

## TOP 10 THINGS TO KNOW ABOUT NAVIGATING THE IN-PATIENT HOSPITAL EXPERIENCE

- 1** The hospital may feel like a different world to you. You may feel disoriented – initially. Stress & anxiety are natural responses.
- 2** The care team at the hospital can be complicated, especially if it is a teaching hospital when there are more people rotating ‘on service. Your child’s nurse can help you understand the flow of people coming in & out of your child’s room.
- 3** If there are many specialists on your child’s care team, you may be given a lot of medical information & have questions as a result. It is appropriate to ask questions & to ask the specialists to explain things further. If you have questions but don’t know who to ask, ask a member of your child’s medical team to help you get the answer. You will not be judged for being confused or for needing more information.
- 4** You may find yourself repeating yourself to the different specialists & wondering why they don’t check in with each other. While this can be frustrating & tiring, it is just the way it is. Each new person wants to hear from you. You are your child’s best advocate.
- 5** Many hospitals offer palliative care, which can help coordinate your child’s care. This service can be especially helpful if you have many different specialists on your child’s team. It is always appropriate to ask if a consult to palliative care is possible for your child.
- 6** Ask your nurse, social worker, or palliative care clinician if the hospital offers programs that will help you to take care of yourself (e.g., massage, meditation room, gym memberships).
- 7** Ask your social worker if the hospital offers vouchers for parking or public transportation.
- 8** While it may be hard to leave your child alone in a hospital room, it is important to try & get out at least once a day so that you can rest, relax & ultimately be your best for your child. You can work with your nurse to find the best time to take a break.
- 9** Make sure to prioritize sleep & food when you can, to help with your mood & stamina at your child’s bedside.
- 10** You may not be able to be in the hospital for periods of time with your child: perhaps other children at home or your job & professional commitments mean you cannot be there. It can be helpful to explain the needs of your family to your child’s medical team so they can support you, including in those instances when the team believes it is important for an adult to be present.