

A Guide to Navigating the Hospital



INTRODUCTION

A Safe Yet Challenging Place

If your child is seriously ill, you may find yourself spending quite a bit of time at a hospital. Hospitals are good places to be, as your child will be safe and cared for by experts. But hospitals are also challenging. Understanding and anticipating this new environment will help you feel more in control, and better able to support your child.

You May Feel Disoriented — Initially

No matter if the road to diagnosis is short or long, straightforward or twisting, you will likely approach the hospital in a state of confusion and shock. Two things are going on at once: first, absorbing or trying to get to a diagnosis. Then, learning a new system that most of us who aren't medical providers know very little about. No doubt you really don't want to be here, in this strange place, because it means that your child is unwell. Stress and anxiety are natural responses.

The Hospital is Like a Foreign Land — Ask for Directions

The hospital may feel like a different world to you. Everyone else is moving quickly and seems to know where they are going. The clinicians are using terms that may or may not be familiar, or a familiar term in a sentence that is otherwise impossible to understand. Things change daily, weekly, monthly. And no matter how warm and comfortable the hospital staff tries to make the space, you are not home.

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● **Getting to Know the Medical Team**

If your child is hospitalized overnight and for more than a day, you will probably meet with a number of providers: nurses, physicians, fellows, residents, therapists and other specialists. You will have questions but may not know whom to ask about what. Ask anyway. Everyone wants to help, and they will direct you if they can't address your concerns. (To understand the different provider roles, see page 5.)

● **Learning the Schedule**

Who is on your child's care team, and who is in charge, is complicated because over the course of 24 hours, there is a shift between the day and night teams. Also, the team may change, or rotate, daily or weekly or monthly. Your nurse can help you understand the flow.

The primary team caring for your child visits daily to see how things are going. This visit is called "rounds." Most rounds happen in the morning, but some specialists may come later in the day. You can use this time to discuss your child's condition and progress. The care team may also ask you questions, because they understand that you know your child best.

As the team and then the specialists come and go, you may notice that they ask similar questions. They do this so they can make sure they hear and understand everything themselves, but it can get tiring to repeat yourself and to have to be "on" for so many people. Understanding their intention, and knowing that you are helping them help your child, may help you feel more empowered—and more in control.

Working as a Team

If your child has a complex illness, the medical team probably includes multiple physicians with different specialties, known as sub-specialists (for example, Cardiologist, Pulmonologist, Neurologist, Gastroenterologist). Each of the specialists and sub-specialists will give you lots of medical information and will have suggestions for how to proceed with your child's care. Sometimes you may have questions about how their plans fit together, or about how to decide between different options they offer. This can all be very stressful.

● **Advocating for Your Child**

It is appropriate for you to ask questions whenever you have them, and to share your feelings with the providers. It is totally acceptable to say to any member of the team, at any time, "Please help me out, because I am getting mixed messages from all of the doctors. I am confused. Can you please communicate with each other and then come back to me to explain the plan?"

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If the providers don't address a topic that concerns you, you can say, "This is what we understand is going on. Are we correct? This is our major concern. Should we be worried about this?"

You can also request a family meeting, which is an opportunity for you to sit down for a discussion with your child's health care providers. You can ask questions about your child's care plan and request updates and recommendations from the various members of the team.

● **Feeling Judged by the Team**

All parents want to feel that they are doing the very best they can for their child. At the hospital, surrounded by "experts," you may feel like you are being watched and judged. It is natural to want the medical team to like you and respect you.

Know that providers are not there to judge you; they are there to provide the best possible care for your child. They know that you are your child's #1 advocate and they want to hear what you have to say. They know that you are worried and stressed, and they completely understand that you will have hard days. (They have them as well.) They don't care if you haven't combed your hair all day! It helps if you tell them how you are feeling: "I'm having a tough time. Can we talk later?"

● **How Palliative Care Can Help**

Many hospitals—and the number is growing—offer families support from a palliative care team. The members of this team are physicians, nurses and nurse practitioners, social workers and others who can act as a sounding board to help you discuss and share your goals for your child and family. The palliative care team can also help coordinate your child's care which can be especially helpful if you have many different specialists on your child's team.

Palliative care may sound scary, because many people confuse it with hospice. They are very different things. Palliative care focuses on quality of life and what matters most to you and your child, not prognosis. A team can work with a patient or patient family at any point in the illness journey—for many, the earlier, the better. If a team is not assigned to you, you may wish to ask about it.

Taking Care of Yourself and Other Family Members

No parent wants to leave their child alone in a hospital room, but it is really important to get out at least once a day. Taking care of yourself will help you take the best possible care of your child. Over time, you will find the people who you trust to be with your child so that

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you can take a break. If you need someone to come into the room so you can leave, ask the nurse. If you know when rounds will occur, you can schedule your break around the team's visit so that you don't miss it. This may help you feel less anxious about leaving your child.

● **Staying Connected**

Many hospitals have special programs to help family members take care of themselves, such as massage, meditation rooms, gym memberships. Ask your social worker or nurse what is available for you. If appropriate, schedule visits with your partner, other children, family members and friends. Everything that helps you feel part of a bigger world will help you cope.

● **Getting Rest**

When you are with your child in the room you may still want quiet time. Here is a suggestion from a family: "We put a little sign on the door that said, "Hi, my name is Jack. There are so many people who are helping take care of me. But if you don't really, really need to see me today, can I ask you to please come back tomorrow so I can have some quiet in my room." The providers will respect this as much as they possibly can.

And then, sleep. When you are first in the hospital, especially if there is a crisis, you will not want or be able to sleep. Hospitals are noisy places, with people coming and going and machines beeping. You will feel the need to be alert at all times. This, again, is natural.

But consider: you will need nourishment and sleep to be able to function well for your child and to communicate with the medical team. Depriving yourself of food and sleep is not heroic; it does not help you be strong for your child or your family. Nurses will encourage you to rest and to eat. Let them help take care of you.



CONCLUSION

A Team

The hospital feels like a big, scary, foreign place. For most of us, it is just that. The more you know, the better prepared you will be to navigate the experience. It is important to remember that you are becoming a part of a team that is focused on caring for your child. The more you communicate your ideas, observations, questions, concerns, worries and hopes, the better prepared the other members of the team will be to work with you.

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Addendum 1

Provider Roles

Attending Physician	This is a doctor who has been educated, trained and licensed to practice medicine, and who is the ultimate person responsible for the care of your child. The attending physician supervises the care performed by residents. There are attending physicians in each subspecialty, for example, Cardiology Attending.
Resident Physician	This is a doctor who has graduated from medical school and is now in training at the hospital as part of his/her graduate medical education. Resident physicians are supervised by an attending physician.
Intern Physician	This is a resident who is in his/her first year of residency.
Chief Resident Physician	This is a physician in the final year of a residency program or in the year after the residency has finished, playing an important role in guiding new residents.
Fellow	This is a doctor who has completed residency and is getting advanced training in a certain subspecialty.
Hospitalists	These are licensed attending physicians who spend most of their time serving as the physician for children who are inpatients in the hospital. Hospitalists take over the care of hospitalized children and then return them to the care of their primary care providers upon discharge.
Physicians' Assistant	This is a health care professional who is certified and licensed to practice certain aspects of medicine care such as history taking, physical examination and diagnosis, the treatment of common medical problems under the supervision of a licensed physician.
Rounds	Rounds refer to the time of day when the doctor visits you and your child in your hospital room to see how everyone is doing. Rounds typically happen in the morning. If your child is in a teaching hospital, rounds will include the Attending and the residents. Rounds are a good opportunity for you, as the parent, to ask questions of your child's medical team.
Nurse Practitioner	This is a registered nurse with at least a master's degree in nursing and advanced education.
Registered Nurse (R.N.)	This is a nurse with a bachelor's degree, who has graduated from an accredited nursing program and has been registered and licensed to practice by the state.

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Licensed Practical Nurse (L.P.N.)	This is a nurse who has graduated from a school of practical (vocational) nursing and is licensed to practice by the state.
Allied Health Professionals	The hospital has a variety of allied health care professionals trained in areas such as drawing blood, using diagnostic scans, performing laboratory testing and regulating dietary needs.
Social Worker	The hospital social worker has a graduate degree in health care social work and works with your child and family to make sure you have all the non-medical supports and resources you need. This can include providing or finding counseling and expanding or strengthening the social supports in your community. For example, the social worker can talk to your child's teacher and school. Social workers are trained to be excellent listeners and problem-solvers.
Chaplain	The hospital chaplain has a graduate degree in theological education. Chaplains tend to the spiritual, religious, and emotional needs of you and your family. Chaplains care for people of all faiths and those who are not religious at all. Chaplains are trained to be excellent listeners and sources of support. Rather than promote any specific beliefs, they honor every journey and will assist with your unique spiritual needs.

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Addendum 2

Hospitals Must-Haves

Hospital Bag	Having a bag packed and stored in your closet will save you a lot of time of running back and forth to the hospital. In the bag, we suggest packing socks, under garments, basic toiletries, pajamas, extra shirts, and pants.
A Snack Pack	Most floors of a children's hospital will have a lunch room that has microwaves, refrigerators and freezers. Having a snack pack full of quick easy snacks and microwaveable foods will save you in a pinch. If your friends want to help you, the best thing to ask for is a care package that includes easy boxed foods, dried or fresh fruits, and microwave meals.
Phone Charger	Having access to your phone or tablet will be a critical way for you to stay connected with friends and family while you are in the hospital. Make sure you pack a phone charger. Also, you may have HOURS to burn sitting by your child's bed. Phones/Tablets can provide you hours of entertainment as you sit with your child.
Inflatable Mattress	Your child will have a nice bed that is soft and full of nice blankets. You will be stuck with a small couch that is hard as a rock. Most children's hospital rooms will be large enough to squeeze an inflatable bed on the floor. Pack an extra set of sheets and some pillows and a blanket.
Flip-Flops & Slippers	Hospital floors are very cold. They are also not the most sterile places, so having your feet protected will save you from any bacteria floating on the floors.