

# A Framework for the Difficult Decisions

*Adapted by Patricia O'Malley, MD from "The Serious Illness Conversation Guide" (the Serious Illness Care Program at Ariadne Labs)*

Over the course of your child's illness progression, you will consider some very difficult questions regarding your goals of care for your child, especially if his/her condition worsens or medical crises occur.

**Optimally, your child has a medical team who will engage you in an ongoing conversation and lead you through these questions over time.** Through this continuing conversation, you and your child's team can identify what your hopes and plans are for your child's care, which will help the team deliver the care experience you hope for your child. These may be helpful questions to consider with your child's medical team, **before** you make any choices about medical interventions.

## Questions to consider and discuss with your child's team

**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?

**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 stopping treatments?

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

**Fears/worries:** What are your biggest fears and worries about the future given your child's condition?

**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?

**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?

**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 her life.

**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?

**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?