



# Complex Child E-Magazine

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## Tips for Coping with Extended Hospital Stays

by Susan Agrawal, Shannon Gonsalves, and with tips from Fay, Sasha, L. Kelly, Debbie, Sarah, Michele, Chris, and Kari

It is an unfortunate fact of most of our lives that our children need to be in the hospital for extended lengths of time. It is, of course, very difficult to move your entire life into one tiny little hospital room (or half of one in some cases), especially if you are like most parents and rarely leave your child's bedside.

We asked a group of very experienced mothers to share their tips and experiences for surviving a hospital stay. They've provided us with lots of great ideas, which we have listed out below.

### **First Things First: Checking out the Accommodations**

While this may not be a possibility for some families in certain locales, some families may have a choice when it comes to choosing a hospital for a specific stay. Even if you don't have a choice of facilities, it may be a good idea to check out what accommodations are available for families. Some of the things you may want to look for include:

- Private rooms
- Bathroom with shower in the room
- Laundry facilities for parents, preferably on the floor or in the unit
- Kitchen or refrigerator/microwave for parent use
- Wireless internet access
- Cell phone use allowed
- Pull-out bed for parent use
- Parent lounge
- Discounted or free meal vouchers

### **Making Your Child Comfortable**

Hospital stays are hard on everybody, but your child is of course the one who is most likely to be in pain or otherwise uncomfortable. A few little homey touches may make all the difference. Here are some suggestions from our group of mothers:

- Bring your child's favorite blanket and pillow from home, and some families even suggest bringing cute sheets.
- Bring your child's own pajamas or clothes. Since these may need to be modified for IV or feeding tube use, you might want to consider inexpensive items.
- Don't forget pacifiers, loveys, or a favorite stuffed animal!
- Slippers and socks are much nicer than hospital booties, so bring whichever your child prefers.
- A robe can also be helpful.
- For younger children, bring their own bottles or sippy cups.
- Bring some of your child's favorite snacks if applicable.
- Decorate the room with balloons, cards, flowers, artwork, and so forth. Change up the decorations frequently.
- Bring whatever your child likes to sit in, whether it is a wheelchair, positioning chair, bouncy chair, baby swing, etc.

### **Keeping Your Child Entertained**

A day in the hospital can sometimes seem like a month, and a month can easily feel like a year. Your child, even if rather sick, is also likely to be rather bored. There is nothing worse for a child than being trapped in a tiny room day after day, staring at the same ceiling tiles and hearing the same sounds over and over. Here are some suggestions for making things a little bit more fun:

- Bring a few of your child's favorite toys from home. Games, building kits, handheld devices (like a Leapster), card games, coloring books, and puzzles are all good choices. If your child has physical limitations, definitely bring some switch or adapted toys since these may not be available at the hospital.
- Bring a DVD player and DVDs or a laptop that can play DVDs. Most hospitals also have DVDs or VCRs available and a wide selection of movies.
- Bring several favorite books and ask the hospital about book cart or book closet programs.
- Bring an iPod or other portable music device loaded with favorite songs.
- Arrange to take your child on walks or rides through the hospital and available outside areas. Many hospitals have wagons, some even with IV poles, to make this easier. The IV pole can also be tied with a towel to the wagon. A change of scenery can make a huge difference.
- Take your child to the hospital playroom or Child Life center daily if possible.
- If your child cannot go to the playroom, ask Child Life to bring toys to your room.
- For children over age three, arrange for school services at the hospital, which may include going to a schoolroom or having the child tutored bedside.
- For babies, a musical mobile is a really nice addition to the crib.
- Bring or ask for arts and craft supplies and let your child do a bunch of projects. The good thing about these projects is they also serve double duty as decorations for the room!

- Take advantage of any visitors or special programs at the hospital, such as visiting clowns, musicians, dog therapy, theatre productions, silly hospital-wide games, and so on.
- Bring a long chapter book to read to your child. Many families have made it through much of the Harry Potter series this way!
- If your child is allowed to leave the hospital on a day pass, take advantage of it!

### **Making Yourself Comfortable**

Hospital accommodations are rarely comfortable for parents. You are often squeezed in a corner sleeping on a lumpy vinyl couch. While there is little you can do about the uncomfortable beds, there is a lot you can do to make the best of things. Here are a few suggestions from our group of mothers:

- Bring your own pillow, and if you prefer, your own sheets and blankets. Hospital pillows and bedding are notoriously uncomfortable. You may even want to bring towels.
- Bring all your own toiletries, including everything you need to keep yourself clean and comfortable.
- Bring comfortable clothing, such as sweats, slippers, and a robe, to wear at night.
- Have several changes of casual clothing available since many items may end up covered in vomit, poop, blood, or other bodily fluids.
- Bring lots of things to do, such as books to read, crossword or Sudoku puzzles, knitting, or crafts.
- Bring a laptop or borrow one from the hospital if that service is available. Make use of the wireless internet when available.
- Bring your cell phone and charger, or a calling card for floors that do not permit cell-phone usage.
- Bring lots of paper and pens to write down information from the doctors or questions you want to ask the doctors.
- Ask if there is a Ronald McDonald House or similar program nearby. Even if you end up sleeping in your child's room most nights, it can be very helpful to have a place to do laundry, cook meals, take a shower, or take a quiet nap. Many of these houses also offer free dinners and other activities.
- Bring lots of healthy snacks and a few indulgences for those difficult times. Some hospitals prefer that you do not eat in the room, but it is still good to have snacks on hand.
- Keep lots of frozen meals and leftover takeout in the parent fridge. If possible, make your own meals when you can.
- Make sure you bring a reusable water bottle or jug so you always stay hydrated. Some soda, milk, or juice may also come in handy.
- You may want to bring your own small fridge or cooler to keep your items cold.
- Bring quarters and dollars for snack and soda machines.
- Sleep when your child sleeps, even if it is 11am.
- Shower every day, even if it means leaving your child alone for a brief time.

- Accept and ask for help, especially assistance with laundry, meals, and your other children.
- Don't forget your own medications and vitamins. Bring extra contacts and glasses as well.
- Ask if you can keep breastfeeding siblings with you in the room. Most hospitals will allow breastfeeding infants to stay.
- Some hospitals offer parent massage, parent support meetings, chaplains, and similar services. Take advantage of these programs whenever you can.
- Take breaks, go on walks, and trade off with your spouse or other family member if you can. A few hours or nights away can make a big difference.
- Invite YOUR friends to visit YOU.
- Most importantly, take care of yourself. You cannot take care of your child if you are sick or depressed.

### **Medical Matters**

A lot can go on during a day at the hospital. The following tips are meant to help you and your child cope with all the medical information and make sure your child receives safe and appropriate care during the hospital stay.

- Bring all of your child's home medications. You never know when one might not be available at the hospital.
- Bring a summary of your child's medical history. It will speed things up greatly and comes in handy for those critical moments when you cannot remember anything.
- Bring a few days' worth of all your child's home medical equipment and supplies. The hospital may not carry things like the appropriate sized caths, feeding tube extensions, the appropriate formula, and so on. Your hospital may also let you use your own portable equipment (such as a feeding or IV pump) that can mean a little more freedom for you and your child.
- Be prepared to stand up for your child!
- Write everything down, including what the doctor says and what you are thinking.
- Always explain to your child what is happening in terms she can understand. Ask Child Life for assistance as needed. They often have dolls or sample devices to show your child what will happen.
- Ask Child Life to assist during difficult procedures. They may be able to play music, show a movie, or otherwise entertain your child during the procedure.
- Tell them when it might hurt, but don't scare them.
- Do as much of your child's care as you are allowed. Your child will always get better care if you do it yourself.
- Check any medication that is brought in for your child to make sure it is correct. Medication errors are incredibly common, and often happen daily.
- Ask for identification or check for a badge on everyone interacting with your child.

- Be cautious of hospital-borne infections. Make sure you and your child wear shoes when out of bed and use hand-sanitizer liberally. Make sure medical personnel wash their hands before touching your child.
- Bring rewards, such as small toys, lollipops, or temporary tattoos, for your child after procedures.

### **Saving Money**

Hospital stays can be expensive, even if you don't count the hospital bill! You often need to provide transportation and lodging for some or all of your family. You will also still need to eat while at the hospital. Here are a few ways to cut down on expenses:

- Stay at a Ronald McDonald House or similar facility when you can. These charge a nominal fee, which is optional.
- If you need to stay in a hotel, have the hospital set it up since they can often negotiate discounts.
- Sleep in your child's room to avoid lodging costs completely.
- The hospital may also be able to negotiate discounts on airfare and local transportation. You can also use a charitable medical airflight service.
- Bring your own medical supplies. A piece of gauze that costs you a penny may be billed for \$1. Bringing your own supplies lowers your bill and saves your insurance money.
- Cook your own meals in the hospital microwave. Takeout gets very expensive very quickly, and the hospital cafeteria can be expensive, too.
- Eat meals that are provided by friends, family, or charities (such as at Ronald McDonald Houses).
- Ask if cafeteria vouchers or other parent discounts are available.
- Do your own laundry, either at the hospital or at a Ronald McDonald House.

### **Sibling and Family Issues**

Hospital stays can be really difficult for family members, especially siblings. They may not get to see their brother or sister for a long period of time, and either mom or dad may also be away. It is especially difficult if one parent needs to work and there is no childcare available. Here are some suggestions from our group of mothers:

- Call your other children and spouse every day. Bedtime is often a good time to call.
- Have your other children and spouse visit as often as possible.
- Make sure to talk to your other children in advance so they are not scared by the hospital or their sibling's appearance. Keep them updated on your child's condition in terms they can understand.
- Do not force a child to visit a hospitalized sibling if he is scared or uncomfortable.
- Give some small gifts to your other children so they do not feel left out.

- ❑ Spend some one-on-one time with your other children, even if it is in the hospital cafeteria.
- ❑ Invite a grandparent or other relative to stay with your other children, or send them to visit a relative. Try to make it a special trip for them.
- ❑ Keep home and school routines as normal as possible.
- ❑ Try to spend some one-on-one time with your spouse. Get out for dinner together occasionally if possible.
- ❑ Have patience with both your other children and your spouse. The hospital stay is likely to be as difficult on them as it is on you. Expect regression and behavioral issues from your children and conflict with your spouse.

### **You Can Do It!**

No hospital stay is ever easy. But you can do it, and we hope these tips will make things a little bit easier.