

Preparing for the Difficult Decisions



Adapted from *“The Serious Illness Conversation Guide”*
(the Serious Illness Care Program at Ariadne Labs)
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INTRODUCTION

A Continuing Conversation

Over the course of your child’s illness progression, you will be prompted to consider some very difficult questions regarding your goals of care for your child.

Optimally, your child’s medical team will engage you in an ongoing conversation and lead you through these questions over time. Sometimes, however, you will need to make relatively quick decisions, especially if your child’s condition worsens or medical crises occur. Through an open channel of continuing conversation, you can work together to identify what your hopes and plans are for your child’s care—and you can re-visit your answers over time. Your direction will then help the team deliver the care experience you envision for your child.

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Questions to Consider and Discuss with Your Child's Team

These may be helpful questions to explore with your child's medical team, and/or on your own, before you make any choices about medical interventions.

● Communication

PERSONAL DIGNITY

What do you want medical providers to know about your child and you, as a person and as a family, in order to help you make the best plan of care?

INFORMATION PREFERENCES

How much information do you want and can your child handle about what is likely to be ahead with this illness?

FAMILY

How much have you, your family, and your child talked about these issues? Would you like help talking with other family members about these difficult issues?

● Decision-Making and Goals of Care

DECISION-MAKING

What are the touchstones you use to make these difficult decisions? What could help you feel that you have made the best decisions you could for your child? What do you feel your child is telling you? Do you see any difficult medical decisions ahead? How will you know if it is time to consider changing, or stopping, treatments?

PRIORITIES

What are your priorities for your child and your family now? Do you see those changing over time?

HOPES

Given what you know about what might happen, and what your child is up against, what are your hopes for your child and family?

FEARS/WORRIES

What are your biggest fears and worries about the future, given your child's condition? Is there anything that you or your medical team could do that might make you less fearful about the future?

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● Transitions and Trade-Offs

GOALS

If your child's health situation worsens, what are your most important goals, for your child, and for your family?

FUNCTION

Are there specific life conditions or states that you would not find acceptable for your child to be in; for example, being on a ventilator for the remainder of their life?

TRADEOFFS

If your child becomes sicker, how much do you think it makes sense to have him/her go through different treatments for the possibility of gaining more time with you and your family?

END OF LIFE

If it must be that your child will die, where would you and your family want your child to be when dying? Is there the possibility of a "good death" for your child, and what would it look like, for you, your family, and your child? Is there anything that you or your medical team could do that might make you less fearful of your child's death?



CONCLUSION

The Conversation Continues

Caring for a seriously ill child is like a series of steps. There are ups and downs, and there is also a progression. When you have considered some of these difficult questions in advance, you will feel better prepared to respond to what's happening in the moment. This will help you feel in control. It will also help your child's medical team work with you to develop a plan that responds to your family's values and goals.