

Preparing For Your Child's Hospital Stay



Supporting those with heart defects

Preparing for a procedure or surgery:

- Make sure you understand the procedure, what is involved, and what the risks and benefits are for your child. Ask if there are any alternative procedures that can be done and what their risks and benefits are.
- Tour the facility so you are familiar with it ahead of time. If you have a choice of hospitals, try to visit each of them to choose the one where you are most comfortable. Look at all areas where you or your child will be (exam rooms, ICU, general floor) as well as where you will stay (parent rooms or a nearby hotel). Note how organized the personnel are, how clean the facility is, how closely monitored the patients are, how helpful the staff is in answering your questions, etc.
- If your child is old enough you may want to take him or her with you on the tour. See if there is a Child Life Specialist who can help prepare the child and/or siblings and give you tips on how to prepare them. Often, they can give you ideas on how to talk with your child in an age-appropriate manner as well as provide books, dolls or other ways of preparing the child and help alleviate fears.
- If you are unsure about the procedure, or would like a second opinion, contact physicians who specialize in that area to discuss your child's condition.
- Ask if any medications need to be discontinued well ahead of the procedure (for example, aspirin is sometimes discontinued prior to surgeries.)
- If you have an infant that is having surgery or a procedure, and you will have to give only clear liquids prior to the procedure, you can prepare weeks ahead of time by getting him familiar with jello, juices, and other allowable foods and beverages. This will help deter the hunger while awaiting the surgery, and avoid the anxiety of trying new foods just before the procedure.
- Ask if you or your family can donate blood prior to the procedure for your child.
- Well ahead of time, make sure you get the procedure pre-certified **in writing** by your insurance company to avoid any payment problems after the fact. Make sure that the hospital AND the doctors contract with your insurance company – they may be two separate entities. It's important to understand exactly how much your insurance will pay, and what you will be expected to pay.

At the Hospital:

- Ask if something unexpected comes up during the procedure, how/when you will be notified and if your consent will be requested before proceeding.
- If you are giving birth to a baby that will need to be evaluated right after birth, request ahead of time if you want to hold the baby before he is taken away to be examined. With prior approval, in most instances, you should be able to hold your child and get video or still pictures prior to the examination and/or procedure. Also, ask if a parent can be present during this initial assessment.
- Sometimes large teaching hospitals have doctors in training help with the care of patients. You can request that if a resident, intern or fellow is taking part in the procedure, that a senior physician must be in the room at all times. Make your wishes known ahead of time and ask what the procedure is for requesting this.
- If it is difficult to obtain a blood draw from your child, make sure you request someone who has a lot of experience. It is often helpful to work with those who work primarily with children. You can also ask for EMLA cream to numb the area prior to the draw.

- At the hospital, many people will help care for your child and it's not unusual for conflicts to sometimes arise. If you encounter any nurses or other hospital personnel that you have issues with – talk with the nurse manager on duty to see if they can help resolve the problem. Express your concerns in a clear, concise manner without being accusatory or insulting and you'll find you should get cooperation.
- Prior to the procedure, ask what common side effects can occur due to the anesthesia, medications or the procedure itself so you will be prepared. Also, ask if there are treatments for these side effects so that they can be taken care of right away without experiencing unpleasant side effects for a long duration. (For example, morphine can cause itching, but Benedryl can counteract that and make the child feel more comfortable. If you know this ahead of time, you can make sure that the Benedryl is administered at the first sign of itching.)
- Ask if any tests can be done while the child is sedated from the procedure or surgery to minimize the trauma of additional testing (such as x-rays, blood draws, etc.)
- Hand-washing is extremely important in the hospital setting. Make sure that you and visitors wash your hands thoroughly before entering the room and make sure that all staff do the same. Do not allow any family or friends to visit the hospital if they are ill. This can jeopardize your child's health as well as other patients in the hospital.
- Prior to discharge, request a copy of your child's medical records for you to keep. The hospital will usually send a copy to the child's physicians on record, so make sure that their names and addresses are correct.
- Read all discharge instructions to ensure that you understand how to care for your child once at home. Make sure you know when you are to report for any follow up appointments with your cardiologist or surgeon.

What to take for your child:

- Favorite toys/videos/books. It's a good idea to label them so they are not easily lost.
- Favorite blankets – (However, they may get lost easily with the hospital laundry.) Consider bringing a favorite stuffed animal or something that can't get so easily mixed up.
- Coloring books, crayons, puzzles, hand-held games etc. (for child and siblings). You can wrap presents and have the child open one each day while in the hospital.
- Pajamas, robe, slippers and socks for children; booties and hats for babies (hospitals are often cold.)
- Button down shirts – they are often easier to put on a baby or child after a surgery.
- Posters, pictures, stickers or other items to decorate the room and make it look more friendly and familiar.
- Music cassette tapes to soothe the child and drown out the sound of medical equipment (see if the hospital has cassette players, or bring a small portable one.)
- Bubbles – depending upon the type of procedure or surgery, blowing bubbles can sometimes help the child's lungs after surgery. Ask your doctor about this.
- Small photo album – take pictures of familiar people and pets for your child to look at.
- Arrange ahead of time for friends and family to send cards, letters and emails throughout the child's hospital stay.

Other items to take:

- Insurance cards, phone book, email addresses (if access to a computer)
- Prepaid calling cards if you are going to be calling long distance. Often, the hospital phones don't let you call out without a phone card or credit card. Cell phones are often not permitted in certain areas of the hospital, including patient rooms.
- Warm, comfortable clothes for parents (sweats, sweaters, etc.),
- A pillow, toiletries and a change of clothes if staying the night.
- Journal – a journal to write down your feelings, and keep track of what happens during the stay. In that journal, or in a separate notebook, you can keep track of medication dosages and changes as well as other important information. Don't hesitate to ask questions or have the nurse or doctor double-check a dosage.
- Folder in which to keep copies of forms, physician's drawings of your child's anatomy, notes, discharge instructions and other important information.