

Shared Decision-Making



Learning Objectives

After reviewing this Guide you will be able to:

- Respond to families' concerns about decision-making and fear of regret
- Recommend treatments and interventions in the context of shared consideration and decision-making

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:

- Effectively advocating for their child
- Making decisions that are consistent with the family's care goals and values

Of course, all parents want to protect, provide and help their children thrive. But this is a particularly poignant aspiration for those who are faced with difficult, complex decisions to make on behalf of their child. In particular, it is common for parents to worry about their choices. They fear that they will later experience regret for the decisions they have made. They want to feel that they are making the best decisions they can, given the information they have available to them. Families also want to make these decisions with clinicians who understand and regard their child as a unique individual, not solely as one whose diagnosis will drive the decision made on their behalf. And so, parents need their child's medical team to appreciate the singular, special qualities of their child and to understand the family's priorities in order to help achieve the family's goals.

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Encouraging Open, Two-Way Communication

In a good working team, everyone has opportunities to give and receive information, to articulate and consider the options before them, and to honestly and respectfully discuss their thoughts and feelings.

Families' hopes, worries and needs are at the center of shared decision-making. Clinicians may have strong recommendations, but at the end of the day parents (and their child, if able) are well aware that they are the ones who must live with the consequences of their choices. Clinicians should demonstrate respect for parents' expertise with regard to their child. Their insights may include clues to how the patient and family's history, culture and spirituality affect their decision-making. The family wants to feel comfortable offering their perspectives and asking questions without embarrassment or fear of judgment. When this atmosphere of open, two-way communication is in place, the team can work from a place of mutual understanding—and can revisit their decisions and 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).

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.

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, usually 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.

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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 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

Families caring for children with serious illness encounter countless highly-charged moments in which they are asked to make critical decisions. 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.

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Resources for Families



Handouts/Downloadable Guides for Families

Family Meeting: Being Prepared

Over the course of your child's illness there will likely be family meetings proposed by different clinicians. These meetings may be used as a way to present clinical updates, consider decisions about interventions, check in about how family members are coping, and/or address any questions you or the care team might have.

<https://courageousparentsnetwork.org/guides/a-framework-for-the-difficult-decisions>

Understanding Baseline

Over the course of your child's illness there will likely be family meetings proposed by different clinicians. These meetings may be used as a way to present clinical updates, consider decisions about interventions, check in about how family members are coping, and/or address any questions you or the care team might have.

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Videos

Selected from the Courageous Parents Network unit Shared Decision-Making

<https://courageousparentsnetwork.org/topics/shared-decision-making-2>



“We felt we better step up and show her she picked the right parents.”

Parents of an infant diagnosed with Gaucher Type 2 reflect on how they focused on being happy with her during her short little life and finding a way to see a bigger picture.

<https://courageousparentsnetwork.org/videos/we-felt-we-better-step-up-and-show-her-that-she-picked-the-right-parents/>



“Don't underestimate the importance of [the parents'] goals and values.”

A father of a child with leukodystrophy encourages parents to SAY what they want for their child. They will be heard.

<https://courageousparentsnetwork.org/videos/md-parents-dont-underestimate-the-importance-of-your-own-goals-and-values/>

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“Decision-making and finding the right balance.”

The mother of a boy with severe neurological impairment and his pediatric palliative care doctor talk about how parents look to the clinician for permission not to pursue more tests or treatments.

<https://courageousparentsnetwork.org/videos/offering-parents-information-and-giving-them-the-space-reflect-are-we-getting-the-right-balance/>



“We were actively protecting her from things that wouldn't be right for her.”

The mother of an infant shares how electing not to choose medical interventions at first felt like she wasn't actively caring for her child and how palliative care helped her understand that 'doing things' wasn't necessarily protecting or helping her daughter.

<https://courageousparentsnetwork.org/videos/we-were-actively-protecting-her-from-things-that-wouldnt-be-right-for-her/>



“We created a space where we examined what the next steps are.”

Parents of a son with SanFilippo Syndrome and their palliative care doctor discuss how they considered whether to have spinal surgery (fusion) for their son.

<https://courageousparentsnetwork.org/videos/we-created-a-space-where-we-examined-what-the-next-steps-are/>



“We just couldn't see him with the tubes.”

The parents of a baby with SMA-1 talk about their decision not to elect a feeding tube or trach for their son.

<https://courageousparentsnetwork.org/videos/i-just-couldnt-see-our-son-with-the-tubes-it-was-just-the-way-it-was/>