

Getting Through The First Days and Weeks

Having a child diagnosed with a life-threatening illness is like no other experience. Parents often struggle to figure out how to cope in this strange and frightening new world of doctors, hospitals, tests, drugs and procedures. Many worry about how they will be able to go on with a normal family life and meet the needs of their children when everything has been turned upside down. We have collected advice from parents of children with cancer in hopes that you might be able to benefit from what has been learned by others who have already walked the same path. Here are some of their ideas on matters both great and small.

- ❖ Write everything down in a notebook or planner (Candlelighters provides a notebook and pen in your bag). When you are under stress and hearing a lot of new information, it is nearly impossible to remember it all later. Ask doctors and nurses to spell unfamiliar words and drug names for you and make those part of your records. Keep notes on tests, procedures, medication names and dosages, any side effects you notice, or visits that need to be scheduled. You will find that you refer back to your notes over and over again and you will have a complete record of your child's treatment at any point in the future when someone (the insurance company or a new doctor, for instance) wants to know details regarding surgery dates, drugs, blood counts, etc.
- ❖ Ask questions. Don't feel dumb if you're confused or need clarification on something, and don't hesitate to ask medical personnel or social workers to go over something with you as many times as you need to until you're sure you understand it. It can often help to have your questions written down before you speak with the doctor to make sure you don't forget anything you wanted to ask.
- ❖ Don't forget to be the same old mom or dad. This is one of the hardest pieces of advice to take when you see your child sick or ill-tempered, and you want to give in to every urge to spoil him rotten and drop all the rules! Of course a child has the right to be depressed or irritable, but it's important to remember that your child still needs you to be you, and to see that you still have the same expectations and rules that you've always had. Bedtime is bedtime, good manners are important, even when you're in the hospital. If all the rules and routines that give your child or teenager security suddenly disappear it can be very frightening and disorienting.
- ❖ As one mom put it, when your child is in the hospital you are "parenting in a fish bowl." It's perfectly acceptable to ask medical staff for time alone with your child if you have to handle a meltdown or some inappropriate behavior. Sometimes a child of any age can get overwhelmed by a deluge of medical procedures and examinations, or even by visitors, and need a break. Your child may be relieved if you run interference and give him or her room to settle down in privacy.