertise—when it comes to their child. They hope that clinicians will understand and regard their child as a unique individual. Their insights may include clues as to how the patient and family’s history, culture and spirituality affect their decisions. Except in the cases where a decision really cannot be reversed, they want to know that the door is open to reexamining options as the child’s status changes (for example, forgoing treatments that might have been offered in the past or might be offered in the future).

Styles in Shared Decision-Making

Shared decision-making requires that information is both delivered and processed. It is helpful to consider some common styles, or patterns, that are commonly employed as clinicians and families enter into somewhat difficult, potentially daunting conversations.

Styles in Clinician Communication

- Curator: The clinician has considered the options and makes a recommendation to the family 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.

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Styles in Collecting Information and Making Decisions

Individuals' decision-making styles and preferences differ. Keep in mind that the needs and behaviors of the caregivers may also change over time, based on each new set of circumstances.

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

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

Encouraging caregivers to reflect on how they may have made prior decisions, and especially encouraging them to relate real-life examples, can be helpful to the clinician in guiding caregivers to see patterns. For example: How have they decided which type of flat screen or television to buy? Who was involved in considering the options? Who made the final decision? These reflections can help the clinician adapt their communication style to the family's preferences and expectations.

Weighing Benefits and Burdens

As a child's baseline changes, decisions about medical interventions may become more complicated for both clinicians and family. This is not just because one system affects another (e.g., spinal interventions may affect breathing, breathing issues may affect feeding etc.), but also because the burden of interventions may increase (e.g., oxygen via nasal cannula progressing to CPAP, BiPAP, or even tracheostomy and ventilator). Often families have not considered whether there are interventions they would not want their child to endure. In some cases, especially where treatments might extend life without altering the underlying condition, the burdens on the child and family may outweigh the benefit. These issues are very difficult to openly discuss, and yet lead to the most informed decisions.

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Also consider that parents may not understand that clinicians tend to be focused on treating symptoms or trying to fix the problem. The family may not realize that they have the option to decline interventions that the clinicians recommend. Courageous Parents Network likes to emphasize that there is always a choice—and, further, that in most cases it is acceptable to ask for time to weigh the pros and cons of any particular path.

Note: If a detailed care plan is not yet in place, the clinicians—and the palliative care specialists in particular—might engage the family in creating one. The plan ideally includes information about the family's priorities, and is a valuable point of reference for both parents and clinicians in current and future decision-making.

Scripts

Julie Hauer, MD speaks about offering guidance, asking permission, and then allowing family members to reflect on (and revisit) their choices. Asking implies that there is a choice; not asking implies that there is only one way to proceed. So assuming that there is in fact a choice (i.e., that there really is more than one good option) in your own voice you might use language like this:

“It feels as if we are in a new place/beginning a new stage with [your child]. It would be good to review together whether what is most important to you has changed because of what we know now. I have seen with other families that they worry about making the right choices as their child’s condition declines. They don’t know if doing more is the right thing or not.

“Sometimes doing more feels right, and then sometimes it’s the opposite. Can we talk about this? Would it be helpful to learn how other families have thought about difficult medical decisions?”

For many clinicians, this way of examining options may seem a departure from usual practice. Remember that while helping a family explore what is important to them, you always have the option to make a recommendation.

Conclusion

With any chosen path with any chosen path or option, it is helpful to remember that choices may inform the illness journey, but they do not always determine the outcome. Creating an atmosphere of mutual trust and respect, giving and receiving information, goes a long way toward helping parents feel confident that they are valued members of a team doing the best they can for the child. The more that caregivers believe they are making the best decisions they can with the information they have, the more self-compassion and the fewer moments of regret they are likely to feel.