

8 THINGS TO KNOW ABOUT GOALS OF CARE

- 1** Care goals are related to your ideas about quality of life & your hopes and values: what matters most to you, for your child, & for your family. Values can be informed by your spiritual & cultural beliefs, your relationships, the community in which you live & work, & any past experience with illness.
- 2** Goals of care for your child may focus on curing, rehabilitating, prolonging life, and/or providing comfort. Your goals may change over time as your child's condition shifts or when you face a new decision.
- 3** Conversations about goals of care are “what-if” discussions. When your clinicians ask about your goals of care, they are talking with you about your care preferences as you consider treatment options & make choices for your child.
- 4** You may assume that these are conversations about end of life—but this is not necessarily so. The clinicians want to know what priorities & values will affect how you consider treatment options, & how you will make decisions as your child's illness progresses.
- 5** Goals of care conversations acknowledge that you are the expert on your child. They are an opportunity to engage in shared decision-making with your child's medical team.
- 6** Anticipating what may lie ahead can be daunting & scary. The more you consider what's important for your child and family, the more confident you will feel when you are faced with decisions, & also when you reflect on decisions you have made.
- 7** Some caregivers want to have these conversations, & others want to avoid them. Some prefer to plan, & others want to decide what to do in the moment. You may wish to confront everything at once, or only some subjects. If there is a conversation you wish to have but haven't been asked about, you can initiate it with your child's team. If they are initiating a conversation & you don't feel ready, you can ask for more time.
- 8** Remember, you are doing your best to make choices out of love. There are no right or wrong answers when we talk about quality of life and goals of care.