



## Getting Through those First Days/Weeks

We have collected advice from parents of children with cancer in the hope that that you might be able to benefit from what has been learned by others who have already walked this path.

Here are some of their ideas on matters both great and small.

- **Write everything down.** Information overload can occur very quickly and when you are under extreme stress it is very difficult to remember everything.
- **Ask** doctors and nurses to spell out unfamiliar words and drug names and keep a record of them.
- **Keep notes** on tests, procedures, medication names and dosages, any side effects you notice, or visits that need to be scheduled. When you refer back to your notes (and you will – quite often) you will have a complete record. This record will be invaluable in the future when the insurance company needs information or when you visit a new doctor.

***Helpful hint:* Utilize ACCOIN’s notebook and dividers to separate test results, meds, etc. and keep track of papers/appointments.**

- **Ask questions.** If you are confused or need clarification on something, 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 are sure you understand it.
- You can never ask too many questions.

***Helpful hint:* Have your questions written down before you talk to the doctor. Sometimes questions arise when the doctor is unavailable. Writing your questions down and having them available when you see the doctor will ensure that you have your concerns addressed.**

- **Discipline is still important.** Don’t forget you are still the same mom and dad. This is one of the most difficult pieces of advice to take when your child is sick or ill-tempered and you want to give in to every urge to spoil them rotten by dropping all the rules.
- There are times when your child will be depressed or irritable and you will need to trust yourself to know when to fight battles and when to let it go. They are looking to you to show them how to handle this road you are all now on.
- They need you to provide as much stability as possible in this frightening and disorienting atmosphere. Bedtime, manners, respect, etc. are still important and can provide needed security.

***Helpful Hint:* Encourage your child to use age appropriate methods to let off steam - punch a pillow, cry, etc. Child life specialists or other parents can be great resources and provide ideas.**

- **Life in a Fishbowl.** When your child is in the hospital, it is like living inside a fishbowl.
- It is perfectly acceptable to ask medical staff for time alone with your child if you have to handle a meltdown or other inappropriate behavior.
- Sometimes a child of any age can get overwhelmed by a deluge of medical procedures or examinations, or even by too many visitors and they need a break. Your child may be relieved if you run interference and give him or her room to get things settled down in privacy.

***Helpful Hint:* Pull curtains or cover windows and put a sign on the door if you are not up for visitors. Don't worry about hurt feelings – your child's welfare needs to come first and most people will understand.**

- **Siblings.** Their world has been turned upside down too. As parents, we must focus our attention on the immediate needs of our sick child.
- Be aware that siblings can sometimes feel forgotten and neglected – even if they seem to be old enough that they should understand, they are scared too.

***Helpful Hint:* Enroll in ACCOIN's sibling group, sign up for SuperSibs, attend ACCOIN family events**

- **Support Groups.** There are many parents that are eager to assist. And although each family is unique, many feelings are similar. It helps to talk to others who have felt what you are feeling now.
- **Child Advocate.** You are your child's best advocate. How do you advocate effectively when you are uncertain of so many things? There can sometimes be many confusing options presented. Talking things over with other parents can help.
- Begin slowly – learn about the disease. Too much information too soon can result in overload.
- Remember that your child is unique and you know them better than anyone else. Also remember that statistics cannot tell you where your child will fall in outcomes.
- **Educate yourself.** The more you know, the better your decision making ability.
- **Take Care of the Caregiver - You:** Remember that you also are undergoing tremendous stress. This is probably the most difficult thing to do but it is crucial to good decision making, advocating for your child, and staying strong. Even 10 minutes of quiet can do wonders. Better yet - have a Parents Night Out on ACCOIN.

***Helpful Hint:* Join ACCOIN's Parent Support Group \* Read the following on self-care written by a parent who has been there.**