

# Preparing for Hospitalization

The hospitalization of a child can be very stressful for everyone involved. Treatment advances now allow many types of illnesses and conditions to be managed on an outpatient basis. But infants and children with Congenital Heart Disease may still require admission to the hospital – to manage new onset congestive heart failure, adjust medication, treat an infection or for diagnostic procedures, just to name a few of many possibilities. Preparing a child, when age appropriate, and the family will help decrease anxiety and stress for all concerned.

An emergency or unplanned admission, however, leaves little time, if any, for preparation. Families of children with Congenital Heart Disease may want to seek help from their extended families, friends, neighbors, church group or hospital's social services staff during an emergency. Parents and caregivers must focus their attention on the hospitalized child and let others assist with other children, household tasks, etc. It is important to remember that siblings of a hospitalized child are also going through a stressful time and they need their own support systems in place.

## Discussing the Hospitalization

The preparation of a child for hospitalization varies depending on the age and cognitive level of the child. Previous hospitalizations also need to be taken into account, and whether they were "good or bad" experiences will be key. No matter what the child's age or previous experience is, however, the parents need to convey a positive attitude when discussing the hospitalization. Statements like, "They'll make you listen in the hospital," or "You'll have to stay in bed all day," should be avoided. Telling children too far in advance about an upcoming hospitalization may cause them to worry unnecessarily. But keep in mind, it is frightening to a child to walk in a room and have the conversation stop or have adults spelling out words.

One rule of thumb for discussing an upcoming hospitalization is to begin explaining what is coming up as many days in advance as the child's age in years. For example,

a 2-year-old should be told 2 days ahead of time, and a 5-year-old should be told 5 days in advance. This is a general statement and each family should assess their own child and determine what is best for him or her. Children over the age of 7, in most circumstances, can be told of an upcoming hospitalization as soon as the parents learn about it.



## **Preparing the Infant**

Because an infant cannot understand any explanations of an upcoming hospitalization, preparation is minimal. Separation from parents or caregivers can cause stress and anxiety for a baby. Whenever possible a parent or caregiver should stay with the baby. Bringing a favorite toy, blanket or bottle can help make the infant feel secure and decrease this separation anxiety. Infants can sense parental stress; remaining calm while you are with your child can make the hospital stay easier for everyone.

One way to decrease stress for yourself is to keep well informed about your child's progress. Ask questions and speak with your child's doctors and nurses frequently. In most hospitals, daily "rounds" are made on each patient. While the parents may not be present for the rounds, you can find out afterwards what the plan of care is, the latest test results, and many other aspects of your child's hospitalization that had been discussed. Another way to decrease stress for yourself and your child is to continue to be involved with your child's daily routines while in the hospital. If possible, keep the feeding schedule, nap and play times as close to the home routine as you can. Many times home schedules cannot be followed because of tests, procedures and the like. But sharing your schedule with hospital staff members can be helpful when the plan of care is being discussed. If the staff knows the home routines, they can at least attempt to incorporate them into the hospital stay.



## **Preparing the Toddler**

Toddlers and preschoolers are probably the most difficult group to prepare for a hospitalization. They have a limited comprehension of explanations given to them, and a fear of being separated from their primary caregivers. Toddlers fear the unknown

and fear loss of control. Moreover, since that cannot easily verbalize these fears, they often "act out" their fears, by screaming and/or having a tantrum.

To help alleviate these fears, the toddler can be prepared for a hospitalization no more than one to two days ahead of time. Explanations need to be kept very simple and on their level, avoiding words with multiple meanings. Keep the explanations short and, if at all possible, allow your child to touch hospital equipment ahead of time. Many hospital child-life departments have hospital and surgical tours available to you before admission. If these are not available, ask your physician's nurse for a tour.

Whenever possible, minimize the time you will be apart from your child. Bring favorite toys, blankets, etc. to the hospital. This is not the time to buy a new toy and bring it in for the child; he or she needs the comfort and familiarity of things from home. For prolonged stays in the hospital, however, new toys can be brought in to help with the boredom that often sets in.

When a parent does have to leave the hospital, it is helpful to the child if another parent or caregiver remains. When this is not possible, leave something belonging to the parents at the hospital, such as a familiar sweater from mom or dad or a scarf or t-shirt.

It is important to recognize that no matter what preparation was done ahead of time, a hospitalization is going to be stressful. The pediatric staff is familiar with these stressors and often has "tricks of the trade" that they can offer to your family. Do not hesitate to ask for help and accept help from the hospital staff and volunteers.



## Preparing the Preschooler

Preschoolers are typically difficult to prepare for a hospitalization. Preschoolers fear bodily injury and mutilation. They are often afraid of the dark and of being left alone. Preschoolers take words very literally and relate them to what they are most familiar with. For example, when explaining surgery, if you use the word "cut," your child may think of taking scissors or a knife and cutting something. Tell him instead that the doctor will fix his heart. If your child has more questions about a hospitalization, ask the hospital staff to help answer them.

Preschoolers generally have vivid imaginations. When you begin preparing your child for hospitalization, usually no more than two to four days prior to the event, you can use your child's imagination to your advantage. Drawing, play-acting or using dolls are some ways to prepare your child. Whatever way you choose, be sure to remain positive and reassure your child that he or she did nothing wrong to cause a problem. Hospitalizations should never be viewed as a form of punishment for the child. Once in the hospital, try to reinforce what was done at home during preparation. Do not assume your child remembers drawing or play-acting. Fear and anxiety often cause the preschooler to forget what was done at home to prepare for coming to the hospital.

Probably one of the most important things to remember when preparing your child for a hospitalization is to tell them the truth. Children remember if they are told, "This will not hurt," or "You won't have to stay overnight." Better to tell your child, "It may hurt, but we'll give you something for the hurt," or "You do have to stay overnight, but I'll stay with you." If you don't tell them the truth, you'll have a difficult time getting your child to trust and believe you the next time.

Don't tie evaluations of your child's behavior to his or her hospitalization. For example, avoid saying, "You're a good boy for holding still." Say instead, "That was good to hold still for the nurse."

After a hospital stay, it is important for children to verbalize or play out their feelings about their stay. Young children often go home and pretend they are still in the hos-

pital. This behavior helps them understand and integrate their hospital experience, as well as help alleviate some of their fears. They are now at home in a safe environment and often feel better about expressing themselves.



## **Preparing the School Age Child**

School age children have some of the same fears as toddlers and preschoolers. In addition, at approximately the age of 7 years, children develop the concept that death is permanent. Their concept of time is emerging, thus leading them to understanding the finality of death. Experiences with death in the family or community or what they see on television help them formulate their concept of death. It is also during this time that they realize their parents are powerless to prevent death. Children at this age often need clarification on the causes of death and reassurance that they are unlikely to die soon.

School age children may be reluctant to ask questions and admit they do not know something. For this reason, they need to have an upcoming hospitalization and procedures explained to them, and then they should be asked to explain what they understand. Children 7 years and older should be told about their hospitalization at least 1 week in advance and allowed to process the information given to them and ask questions. Children at this age learn well with concrete examples and "hands on" learning. They often like to see and touch equipment that will be used, as well as seeing pictures or using dolls to represent what will happen in the hospital. Many facilities offer hospital tours that allow children to see and touch equipment that will be used, as well as answer questions. Child-life therapists and nurses who deal with children everyday usually conduct these tours and they can be wonderful resources to patients and families.

It is important to remember that a child's cognitive and psychosocial development may not always match his or her chronological age. Development may be delayed in one or both areas. Chronically ill children are particularly at risk, so pre-hospital preparation may need to be adjusted accordingly. Make sure your hospital preparation is done in such a way that your child understands what is being said.



## Preparing the Adolescent

Adolescence is a time of change for children. Their bodies are changing and maturing. They are striving for independence and are very involved with their peer group. Adolescents' behavior is often inconsistent and unpredictable. It is normal for them to have mood swings, occasionally be depressed, or exhibit mild antisocial behavior. A hospitalization during this time can be very stressful for everyone involved.

It should never be assumed that an adolescent understands what will happen during a hospitalization, even if he has been hospitalized before. Explanations are very important. Include him in the plan of care. Control is also extremely important to the adolescent, so include him in discussions about a surgery or procedure. Acknowledging your child's frustrations and fears about the hospital stay will help him work through some of his many emotions.

Adolescents are often very self-conscious about their appearance and body image. Assure her that every effort will be made to maintain her privacy while she is in the hospital. She may or may not want to have contact with friends while in the hospital. If she does want friends to visit, give her some visiting time alone with her peers. It will help her to cope better with the hospital stay.



## Preparing Yourself

Having a sick child in the hospital is very difficult for families. Whether you have time to prepare for the hospital stay or not, it is important to take care of yourselves during this stressful period. Accept any help that is offered to you and your family. It is important to eat regularly and get rest. Alternate staying at the hospital overnight with other family members, so you can get away from the hospital for a period of time. You need to be ready for your child to come home, when he or she will need you even more. An exhausted, stressed parent will have difficulty being supportive for a hospitalized child.

When you have questions or concerns about your child, don't be afraid to ask. Write down your questions, and even the answers if it helps. Make sure you understand what the various tests and procedures are for and find out about test results. Ask about the

medications that are being started or adjusted and what therapies are being administered. You want to be as familiar as possible with your child's care prior to discharge. You are your child's best advocate and you need to stay informed. If you don't understand something, ask to have it explained again until you are comfortable with the answer. If your child has many consulting physicians, ask for a patient care conference. This is a group meeting that involves all the physicians caring for your child, along with you, the primary nurse, and often the unit social worker. The child's hospital course and future plan of care is discussed, and usually discharge concerns are addressed at this time. Many families find these meetings very informative and helpful.

When age appropriate, include your child in discussions with his nurses, therapists, physician, and residents, so he can actively participate in his care and understand what is happening. Encourage your child to ask questions and become familiar with his treatments, medications, therapies, the disease process, and surgery. This knowledge will help give him a feeling of control. Let your child be his own advocate, with your support of course. This can be excellent practice for his future encounters within the health care system.

Although this can be very difficult, you need to try to remain positive about your child's hospitalization whenever you are together. Children pick up on fears and anxiety from their parents and family. The greater the parents' anxiety, the greater the likelihood that the child will have difficulty dealing with hospitalization and illness. If you can, remain positive. It will help your child cope with the hospitalization much better. Studies have shown a correlation between parents' anxiety and the child's difficulty in coping with hospitalization and illness.

Of course, it is perfectly normal to feel anxious and scared. But try to deal with your stress away from your child. Look to your family, friends, community, church group or hospital staff to help you work through your anxiety and fears. But don't hide or ignore your own feelings. You need to be healthy and prepared when your child is discharged home after the hospital stay.



## **Preparing for Discharge After a Medical Admission**

The preparation for your child's discharge should begin shortly after admission to the hospital. Except for prolonged hospitalizations, physicians, nurses, and other hospital personnel will begin discussing plans for sending your child home almost immediately. The reason for admission will dictate the discharge plans.

Nurses and discharge planners are usually very good about teaching parents what will need to be done at home, but it is never too early to start preparing to take your child home. If your child's care will involve treatments to be done at home – such as dressing changes or insertion of a feeding tube – you should have at least two, preferably three, people learn the routines. Parents or caregivers should learn, as well as a back-up person, such as a baby-sitter or another family member. Other family members or support persons to the family are welcome to come to the hospital to learn about home care.

Care for a sick child should be shared whenever possible, so the primary caregiver doesn't get "burned out." If the child is old enough and capable of doing some of his own home care, encourage his involvement. Children as young as 5 or 6 years old can definitely participate in their own care. If the child is involved, and given explanations as to why things are necessary, he is much more likely to comply with the treatment plan. Children need to be in control of things that are happening to them; doing for themselves gives them that control.

Your discharge instructions should include signs and symptoms to watch for that may indicate a change in your child's condition. Again, if it is age appropriate for your child to be included in these instructions, include her in the teaching. The best person to tell you how your child is feeling is your child.

Make sure you have all of your questions answered before you leave the hospital. Have a follow-up appointment made with the appropriate physicians or a time frame within which a follow-up visit will occur. After discharge, if you have questions or concerns about your child that are not of an urgent nature, write them down for your next physician visit or phone call. Make sure you have contact numbers to call dur-

ing the day, at night and on the weekends if questions or concerns arise.

If your question or concern is of a more urgent nature, then write it down and call your physician's office. Writing down questions helps you organize your thoughts and remember what it is you need to ask your child's doctor. Many families use a notebook to record their questions and answers as well as hospital discharge papers and instructions so they have the information readily available when further questions arise. This notebook can act as a valuable resource for your child's health history, and be very helpful on subsequent hospital admissions.



### **Preparing for Discharge After a Surgical Admission**

Preparing for discharge after a surgical admission is slightly different from a medical admission. After surgery, care instructions may include care of the incision, bathing, activity restrictions, signs and symptoms of infection and pain management. Each group of surgeons usually has a set protocol for discharge teaching, and many surgical groups have clinical nurse specialists that work with patients and families to help with discharge teaching.

Include your child in the discussion, if age appropriate, and make sure she understands what the instructions are. Encourage her to ask questions and clarify anything she or you do not understand. Make a follow-up appointment with your surgeon, or know when the appointment should be, before you go home. Generally, one visit with the surgeon after discharge is necessary. This visit is to make sure there are no problems related to the surgery. The incision and sternum (breast bone) may be checked to make sure they are healing properly, the activity and diet of the child may be assessed, and any of your questions should be answered. Unless a complication or problem is identified during this visit, a return visit to the surgeon is usually not necessary. However, if after this visit, a problem or question does come up at home, do not hesitate to call your surgeon or the surgeon's nurse to get an answer.

Once you have seen the surgeon, it is usually recommended that you follow up with your cardiologist within two to four weeks. These time frames can vary, however, so always check with your physician.



## **At Home Following a Hospitalization**

Once you are finally home from the hospital with your child, you may think, "I'm so glad to be home, so everything can go back to normal." Although this is a nice thought, don't expect everything to return to normal immediately after your arrival. Hospital admissions can and do throw off everyone's schedule. Feeding schedules, naps, etc. are often not followed in the hospital and it may take a few days at home to help everyone get back on track. Gradually attempt to get your child back on his home routines. Don't set your expectations too high; it will only frustrate you and your child. Expect his appetite, sleeping patterns and behavior to be altered. Many times after being in the hospital, children come home and don't want to eat or they still aren't feeling well and have little or no appetite. Usually offering them foods they like to eat in small quantities and more frequently works well. If your child is taking medications at home, check with your physician or pharmacist to see if the medications should be given with or without food, then develop a schedule to accommodate this.

Your child may regress in some of his behaviors once he is back home. Children that are toilet trained, for example, may return to needing diapers, especially if this was a recent accomplishment before being admitted to the hospital. Young children may want to start drinking out of a bottle again, and it is not uncommon for parents to notice their children needing more attention once they get home. These are all fairly typical behaviors of children who were recently discharged from the hospital, and all these behaviors do resolve after several days of being back home. Being warned about these behaviors and knowing that they commonly happen – and that they go away – may make the situation easier to tolerate.



## **Sibling Issues**

Siblings of hospitalized children often have difficulties of their own that need to be recognized. They often feel left out or forgotten because of the large amount of time that their parents spend at the hospital or talking about the sick child. Depending on the age of the sibling, he or she may not understand what is going on with their brother or sister. She may even feel responsible for the illness or that fighting or arguing with her sibling somehow caused the problem. Siblings can also begin to

demonstrate behavioral changes, especially with sleep and eating patterns or school performance.

Siblings should be included in the hospital preparation of the child. If a hospital tour is offered or books are read to the sick child, the siblings should be included, if age appropriate. Hiding information or not discussing the progress of the child in the hospital can be very scary and upsetting to the sibling. If the hospitalized child is old enough and agrees to visitation, siblings should be allowed to visit. This will help siblings see that the hospitalized child is all right and alleviate some of their fears.

As with anyone visiting a patient in the hospital, siblings should be healthy. If they have a cold, sore throat or any symptoms of being sick themselves, they should stay away from the hospitalized child. If they have recently been exposed to a contagious illness at school or daycare they should not visit. Conversely, if the hospitalized child has a viral or bacterial infection, or any other illness that can be transmitted to the sibling, they should not be together. In these situations, phone calls, sending pictures or drawings back and forth, or any other means of communication is preferred over the visitation. Keeping the whole family involved in the hospitalization helps everyone cope during this very stressful time.

Siblings should be encouraged to express their feelings. They often are scared, worried and jealous of the attention their brother or sister is receiving. Spending time with other family members does help, but depending on the age of the child, this will soon be an inadequate substitute for their parents. Although it is difficult when one child is in the hospital, parents should spend time with siblings, too. Parents often feel they need to be at the hospital at all times, and feel guilty about leaving their sick child. Whenever possible, parents should alternate visitation, so one is at the hospital and one can be with the other children. Spending a couple of hours at home can make a big difference to siblings.



## **Know What's Best For Your Family**

These suggestions are only general recommendations. You should evaluate your own situation and decide what is best for you and your children. If you are unsure of what to do, discuss your concerns with the hospital social worker, child-life therapist or

nurses caring for your child. They will help you make an informed decision and will help facilitate the visitation.

Hospitalization of a family member is a very difficult time for any family. Uncertainty about the child's illness and fears about the hospitalization are stressful. Take time for yourself. Accept help that is offered to you. Ask questions as they come up. Ask for clarification on anything you don't understand. Keeping yourself, your child and the rest of your family prepared and informed will make things easier to handle in the long run.