

Family Meeting: being prepared



INTRODUCTION



Preparing for Your Family Meetings

Over the course of your child's illness there will likely be family meetings proposed by different clinicians. These meetings may be used as a way to present clinical updates, consider decisions about interventions, check in about how family members are coping, and/or address any questions you or the care team might have. Optimally, your child's medical team, specialists and/or pediatrician will engage you in multiple conversations over time. Sometimes, however, you will need to make relatively quick decisions, especially if your child's condition worsens. Your initial, and then ongoing, input will help the clinicians make recommendations and decide with you which interventions and plans of care are most consistent with your goals and values.

Topics to Explore with the Care Team

- **What do you want the team to know about your child and your family, in order to help you make the best plan of care?**
 - Sharing your child's likes and dislikes
 - Bringing a photo of your family
 - Having a support person to attend meetings with you to listen, to take notes
- **How do you feel your child is doing today?**
 - Noting what may have changed since your last conversation
 - Writing your questions out ahead of time

(continued)



COMMUNICATION

How do you like to receive information? How much information do you want in this meeting?

- Do you like to read, listen, or watch videos?
- Big picture or just today?

How should you address with questions your child, or his/her siblings, asks about illness/treatment/prognosis?

- Social workers, child-life specialists and other clinicians can help

DECISION MAKING

● **Who or what help can help you in making decisions?**

- Remember what/who has helped you in the past
- You can ask for time, information, resources

● **What are your biggest fears and worries about the future, given your child's condition?**

- Saying it aloud can help clarify what is most important for your child and family

● **What are the next steps?**

- Ask for recommendations
- Clarify the care plan

CONCLUSION



The more prepared you are, the more confident you will feel.

Caring for a seriously ill child is a series of steps—but the size and length of each step is not always predictable. There may be ups and downs, and sometimes a progression in the illness. When you have considered some of these questions in advance, you will likely feel better prepared to respond to what's happening in the moment. Conversations about these topics and others will remind you and your child's medical team of what is important to you as you care, together, for your child.