

Talking with your care team about the future

At your next family team meeting, your team would like to talk with you about your baby's illness, your goals and wishes for your baby and family, and planning for the future. You may already have an Advance Care Plan for your baby which we will need to review as an important part of the care we provide for all of our patients.

It is important to meet regularly with your primary and specialist team and as needed – such as times of transition, when symptoms arise or if there are changes in your baby's care. Families & parents who think through what is important to them and what their wishes are often feel less anxious, more at peace, and more in control of their situation.

Before your next appointment

Please prepare for your conversation by thinking about these things, using the second page to make notes:

- What would you like to know about your baby's illness and what is likely to be ahead?
- What kind of information would help you make decisions about your baby's future?
- What is most important for your baby to have a good quality of life?
- What are you afraid of about your baby's illness?
- What kinds of medical information (if any) do you not want about your baby's illness?
- What do you think it would be like to share these thoughts with your children and family members?

Why is this conversation with your baby's healthcare team important?

Thinking about and sharing your wishes for your baby. It will give you more control over the care your baby receives. It will also help prepare you for unexpected complications. Knowing what you want for your baby will ease the burden on your family of making hard decisions during times of crisis should they arise.

Talking about the future for your baby won't change your ongoing care

Talking about the future won't change the plans we have made so far about your baby's treatment, unless, of course, you want it to. We will keep providing the best possible care to control your baby's disease.

You may find it helpful to bring other people to your next meeting

You can choose to bring anyone to your baby's next meeting so they can be a part of the conversation. Often families find it helpful to have a team of trusted family and friends who are aware of your goals for your baby.

We understand that your wishes may change over time

This is the beginning of an ongoing conversation. We know that you may have other questions or concerns in the future. We will keep being here to support you and answer your questions so that you can make informed decisions about your baby's care.

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