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.