

Helping Your Child With Medical Experiences: *A Practical Parent Guide*



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This guide was created by the Department of Psychiatry at Children's Hospital Boston, under the direction of Melissa Van Horn, Ph.D., David R. DeMaso, M.D., and Debra Lefkowitz, Psy.D. Special help was provided by Leslie Campis, Ph.D. and by the Center for Families at Children's Hospital Boston. We have put this guide together with the help of families who have had their children hospitalized, and we have used their words throughout the manual.

Introduction

If it has been recommended or you have decided that your child is in need of a significant medical procedure or hospitalization, this Guide is for you. It was created to help prepare you for what will happen during your child's hospitalization, and to give you information about specific ways to help you and your child cope with medical procedures and with the hospital stay. We hope that this Guide will help you in managing this experience.

This Guide was written with the help of parents and professionals who understand that having a child hospitalized can be stressful, confusing, and frustrating. This Guide is intended both for families facing a new illness and for those facing a chronic or long standing illness. The advice and guidance in these pages can help clear up confusion and reduce frustration. Everyone's situation is different, and you may have a lot of questions about what will happen when your child is hospitalized. This Guide will begin to answer some of those questions.

If you would like more detailed medical information about specific illnesses, please visit the Children's Hospital Boston's website at www.childrenshospital.org and then going to the Child Health A to Z section. This Guide can be found at <http://www.experiencejournal.com/cardiac/clinic/parentguide.shtml>. With this information in hand, you can be a more effective source of support for your child, your family, and yourself.

Table of Contents

<u>PART 1:</u>	Preparing for Your Child's Medical Procedure or Hospitalization	4
	Preparing Yourself	4
	Telling your Child	7
	Getting Ready to Go	11
<u>PART 2:</u>	Coping With Your Child's Procedure or Hospitalization	14
	Getting Yourself Through It	14
	Helping Your Child Cope	15
	Helping Your Other Children Cope	19
<u>PART 3:</u>	Going Home	21

PART 1

Preparing For Your Child's Medical Procedure or Hospitalization

Medical procedures and hospitalizations can be stressful for many families. Children show a wide range of reactions in medical situations. These reactions are shaped by many factors, including their personality, developmental level, style of handling stress in other situations, and experiences with past medical procedures.

It is impossible to eliminate all of the stressful, painful or scary parts of many medical experiences. Fortunately, there are many ways to help children and parents cope with them in the best way possible. This guide includes information designed to help parents and children facing medical situations. Good preparation before medical experiences can reduce fear and distress, and can help parents and children deal with their experiences effectively.

Preparing Yourself

Studies have shown that it is just as important for parents to prepare themselves as it is for them to prepare their children. It is normal for parents to feel worried or nervous when their children are having procedures done, or preparing for a hospital stay. Parents often have many questions and concerns about how medical experiences will affect their child and the rest of the family. They are often worried about the medical reasons leading to the procedure or hospitalization, and are trying to understand new and confusing information. They are concerned about how to help their child get through operations and tests, and how to help their child deal with pain.

Parents have the challenging task of coping with their own worries and fears about the hospitalization while providing support and comfort to their child. A child's pain and distress is difficult for most parents to bear, and can make parents feel helpless, guilty and frustrated. Parents who can control their worries and be as relaxed as possible about hospitalization send helpful messages to their children. Children's responses tend to be influenced by the responses of their parents; as a result, staying as calm as possible is one way to help children be less distressed.

“You can’t prepare for everything, but I found that getting myself as ready as possible really helped me to stay calmer, which in turn helped my child to cope better.”

It is important for parents to remember that no parent can handle all situations perfectly, and that there is not an absolute “right or wrong way” of doing things. Parents need to trust their instincts as the person who knows their child best, while also being open to input from others. Most parents are able to do the best they can to help their child, even under stressful and scary circumstances.

When a child will be hospitalized, it is important for parents to start making plans so that they can be at the hospital as much as possible. This usually involves arranging time off from work and asking for help with the care of other family members and the household. Parents often find that family, friends, neighbors and members of their religious community are very willing to help, and are also good sources of emotional and practical support to them.

Learn as much as possible about your child’s illness and treatment.

Your child’s health care team may be able to provide parent-friendly information packets or videos about your child’s medical condition and treatment. They may also be able to direct you to other information sources that can be obtained through the library or on the Internet.

It is very important that parents feel comfortable asking all kinds of questions of the doctors and nurses. It is their job to answer your questions and address your concerns. Sometimes it helps parents to make a list of questions to ask, as it can be hard to remember everything during meetings with the team.

If your child will be hospitalized, learn as much as you can about the hospital.

As a starting point, it can be helpful for parents to read the Children’s Hospital Guide for Patients and Families. The guide provides detailed information about inpatient and outpatient services, as well as resources for children and families. The Center for Families, which is located next to the cafeteria, can also help families find resources.

It can also help to take a tour of the pre-operating holding area, the recovery room, and hospital rooms. If possible, it is nice to meet the staff that will be involved in your child’s care, and to ask them about their roles on the health care team. Parents can also ask staff if any parent or patient support groups are being offered, and can find out what kinds of activities are available for patients admitted to the hospital.

“Make sure you write down any questions you have, so you don’t forget them when you meet all of the doctors.”

Common questions that parents may have include:

- ♦ How long will the operation or procedure take?
- ♦ What are the risks involved?
- ♦ What kinds of medical equipment will be used?
- ♦ What does that equipment look/sound/feel like?
- ♦ What will happen just before the procedure?
- ♦ What will be expected of my child?
- ♦ How long will my child have to go without eating beforehand?
- ♦ Will my child be awake during the procedure?
- ♦ If so, how long will my child be awake before the procedure?
- ♦ What will be expected of me?
- ♦ Will I need to leave the procedure room?
- ♦ Will I be with my child when he/she wakes up?
- ♦ How will my child feel when he/she wakes up?
- ♦ Will my child be in pain? If so, how will it be managed?
- ♦ How long will it take for the anesthesia to wear off?
- ♦ How long will my child need to stay in the hospital?
- ♦ What medications will my child need to take?
- ♦ Are there any side effects of those medications?
- ♦ How long will it be until my child can go back to school?
- ♦ Will my child need to restrict his/her daily activities?

Find ways to manage your worries, concerns and stress.

Social support can be very helpful to people facing stressful circumstances. In particular, we know that parents who actively seek support for themselves cope better with their child's hospitalization and are better able to care for their children.

- ♦ In addition to talking with friends and family about concerns, parents often find it helpful to talk with parents of other children in the hospital and/or parents of children with similar medical conditions.
- ♦ Parents who are less comfortable talking with other people often find it helpful to write about their child's medical experience in a journal.
- ♦ It is important for parents to take breaks from caring for an ill child when possible, even if simply to get a cup of coffee.
- ♦ Deep breathing, relaxation, meditation and exercise are all excellent ways to manage anxiety.

Telling Your Child

Many parents worry about when and how to tell their child about having a procedure or going to the hospital. Parents sometimes wonder if hiding the truth for as long as possible will make it easier and less scary for their child. However, children are often more frightened when caught by surprise.

Also, when children are not given information about what is going on, they may invent their own explanations. These explanations are often incorrect and more frightening than the truth. When children do not know what is going on, it is harder for them to express their worries and get support from others. Most children respond best to **simple, honest and straightforward explanations** about the hospital. Some children do better when this information is presented in multiple discussions and not all in one conversation.



Trust your instincts – some children cope better when they are armed with information beforehand, whereas some children cope better when given very little notice. How has your child coped with stressful situations in the past? Thinking about this can give you useful information about how much information to share with your child and when to share it.

Think about your child's age before deciding WHEN to tell him/her about the procedure or hospitalization.

- **Young children** do not understand time the same way as older children and adults. Their understanding of time is much shorter than that of older children. The young child is slowly learning about the days of the week, so that preparation one month or even one week ahead may be too abstract and may not be helpful.
- One or two days is more appropriate for the **preschool child**.
- **School-aged children** can be told about a week ahead of time
- **Teenagers** usually do best when involved in treatment planning as it happens.

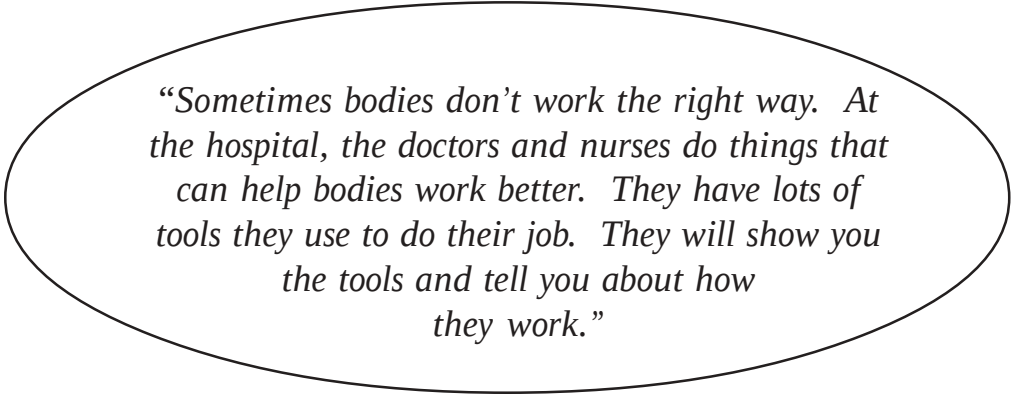
Sometimes children overhear conversations between parents and doctors about scheduling procedures or hospitalizations. Children may ask questions based on what they heard. In such cases, it is best to talk with children about what will be happening, rather than try to hide it until closer to the time it will occur. This will reduce the risk that children will worry or develop misunderstandings about the situation.

Other factors to consider when you tell your child about an upcoming procedure and/or hospital stay:

- ♦ Use a calm, relaxed tone of voice.
- ♦ Choose a quiet time to talk with your child.
- ♦ Tell your child that he/she will be going to the hospital for an operation, test or treatment.
- ♦ Tell your child when the procedure or hospitalization will be and how long it will last.

Use honest, simple language.

Your child's age and developmental level will determine their ability to understand medical information. You need to use language and concepts appropriate to your child's age. For example, when describing the hospital, you might say:



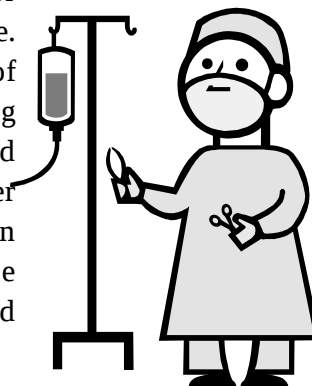
“Sometimes bodies don’t work the right way. At the hospital, the doctors and nurses do things that can help bodies work better. They have lots of tools they use to do their job. They will show you the tools and tell you about how they work.”

Choose “soft” words rather than “hard” words when describing what your child will feel.

Some words sound scarier to children than others. Think carefully about the words you use to describe procedures and sensations to your child, and try to choose words that are neutral or soft. For example, you might say that the nurse will “slide” the needle into your child’s arm, rather than that the nurse “stick” or “poke” your child. You might describe certain sensations as “warm,” rather than “burning” or “hot.” You might tell your child that the doctor will “make a small opening,” rather than “cut a hole.”

Focus on what your child will actually feel, see, hear and smell.

In talking with your child, focus mostly on what he/she will directly experience. It is less important to talk about what will happen while your child is sedated, as too much detail can scare children. Describe what your child will see in the hospital, like what the doctor will be wearing or what the medical equipment will look like. Describe some things your child might hear, such as the sounds of medical equipment. Let your child know if he or she will be wearing a hospital gown or an identification bracelet. Also, let your child know where and how the nurses and doctors will touch his/her body, and how that might feel. For example, you might explain that the doctor will listen to your child's heart and lungs, and he will use a tool that looks like a big quarter and sometimes feels cold on the skin.



Tell your child about the doctor's office or hospital.

Going to the doctor's office or hospital can be a scary experience for children. They find themselves in a strange new world filled with unfamiliar sights, sounds and smells. This world is filled with busy people wearing strange clothes, children who have obvious signs of illness, and lots of machines. Children may be faced with being away from their parents during procedures or for overnight stays, and will not have the comforts of home to help them cope. Children may also be faced with scary and painful medical tests and procedures.

Tell your child if he/she will be staying overnight at the hospital.

It is important to let your child know if he/she will be sleeping at the hospital and to describe what it will be like. Many children become anxious or afraid when spending the night away from home, even when at a more familiar or fun place. Your child may need reassurance that you will be there and that he/she will be able to go back home eventually. For example, you might say:

"Lots of kids will be at the hospital, and many will sleep there overnight. Moms and dads are also allowed to sleep over. We will be able to take favorite blankets, pillows, stuffed animals with us when we go to sleep over. You will have your own bed and television. Then, when the doctors finish up all their work, you will come back home again."

Other things to tell your child:

- ♦ Tell your child that friends and family will be able to visit.
- ♦ Encourage your child to ask you, the doctors and the nurses lots of questions.

Ask your child questions to make sure he/she understands what you have said.

Children often develop unusual beliefs about why they are sick or hurt, and why they need to go to the hospital. They sometimes believe it is because of bad behaviors or mean thoughts and feelings. It is important to make sure they understand that children go to the hospital when their bodies are not working right, not because of anything they do, say or feel. It is important to make sure that your child understands that going to the hospital is not a punishment.

Let your child know it is okay to have many feelings about going to the hospital.

Your child have many feelings about being in the hospital, including fear, frustration, and anger. You will also have similar feelings. It is important to let your child know that it is normal to have many different feelings about going to the hospital.

Listen to your child's feelings, and help him/her talk about them.

It is helpful for your child to have you listen to and support his/her feelings. You can help their child put these feelings into words and encourage their expression. Younger children often use play to express their feelings. Medical play kits can be used with dolls, puppets, or stuffed animals, and can help your child become more comfortable with medical procedures. Children also enjoy “playing doctor” with parents, friends or family members. They also can use creative arts such as drawing and painting to express their feelings.

Read books together about going to the doctor or the hospital.

The children's book section of many bookstores has picture or storybooks about being sick, going to the doctor or going to the hospital. In addition, the Center for Families at Children's Hospital can provide you with an information sheet titled “Books to Read about the Hospital.” Some recent titles are listed below:

A Visit to the Sesame Street Hospital

Going to the Hospital, Fred Rogers

Fat Dog's First Visit: A Child's View of the Hospital, Kroll & Jim

Tubes in My Ears: My trip to the Hospital, Dooley

The Moonballoon: A Journey of Hope and

Discovery for Children And Families, Drescher

“Why am I Going to the Hospital?”, Ciliotta & Livingston



Getting Ready to Go

Again, it is helpful to think about how your child has handled stressful situations in the past, including visits to the doctor or hospital. It often helps to think about how your child tends to react to stress, and what tends to help him/her manage it.

Knowing what to expect and being prepared **BEFOREHAND** can help children feel more safe and comfortable once they get there. Nurses and child life specialists can often provide parents with detailed information about what will happen during the procedure or hospitalization, and can offer suggestions about ways to help children get ready.

Before a hospitalization, attend the pre-admission program with your child.

The hospital has pre-admission preparation programs for children of different ages. These programs provide an opportunity for your family to learn more about the hospital and about what your child's stay will involve. The program gives your child information about medical procedures, such as blood tests, and allows him/her to touch and play with medical tools. Your child will also meet some of the doctors, nurses and child life specialists in the hospital, and may meet other children who will be in the hospital at the same time. All of these things can help your child cope with their worries and fears before coming to the hospital.

Play “doctor” with your child.

There are many toy medical kits available today. It can be very helpful to role play medical situations with your child, taking turns being “doctor” and “patient.” Children also enjoy using dolls, stuffed animals, pets and siblings as “patients.” Role-playing familiarizes children with medical equipment, and helps them develop a sense of mastery over the experience.



Ask your child what special things he or she would like to take to the doctor's office or hospital.

Your child can derive comfort from familiar toys, clothing, bedding, pillows, and stuffed animals. Photographs from home can provide a reassuring reminder of family. Favorite videos and music can provide comforting distractions as well.

Practice “coping strategies” to use in the hospital.

“Coping strategies” are things people do to help them deal with stressful or scary situations. There are many coping strategies that can help children get through painful or scary procedures in the hospital. It usually works best if you and your child practice using these strategies before the hospital stay, at a time when your child feels comfortable and safe. When your child feels scared in the hospital, it will be easier to use strategies he/she already knows well.

Things children can do:

Breathe deeply
Pretend to blow the candles out on a birthday cake
Think about a happy or fun time, and pretend to be there
Tell stories or sing aloud
Count backwards
Squeeze your hand
Listen to music
Look at a picture or distracting toy



Things parents can do:

Use a calm, soothing voice
Reassure your child
Coach your child
Give encouragement
Tell your child what to expect
Hold your child's hand
Stroke your child's face or arm
Distract your child
Show that you trust the doctors

Request a psychological evaluation of your child.

A psychological evaluation of your child can provide information about his/her coping style, and can help parents determine how best to help their child adjust. Psychologists can help parents find ways to explain complex medical information to children, and can help parents consider the best timing for surgeries and hospitalizations that are not emergencies. A preadmission preparation program may be developed for your individual child and family to help everyone in the family prepare for and cope with the hospitalization. Psychologists can prepare children for specific tests and operations using medical play therapy techniques, and can help parents find ways to manage their own feelings about the hospitalization.

A psychological evaluation should be considered if your child seems unusually worried and/or frightened about the hospitalization. Your child may show signs of worry or fear by not sleeping or eating well, voicing frightening ideas about the hospital, becoming quiet and withdrawn, or becoming aggressive and angry.

PART 2

Coping With Your Child's Procedure or Hospitalization

Getting Yourself Through It

Even when parents and children are well prepared, getting through the actual procedure or hospitalization can be difficult. People of all ages tend to deal with stress best when they have strategies for handling it. Fortunately, there are many things parents can do during procedures and hospitalizations to make them easier.

In the hospital, parents are faced with a new environment which can be overwhelming and intimidating. Parents have to turn over many of their caregiving responsibilities and roles to the medical team. Some parents feel “left out” when this happens. Parents sometimes worry about being evaluated or criticized by professionals in the hospital, especially if their child has behavior problems while there. They may feel inadequate as parents if medical staff get better cooperation from their child, or seem better able to comfort or soothe their child.

Remember that you are an important member of your child's treatment team.

You know your child better than anyone else. You can help the doctors and nurses by letting them know how your child reacts in medical situations and telling them what helps your child get through those situations in the best way possible.

Make sure you know which doctors are in charge of your child's care.

There will be many doctors and nurses involved in your child's care. When multiple care providers are involved, it is not uncommon for them to have different ideas and opinions about your child's treatment. This can be very confusing and frustrating for parents, and can make parents worry that “no one knows what is going on.” It is very important that you identify the person who heads up your child's team. Parents have also often found that keeping a list of the different medical providers, and information about how they can be contacted, is helpful.

“Be sure to let your doctor know that you expect to be a part of the decision-making”

Keep a list of questions for the doctors and other medical staff.

Helping Your Child Cope

Once you arrive at the hospital, it is important to find ways to make the stay as easy as possible for your child. It is always important to remember that it is normal for children to show lots of different feelings once they are in the hospital and to act differently from how they act at home. Your child's response to the hospital will depend a lot on his/her age and development. There are a number of general strategies that seem to help children of all ages adjust to the hospital.

Follow familiar home and parenting routines as much as possible.

You should feel comfortable engaging in home routines, such as bedtime stories. Providing a structured daily schedule and age-appropriate play activities can also help.

Stay overnight if possible.

Spending the night with children helps them feel more safe and secure in the hospital. When it is at all possible, it is strongly recommended that one caregiver arrange to sleep at the hospital.

Help your child get through painful or scary procedures.

You will need to decide if you can be with your child during medical procedures. If you are able to seem calm and relaxed, it can be very helpful to your child if you are there. Together with the staff, you should decide whether your presence calms your child or seems to make it harder for him/her. The best plan of action is the one that helps your child get through the procedure as easily as possible.

You may feel uncomfortable restraining your child for a painful procedure. It is not necessary for you to do so. You do not need to accompany a child to every procedure. At the same time, you should have the opportunity to remain with your child at such times.

Ask for your child's help.

Being involved can help children control their fears and feelings of helplessness. For example, children can hold bandages or remove tape. It also helps children if you let them know what their "job" is during a procedure. It helps children if you tell them what they can or should do, rather than what they should not do. For example, you can say to your child "It is your job to try to be as still as you can," rather than saying "don't move."

Create “safe zones” where painful medical procedures cannot occur.

It is best if painful procedures can be done in a treatment room, not in your child’s bed if at all possible. This supports your child’s sense of security in their room and may reduce sleep disruptions.

Give your child choices when possible.

Having choices can help children feel more in control. Sometimes you can give your child choices about which arm to have blood drawn from, what type of Band-Aid they would like, or what flavor of medicine they would like.

Stick to the usual limits and family rules with your child as much as possible.

It can sometimes be difficult in a hospital setting to maintain the usual rules and limits that your family has developed at home. You may feel badly for your child, and want to alleviate any physical and emotional discomfort they may have. You might also feel guilty about their illness or hospitalization. However, children tend to do better and to experience less distress when provided with the same rules and limits, to the extent possible, that they are accustomed to at home.



Ask for a psychological consultation.

Sometimes children show more than “normal” amounts of anger, sadness or fear in the hospital. They may also develop problems with eating, sleeping and dealing with pain. In these cases, you can ask the doctor or nurse to arrange for a psychological consultation for your child. A psychiatrist or psychologist will come to your child’s room to talk with you about your observations and concerns, and to offer suggestions about how to help your child.

Understanding how your child's age and development may affect his or her response to being in the hospital

In order to understand a child's response to the hospital, it is important to understand the emotional issues of the different developmental phases.



Early Infancy (Birth - 8 months)

In the first eight months of life, infants rely on others to meet their needs for physical contact and comfort, food and sleep. During hospitalization, infants may show difficulty in feeding or sleeping, may be more prone toward crying, and may be more difficult to comfort. When a long hospitalization is necessary, infants can sometimes seem depressed, as shown by decreased appetite and less interest in the world around them. In most cases, this resolves within a few weeks after going home from the hospital.

Late Infancy/Toddlerhood (8 months-2 years)

Older infants are more aware of separation from their caretakers, and may have trouble being separated from them in the hospital. They also begin to develop fears of "strangers," or unfamiliar people. Older infants and toddlers may cry when parents leave the bedside or hospital, or may seem content when parents are gone, but cry when they return. After going home, infants may be clingier with parents, may demand more attention, and may become unusually upset when separated from parents. This response typically subsides over a period of weeks.

Hospitalized infants and toddlers may temporarily "lose ground" in the development of certain abilities, and may return to more immature behaviors. This fairly common response to stress is referred to as regression. For example, a baby may demand to nurse or bottle feed after having been successfully weaned. Infants and toddlers with more severe illness who are hospitalized for a longer period of time are at most risk for such behavioral changes.



Preschool Children (Ages 2- 4 years)

Preschool children are active, curious, and increasingly verbal. As they start to explore the world around them, they slowly learn that they are separate from their parents. This can be scary for children, who rely on their parents to keep them safe and take care of their basic needs. Thus, separation from parents can be even more upsetting for children during the preschool years than earlier in life. Being separated from parents in the hospital can lead to regressed behaviors, like thumb sucking, feeding problems, temper tantrums, and wetting.



Preschool children understand the world very differently from older children and adults. They often believe that events are caused by their own thoughts, wishes or behaviors. As a result, they may believe that their illness results from their behavior, and that medical procedures or hospitalization is punishment for "being bad." They might also worry that they are sent away to live at the hospital forever.

Preschool-aged children need adults to help them cope with scary or stressful experiences. Unlike older children, they cannot come up with coping strategies on their own. As mentioned earlier, it is best when parents of preschool aged children can be in the hospital as much as possible, and can sleep there overnight.

School Age Children (Ages 5 - 12 years)

School age children are focused on mastering the world around them by learning, doing and accomplishing. They develop self-esteem and competence based on their ability to master their experiences. In the hospital, children are faced with new and confusing information, places and people, and often feel out of control and overwhelmed.

Compared to younger children, they worry more about the illness itself and the effects of medical treatment. They often have fears of harm to their body and worries about “catching” illnesses or being exposed to germs in the hospital. Older school age children can understand the need for hospitalization more fully than younger ones, but may still show signs of fear and helplessness. School age children may show their anger about shots and other procedures, and may refuse to cooperate.

Having anesthesia, or “sleep medicine,” can be very frightening for many school age children and may lead to fears of death or loss of control. Many school age children repeatedly ask, “What if I don’t wake up?” and are reminded of hearing about animals being “put to sleep.” It is important to make sure that they understand the difference between a person having sleep medicine and an animal being put to sleep. School age children also worry about waking up in the middle of the operation. It is important that they understand that the sleep medicine will keep them asleep until the operation is over. Children may also have worries about damage to other parts of their body while in the operating room.

By about age 7 or 8, most children can come up with ways to cope with stressful or scary experiences. They may talk in a way to calm themselves or develop ways to divert their own attention. They may also ask questions in an attempt to understand their medical treatment, and may help with parts of their treatment.



Adolescence (Ages 13 - 19 years)



Adolescents are becoming more independent from their parents, and have needs for privacy and control. They are also developing close friendships that are important to their sense of identity and belonging. They are undergoing rapid physical changes that can make them become self-conscious and worried about appearance.

Compared to children, adolescents are better able to understand illness and treatment, but often think they are safe from illness and harm. Hospitalization shakes this sense of safety, and challenges to the needs for independence, privacy, control and belonging. Adolescents often have trouble following the rules set by adults in the hospital, and can become angry about their lack of control over treatment.

It is hard for adolescents to have privacy in the hospital, which can make them feel angry and helpless. They also worry about the effects of illness and treatment on their appearance. They may also become angry or depressed about needing to depend on others for care, and about being separated from friends and activities. Many adolescents begin to feel isolated and lonely in the hospital.

Helping Your Other Children Cope

Medical procedures and hospitalizations can be stressful for your child's siblings as well. Because of the circumstances, siblings of an ill child often get less attention from parents and have to adjust to disruptions in normal family routines. It can be difficult for parents to provide their other children with as much support and reassurance as they need during a medical crisis, and they are often forced to become more independent.

These family changes happen at a time when siblings have many feelings of their own about what is happening. Siblings are often worried about the well being of the ill or hospitalized child, and may feel guilty about being "healthy." Illness in a child shakes the sense of security for many children, and can trigger more general fears about safety in the world. Because ill or hospitalized children usually receive a great deal of care and attention, siblings often feel jealousy, resentment or anger toward them. They may become angry with parents as well. These negative feelings are normal, but cause many children to feel very guilty and selfish.

Keep them involved and updated.

Parents may try to protect their other children from worries by limiting the amount of information they receive about the medical situation. Unfortunately, this often makes them worry more, and can damage their sense of trust in adults. It is important to give your other children as much honest information about their sibling's health as they can understand. When possible, siblings should be allowed to visit their brother or sister in the hospital.

It is important to make sure younger children do not have any misunderstandings about their sibling's illness. Preschool-aged children may feel they somehow "caused" or "wished" the illness to occur, particularly if they have trouble getting along with their sibling. They may also worry about "catching" the illness, and need to be reassured in the case of non-contagious illnesses. They may also worry that their sibling will die, and need to know if that is a possibility.



Be as available as possible.

It can be extremely difficult to spend individual time with your other children when a child is hospitalized, but it is important to make every effort. Regular phone check-ins are also important.

Remember to recognize important events in their lives.

It is important to stay on top of the important events occurring in your other children's lives, such as big tests, athletic competitions and special social occasions. It is also important to acknowledge the stress that may be associated with any of these events, and to guard against minimizing it in comparison to the medical situation. Parents need to let their other children know that healthy people are just as important as people with medical issues.



Arrange to have a trusted adult in the home.

If you will be unable to be at home at all during the hospitalization, it is important to arrange to have a trusted adult in the home with your children.

Let them know it is normal to have many different feelings.

It is important to talk openly with your other children about the many different feelings people have when a child is ill. It is also important to provide opportunities for your other children to express those feelings, and to listen to them.

PART 3

Going Home

Going home from the hospital usually brings relief to children and parents. However, many children have trouble adjusting after a procedure or hospitalization, especially if they are still recovering or experiencing pain. Such adjustment difficulties are normal, and may last anywhere from a few days to a couple of months. It is important to return to your family routines as soon as possible, and to maintain family rules and limits regarding your child's behavior.

Often, children do not know how to talk about their feelings after a medical experience, and may not fully understand the feelings they are having. Their feelings may come out in other ways, including having stomachaches or headaches, having trouble sleeping, eating more or less, having nightmares, feeling more afraid of things in the world, clinging to parents, being more irritable, having trouble getting along with others, or misbehaving. Children may also “regress” to an earlier stage of development, such as return to thumb sucking or wetting the bed.

If behavioral changes in your child last longer than two months, a psychological evaluation may be helpful. Children at greatest risk for adjustment problems are those with hospitalizations lasting greater than one week, those with many hospitalizations or those with prior emotional or family problems.

