

Tips from Tender Heart Parents for a Hospital Stay

From one mom of a 6 year old with a CHD:

- * Take an environmental "noisemaker" (streams, waves, etc...) to put on your child's pillow post surgery. It worked beautifully to block out all of the bells and whistles, voices and noises, which allowed our son an opportunity for better uninterrupted sleep. Make sure it is able to be battery operated as outlets are hard to come by.
- * Take a pre-paid phone card.
- * Crass as it sounds, take several joke books to read during the surgery. Comic relief can work wonders.
- * Bring lots of beanie baby size stuffed toys so the nurses can prop tubes up with them in the crib.
- * Make friends with the housecleaning crew--they can be an invaluable resource if you have a special request. Most of these workers welcome the friendly interaction.
- * ASK, ASK, ASK! Always question the nurses---most will appreciate your concern and be more than happy to help in any way. It always pays to pay attention--you are your child's ONLY best advocate!
- * If you don't see someone wash their hands upon entering the room, don't be afraid to ask if they have washed their hands. It can be awkward, but well worth it in the long run. Just tell them you have a special deep fear of hospital germs! Also, watch to make sure that the nurse (innocently and out of playful interaction) doesn't let your little one "fiddle" with her/his pen or name tag...they are covered with germs for sure! Always take your own pen to use ANYWHERE in the hospital, for paper signing or whatever.

Another mom advised:

- * Crayons (or colored pencils) and coloring books are a great way to pass the time away. There's just something about completing a picture. If you look in art/craft stores, or in airports, you may find ones that have intricate designs and perhaps more enjoyable than grabbing one made for children.

From Beckie Reilly, mom to Collin, born with HLHS:

- * Bring clothing that snaps up the front (especially for those getting open heart surgeries).
- * For the babies, bring receiving blankets for their "beds" while in CICU. It looked so much more comfortable to see babies sleeping on their own blankets vs. the hospital ones.

From Kirsten Archibald, codysdn@verizon.net, mom to Renee, 3, born with HLHS:

- * We found it really helpful to have a few craft activities with us to do with older sibling. Renee would not want to participate, but she did like to watch us do things.
- * Also, if you're bringing videos from home, make sure you bring some VHS and some DVD. When we were at CHOP last year, the CICU could only play DVD, and 6 West could only play VHS. You may want to bring favorite movies in both formats.
- * Make clear to the nurses that anyone entering the room (whether you're there or not) has to tell your child who they are and why they are there. Renee was pretty freaked when anyone came into her room, so it was important for them to tell her if they had come to take the trash out etc.
- * Be prepared to watch the same movie over and over. This familiarity can be a great comfort to little ones.
- * With babies, I recommend getting as much sleep as you can, but with older children (especially toddlers) be prepared to have someone with the child at all times. Come prepared for one parent to sleep in the room (if possible) and have breakfast, snacks etc. available. It makes life much easier.
- * Ask the nurses how you can be helpful. Be actively involved in your child's care. If the nurses trust you, you will be more easily able to help and comfort your child as you can take over some of the care. You will also be able to negotiate how often they bug your child during the night etc. You will need to advocate at times to allow your child to get enough sleep. This works best if the nurses like you!
- * Give your child as much control as possible. Renee needed to have a new IV placed every day for a week. It helped that she could decide where to get the IV placed, did she want to be in a chair or bed etc.

Having control over the little things made the traumatic times much more tolerable.

* Bring a notebook and use it. I promise it will all be a blur after a few days, and you won't remember a thing unless you write it down.

* Learn or make up a song to comfort your child. I was amazed how comforting she found it when I sang to her.

* In addition to asking questions, make sure you ask why decisions are made and share your thoughts, too. Be persistent if you want/need something, but in a nice way of course. At the end of our second hospital stay, Renee was so stressed out that she wasn't sleeping well and I became convinced that she would do better at home. I discussed my concerns with the docs and they sped up her dismissal, letting her go the same day instead of the next.