



Hospitalization Tips

by Amy Herrington

The last time I set foot in Oakland's Children's Hospital in the middle of a shunt malfunction, I was days away from my thirteenth birthday. Between an excruciating headache, vomiting, and bouts of consciousness, I was once again reminded that shunts are not capable of paying attention to a family's social calendar, or a child's school schedule. As a twelve-year-old, my life was once again being challenged by hydrocephalus, whether or not I had things to accomplish.

To this day, I still remember vivid details of my childhood hospitalizations. I marvel at the inner strength my parents held when they watched their shunt-dependent daughter walk that fine line between health and illness. My last shunt revision in 1988 was only the seventh shunt surgery since my birth in 1975, but I knew the hospitalization routine by heart. I knew how my parents, brothers, and extended family would react with fear and concern for my well-being. I knew the routine of being released from the hospital within three to four days, being back in school facing math tests or English classes. And neither peers nor school staff would realize that I'd had surgery. That only made it easier for me to put my experience behind me, and to bottle up feelings from my hospitalizations. My family did not talk much about my hospitalizations, these experiences were more of a temporary interruption of our "normal life" than anything else.

By the time I hit my teen years, I was really hungry to talk about my hydrocephalus and hospitalizations, but I feared that if I pursued this need of mine, it would only upset my family. I finally found the courage to let my parents know my feelings of living with this chronic illness. It wasn't easy, but it was something I had to do. As a young adult, the memories of revisions, and an anxiety about future revisions are going to remain a part of me for the rest of my life.

For the last few years I've been involved with the Hydrocephalus Association, sharing my experience of having hydrocephalus with families searching for that hope and support that can be so hard to find within this big world that is still not used to hearing the term hydrocephalus. In August 1995 I made some new connections at Children's Hospital in Oakland, and began writing a support pamphlet for parents and hospitalized children. As I approach my third year of college, with life progressing along, I am still working on publishing a final draft of the booklet for the hospital. But I wanted to share with each of you some ideas taken from this project. Happy reading!

A hospitalization can be difficult for any child, young adult, or adult. It can also be trying for the parents and family that must watch their loved ones go through such an experience.

No matter whether you are a parent, child, or adult dealing with hydrocephalus and the possible need for shunt revisions, the common threat of hospitalization looms in the midst. If you are a patient, or a family member, you will deal with many emotions before, during, and after the hospitalization. Additionally, leaving the hospital does not mean that you forget about the experience, for it is a distinct part of your child's, and/or your own life.

Here are some tips from my booklet that I hope will help you, your child, or your family get through a hospitalization.

General Suggestions For All Patients and Families:

- You have a right to review your own medical records, or your child's medical records. You also have a right to know what procedures you or your child will receive while in the hospital.
- Bring familiar items from home to make the hospital look more inviting. (Remember to attach name labels to these items.)
- Keep a written or tape-recorded journal of your feelings while you or your child are hospitalized. Talk about your hopes, dreams, fears, and anxieties. Writing or talking out your feelings is an important part of the emotional healing process.

For Parents of Infants:

- Remember that you are your infant's advocate. You have a right to ask questions and receive answers about your baby's health. Become educated on what you can do to help your baby.
- To make the hospital seem a little more inviting, decorate your infant's crib or isolette. Make a poster with your baby's name on it, or put up photographs of siblings or family members, even your pet dog Spot!
- If it is possible, hold your baby. Touch is crucial to an infant's development. If it is not possible to hold your child, you can still talk quietly to him or her. A parent's voice is music to an infant's ears.

For Parents of a Young Child (Ages 2-6):

- You are your child's health advocate. Ask medical and nursing staff questions about your child's health, and learn what your child's health needs are.
- Play and imagination are very important to a child's development at these ages. Ask the nursing staff if your child can visit the hospital play room.
- Draw a map with your child of the distance between the hospital and home. This helps your child understand where he/she is.
- Before you leave the hospital to go home or to work, tell your child when you will return. Relate your return time to your child's meal time. For example, if you will return to the hospital after work in the evening, say that you will be back after your child eats dinner in the hospital.
- Some children feel they have to be brave in the hospital, especially around parents who care about them. Remind your child that it is okay to express feelings of anger, sadness, or frustration in the hospital. Often it is difficult for young children to tell their parents how they feel. Have your child draw pictures of how he/she feels physically and emotionally in the hospital. This can help your child release some possible tensions.
- Just like parents, children feel the loss of control during a hospitalization. Let your child do as much as possible for him or herself. For example, let your child dress him or herself.

Often, if children feel they cannot express their emotions of anger, frustration, or other negative feelings, these emotions find alternate outlets such as:

- Irritability
- Withdrawal from hospital personnel
- Inability to relate to peers

For Parents of School-Age Children (Ages 7-12):

- Remind your child that expressing emotions is okay in the hospital. It is not uncommon in this age category for children to hesitate to tell parents their exact feelings in an effort to protect their parents from emotional stress.
- Tell your child the truth about his or her condition. Remember that medical and nursing staff (and child life specialists) can help with this discussion.
- Have your child draw pictures or write about how he/she is feeling in the hospital.
- Bring familiar items from home, like your child's favorite blanket, toy, book, or music tape.

For Adolescents (Ages 13-18):

- Remember that you, not just your parents, have the right to ask doctors, nurses, and other medical professionals about your health, and about what treatments you will receive in the hospital. These professionals are there for YOU!
- You have a right to feel what you feel. You don't have to keep feelings inside and act like a brave soldier in the hospital if you really are scared or nervous. A hospitalization is a big deal, and lots of people are afraid of the unexpected.
- Tell your parents how you feel. Remember they can't read your mind, so you have to tell them how you're feeling.
- Ask the nursing staff, or your doctor if there are any teen groups that meet in the hospital to talk about the hospitalization experience. Just as there are associations like the Hydrocephalus Association where you can meet young people living with hydrocephalus, there might be groups within your particular hospital that meet periodically. Check it out!
- It is sometimes difficult for parents to express their feelings about your hospitalization, or your hydrocephalus. Give Mom and Dad a break, for they too need time to sort through their own feelings. If you want to talk about your hospitalization, or your hydrocephalus, TELL your parents this.

Adults

- Ask questions, questions, and MORE questions about your health records! You have a right to know what tests you will receive, and what to expect from your hospital stay.
- Share your thoughts about your hospitalization (and your feelings) with a trusted family member, spouse, or friend. Encourage these people to share their feelings with you as well.
- If you feel you need more support, look for written literature or support group phone numbers at your local library. Ask friends to help you. Don't get discouraged if finding resources proves difficult. Sometimes all that's necessary is time.

No matter what stage in life you deal with a hospitalization, the experience brings challenge. Keep in mind that you are human, and it is okay if you cannot immediately talk about your hospital experience. Every hospitalized patient, and every family member, needs time to deal with the emotions and the change that a hospitalization can bring.