



# HOSPITAL CARE GUIDEBOOK



**A**ny hospitalization, whether for a scheduled procedure or emergency care, is a stressful time for parents and children alike. Whatever the circumstances of the hospitalization, it is important for parents to be well informed and prepared when possible. Parents should also consider their own self-care so they can be in a good position to support their child and family. Knowing what to expect and understanding what needs to be done before, during, and after your child's hospitalization can ensure that your child's hospital stay goes smoothly.

This guidebook was developed to help parents prepare for their child's hospital stay. The pages are organized to include what to expect *before, during, and after* hospitalization with thoughtful suggestions to support you, your child, and your family.

- **Preparing Before Your Child's Hospitalization**
- **During your Child's Hospitalization**
- **Emergency Hospitalization**
- **Self-Care During Hospitalization**
- **Sibling Care During Hospitalization**
- **After Your Child's Hospitalization**

It is our hope that the information contained in this guidebook will reduce the stress and anxiety that parents, children, and families may experience with a hospitalization.



## PREPARING BEFORE YOUR CHILD'S HOSPITALIZATION

When a child is hospitalized, it is important for parents to be an active participant in their child's care. To help ease some of the anxiety that your child may have, you can prepare ahead of his/her hospital stay:

- Schedule a time with your child's doctor to go over your child's procedures, risks, expected length of stay, and any follow up care requirements. This will help you have a clear understanding of the medical or surgical treatment your child is expected to have.
- Ask your doctor's nurse or hospital's child life specialist about what, when, and how to tell your child.
- Visit the hospital ahead of time to familiarize yourself with the hospital layout, rooms, and services. A nurse or medical social worker can go over hospital rules for parents staying overnight, visiting hours for siblings and friends, hospital facilities and special services, as well as provide additional preparation tips.
- Pack familiar and favorite items for your child to provide comfort and security. This might include his/her sleepwear, daily toiletries, a special blanket or toy, books, family photo, and portable music player and earphones. Child-oriented websites such as, [Bandaides&Blackboards](#), developed by a nurse, allows children the opportunity to share information about living with a chronic disease and provides suggestions to keep busy while in the hospital.

### ■ Talking to Your Child

It is a good idea to talk to your child about his/her upcoming medical procedure or treatment. In general, children who are reassured of what lies ahead are less anxious and better able to cope. When and what you tell your child will depend on their age, previous experience, ability to understand, and emotional make-up.

- Experts recommend that children under three should be told two or three days before and older children one or two weeks ahead. If there are other siblings, it is a good idea to also inform them of what is going to happen.
- For the younger child, it is best to tell them honestly in age appropriate language the reason for their hospital stay and what they should expect on the day of the medical procedure and during their recovery.
- For older school-age children, they can be given a more detailed explanation of the medical issue, what needs to be done, and the benefits of the scheduled procedure.

A child life specialist can provide additional suggestions and further guidance in this area.



## DURING YOUR CHILD'S HOSPITALIZATION

During the hospital stay, your child will turn to you for emotional support. All children, regardless of age, worry about being separated from their parents. When children are in unfamiliar surroundings, feelings of loneliness or of being abandoned in a strange place are what distress children the most. You can put them at ease by reassuring them of your presence and reminding them of how critical it is to be treated by specialists at the hospital. Your involvement in their care will help your child feel more confident and allow them to maintain some sort of daily routine.

Young children under the age of 5 need a parent or somebody familiar to stay with them, while older children need daily visits by somebody familiar to them. Children need to be encouraged to talk about their experience and feelings.

### ■ Working with the Hospital Care Team

While your child is in the hospital, you will meet many different health professionals, ranging from cardiologists, electrophysiologists, and geneticists to nutritionist, gastroenterologist, occupational and physical therapists, and feeding specialists. You can ensure that your child receives the best medical care by being proactive and staying involved in their care. Educate yourself about your child's procedure or situation, ask questions, and share your concerns. You are the best person to interpret your child's needs and wants and to inform doctors when something seems out of the ordinary.

Here are some basic tips to keep in mind when dealing with your child's medical care team:

- Various medical professionals may be in and out of your child's room to perform tests or gather information without explanation. Do not be afraid to ask questions about your child's treatment and procedures.
- The best time to update doctors on your child's condition and bring up any concerns you may have is during their daily patient rounds.
- Advocate for your child and be assertive when necessary. If you feel that your child needs additional medical intervention or consultations with a specialist, share your concerns with your child's medical team.
- Get to know the nursing staff on a personal level and inform them of what your child finds comforting and upsetting. Your child may feel intimidated about expressing his/her needs.
- Report your observations or recap the day's issues with each new shift nurse. It is helpful to emphasize what you feel are the key issues to be addressed for your child.
- If you leave for any length of time, tell the shift nurse where you will be, when you plan to return, and your phone number for emergencies.



## EMERGENCY HOSPITALIZATION

If your child is admitted due to complications, he/she may be transferred to the intensive care unit (ICU). Specially trained doctors, nurses, and technicians will tend to your child around the clock. Your child's blood pressure, heart rate, and respiratory rate will be monitored continuously.

It may be alarming when you first see your child sedated or very drowsy with various equipment and tubes hooked to him/her. Some of the special equipment may include a breathing machine (ventilators), chest tubes to drain blood or fluid from the chest after an operation, and several intravenous (IV) lines to transport blood, fluids, and medications.

When your child is in intensive care (ICU), there will be many attending doctors, fellows, and residents making rounds to discuss your child's case. During this uncertain time, try to stay positive and make your child feel as comfortable as possible. When it comes to staying overnight with your child, most ICU nurses will advise parents to go home to get a good night's sleep. They feel it is better to take advantage of the constant care in ICU and save your energy for the pediatric ward where there are fewer nurses to attend to your child.

An unexpected hospitalization is an anxious time for the entire family. Some helpful tips include:

- Ask the nurse whether you can hold your child even though he or she may be attached to tubes.
- Continue to talk to and touch your child so that they are aware of your presence.
- Take care of yourself so that you have the energy to manage your child's care.
- Ask questions and gather information about the tests and procedures being performed. Share any concerns or observations with the medical team.

When your child's condition improves, he/she will be moved to the pediatric care unit where you can take a more active role in your child's care. The nurses encourage parents to bath, change, and feed their child because a familiar face makes the child feel more at ease. If you are unsure of how to do something because of bandages and tubes, ask the nurse to show and assist you.



## SELF-CARE DURING HOSPITALIZATION

When your child is in the hospital, the entire family is affected in different ways. It can be a stressful and emotional time for everyone. It is important to remain calm and ask for support before you become overwhelmed.

Here are some practical tips for getting the support you need while your child is recovering.

- Space visits from relations or friends so that they can provide relief or companionship for you. Arranging “shifts” with your child will allow you to go home to rest or take care of household issues.
- Ask friends and relatives for help in specific areas, such as watching your other children, bringing groceries or prepared food, or running errands on certain days of the week. In many cases, people want to help but need to be told how they can best help. Websites and apps such as [MealTrain](#) or [LotsaHelpingHands](#) are resources that can be used to organize meals and other assistance to families.
- Consider designating one relative or friend to communicate important updates to other relatives and friends, so that you are able to focus on caring for your child. Downloadable apps, such as [CaringBridge](#), make communication easier by providing one centralized, private place to share health updates and request help.
- Take time out each day to talk with your spouse or partner. Remember to do something to give yourself a mental break. This might include reading the newspaper, taking a long bath, or exercising.
- If your child has a scheduled hospital visit, try to make domestic arrangements ahead of time so that you can focus on tending to your child with minimal distractions. Work out a plan with your spouse or partner on who will be responsible for different home duties.
- Enlist the help of relatives (grandparents, aunts, uncles) to provide the extra attention and emotional support that siblings may need. You also should spend some quality time each day with your other children so that they do not feel neglected.



## SIBLING CARE DURING HOSPITALIZATION

When a child is hospitalized, the entire family is impacted. Parents may spend a significant amount of time away from the home at the hospital. Siblings left at home may experience varying emotions, ranging from jealousy and anger to loneliness or guilt.

Younger siblings may wish they had a medical problem to get more attention from their parents. They may worry about their brother, sister, and/or parents or feel guilty for having negative thoughts toward their sibling or their own good health. Some may act out and display inappropriate behaviors to gain their parents' attention.

Here are some ways parents can make sure their other children feel attended to when a sibling is hospitalized:

- Address children's fears, concerns, and grief about the situation so they feel valued and supported.
- Maintain open communication with everyone in the family. Explain their sibling's illness in age-appropriate terms and encourage them to ask questions and express their concerns.
- Help children feel like valued members of the family and encourage them to help care for their sibling in age-appropriate ways.
- Schedule exclusive time with other children to make them feel important and secure.
- Let each child know he or she is special and loved. Do not assume they know it.

If other children in the home continue to have difficulty managing their emotions during a sibling's hospitalization, speak to a child life specialist or social worker for other suggestions or resources. Some hospitals offer support programs for siblings of chronically ill or hospitalized children. The [SiblingSupportProject](#) also offers a variety of programs and services for siblings of chronically ill children.



## AFTER YOUR CHILD'S HOSPITALIZATION

When it is time to leave the hospital, you will need to consider how to care for your child at home. Your child's cardiologist will provide guidelines on diet, medications, exercise, school, and follow up visits. At some point, a social worker may visit to help with the following:

- Working with a home care agency or a visiting nurse
- Dealing with health insurance and billing
- Arranging physical or occupational therapists.
- Renting necessary medical equipment (oxygen tanks, feeding pumps)
- Recommending a counselor or support group to address psychological or social concerns

Initially, your child may need a great deal of understanding and reassurance to get back into a normal schedule. During the first week, possible changes with your child may include:

- Being more fearful or concerned about his/her health
- Altered eating and sleeping habits
- A change in relationship with his/her siblings because of extra attention received

With time and patience, your child should be able to readjust to family and school life without difficulties. If you find that your child does not seem to be adjusting to his/her routine, you may want to seek out school counseling services or recommendations from your child's doctor.

### ■ Getting Support

If your child has been in the hospital frequently or for an extended period, it can become physically and emotionally draining. The Children's Cardiomyopathy can help you find the right resources and connect you to other parents for support. Please call 866-808-CURE (2873) ext. 904 or email Cindy Drake, Manager of Family Support, at [candrake@childrenscardiomyopathy.org](mailto:candrake@childrenscardiomyopathy.org).



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