### **Doctor Visits**

When you have received the news that your child has cancer it can be difficult to cope with any more information. Every one of us processes information in different ways so it is important to explain to your doctor if they are providing too much for you to understand. Ask if you can re-schedule the talk, or repeat it when you can bring a friend or family member as an extra pair of ears.

Whether or not you are able to find someone to accompany you to the first few doctor visits, you should always bring a note pad and pen. Write down your questions and make sure you get as many as you can answered in a manner you can understand.

If the doctor is using a vocabulary you do not understand, let them know that you are not following the conversation. Remember that there are some questions that the doctors do not have answers to. Some things take time and some times there are no answers.

You may want to consider transferring your notes into a binder so that you can keep all your information organized and have it for reference during doctor visits. You may have unexpected visits to the emergency room or even have to visit a hospital out of town, it will make you feel much more comfortable knowing what size needle your child needs for his port. Remember that the wait for doctor visits can sometimes be quite long; it is always safest to bring toys from home to occupy your child while you wait. Although hospital toys are cleaned regularly nothing is safer than your child's own toys. Your toy bag should include hand sanitizer and disinfecting wipes to clean any communal toys that your child may want to play with at the hospital.

"Keep a binder filled with all of their information ex. dx, chemo type, radiation dates, visits, blood counts. any med complications, and the size of the needle used to access his/her port-o-cath line (the ER figures this out by trial and error). Our little ones don't need to be poked anymore then necessary".

— Cheryl

"We always took my Mom and Dad into the hospital meetings. I think that more people listen better and take in more information, and also are able to ask more questions".

— Rachel

## **Support Staff**

Each hospital operates with doctors and nurses, but also with a huge number of support staff and volunteers. Find out what services are available and ask to meet the support staff at your hospital. It is comforting to have personally met the people you will need to contact if you encounter bumps along the road.

## Support Staff and Volunteers include:

- Child Life Specialists
- Social Workers
- Music Therapists
- Psychologists
- Chaplins
- Play Room Volunteers

Social workers provide many useful services from providing an ear to listen to assisting you if you encounter problems with insurance, travel to and from the hospital or financial issues.

Child Life staff can assist you with helping to educate your child about their treatment, easing stress and tension in children and working through problems with art and play therapy.

Hospital Psychologists can help if your child is experiencing difficulties adjusting to their new life.

Hospital Chaplains can provide assistance with your spiritual needs during this trying time.

## **Hospital Visits**

Find out what hospital what accommodations and facilities are available for you when you stay with your child in the room. The policies may be different for the I.C.U. or post surgery floor. Be sure to check individually for each situation.

- Find out about child life and recreation room hours, and what other services are available to you and your child.
- Make sure that you are aware of all policies and hours for visitation. The hospital may have limits on the number of visitors or lower age limits on visitors to the room.
- Try to find out what the meal situation is; can you order hospital meals? What restaurants are available in the hospital and in the local area? Collect the menus to local restaurants and put them in a binder for reference.

• Find out if there is a refrigerator available to store food from home or leftovers. If so, make sure to pack zip lock bags clearly labeled with your name. If the refrigerator is in a common area, be sure to throw away all remaining food on your departure from the hospital.

"Sometimes the meds can cause a funny taste in their mouth and that adds to the nausea, Sarah loved Sweet Tarts and that helped kill the funny taste from the meds. Usually a sour or mint flavor does the best.

— Dianne

"I tried hard to keep us on a somewhat normal schedule when we were admitted. Get up, have breakfast (or not...), brush teeth, get up and about for some activity if possible, have some quiet time/nap/movie watching, then up for more activity (if you can walk outside - do it! everyday!)".

- Natalie

### **Start to Chart**

You can use your information binder for hospital visits. It might prove useful to chart your child's food and fluid intake and the medications and doses they are receiving. You may notice which pain meds or anti nausea meds work best for your child. You are with your child more than the nurse and you may notice things from time to time that you may want to point out to the staff.

# **Packing to stay**

It can be difficult to remember everything you will need for a hospital stay, so we suggest a packing list. We have written in some necessary items, and left many blank spaces for you to add your own requirements. Remember to be prepared for the unplanned hospital stays as well as scheduled visits. Always have emergency kits containing over night essentials packed in the car for the unforeseen hospital stays.

If you travel out of town for hospital visits be sure to find out about family accommodations such as Ronald McDonald houses or Hope Lodge. Find out what is available in the area, how far it is from the hospital, the travel arrangements to and from the hospital and if you need to/are able to book in advance.

"Bring your own pillows (use a colorful pillowcase, so you don't lose it to the laundry) and bring a couple favorite fleece blankets. It makes the room a little more personal and a lot more comfortable. I always made up the couch I had to sleep on with sheets and blankets. Put a blanket on first and then the sheets, and it will feel more padded".

— Dianne



# **PACKING LIST**

**KIDS PACKING LIST** 

**PACKING LIST** 

**FOOD PACKING LIST** 

### Item Qty Item Qty Item Qty Underwear Underwear Instant brkfst T-Shirts Coffee Bra's Socks Shirts Tea Pi″S Pants Instant soup Toothpaste Socks Granola Bars Toothbrush Sleepwear Fruit Pillow Shampoo Drinks Blanket Conditioner Snacks Stuffed toy Shower Gel Pop tarts CD/DVD Player Deodorant CD/DVD's Lotion Game Player Toothpaste Games Toothbrush Batteries Floss Books Make up Meds Hair products Goodnights Meds Baby Wipes Pillow Blanket Notebook



# DAILY HOSPITAL SCHEDULE

PATE
IURSE
BREAKFAST
MEANIAS I
UNCH
DINNER
IQUIDS
NACKS
1EDICATION
CTIVITIES
OMMENTS

Copy this page and keep the copies in a file take a with you and fill out every time you visit the hospital

## **Tips for Tots**

- 1. Keep a bag of clothes and toiletries packed in the car at all times, for those unexpected hospital stays. This bag should contain some comfort items from home such as a favorite blanket and pillow or stuffed animal.
- 2. Keep a bag of small toys/movies packed for your youngster also. You will know that the toys are clean and it will keep long waits from being boring.
- 3. Keep a binder filled with all of their information such as diagnosis, chemo type, radiation dates, visits, blood counts and the size of the needle used to access his/her port-o-cath line. Keep records of medications, food and fluid intake, any med complications etc. while in the hospital. Sometimes you will notice trends before the medical staff.
- 4. Try to keep a somewhat normal schedule during hospital stays. Get up, have breakfast (or not...), brush teeth, get up and about for some activity if possible, have some quiet time/nap/movie watching, then up for more activity.
- **5.** If you can walk outside Do it! Everyday!
- 6. If your child has a port inserted, ask nurses for a tube of Emla (numbing) cream. You can apply the cream at home on clinic days. The cream can ease a great deal of stress if the child knows that the procedure will be painless.

- **7.** Take a bath mat for hospital stays, it saves you stepping directly on to the bathroom floor and makes the bathroom feel a little more like home.
- **8.** Keep Easy Mac, Raman noodles, Instant Oatmeal etc. in your emergency bag (if your child is too young to be left alone). Sometimes you just don't have time to purchase food.
- 9. Take advantage of the services offered by your hospital: child life, physical therapy, etc. As a caregiver, you can use that time to slip out for a quick cup of coffee or a few minutes of walking the stairs for some physical activity. You need to keep yourself healthy and relaxed in order to care for your child in the best possible way.
- 10. Keep a binder of restaurants in the hospital area: include numbers and menus. When you do get a chance to order out it saves time.
- **11.** Always remember that you are on the same team as the Doctors, you both have the same goal.
- as "familiar" terms for medical equipment; i.e. A port or central line can have many common names tubey, medicine giver, etc... this can be confusing to a child. Explain thoroughly that although it may have different names, they all refer to the same piece of equipment.

- **13.** Children worry about being separated from parents. If you need to leave for some reason (or your child is having a procedure), try to reassure you child that you will be there when they wake or as soon as you can.
- **14.** Gentle suggestions to those wanting to help out that age-appropriate activities, crafts, workbooks, video games/Leapster games help keep minds healthy and happy. Keep a stash of these activities (and lots of Dollar Store prizes) on hand for bravery gifts.

## **Tips for Tweens**

- 1. Keep a bag of clothes and toiletries packed in the car at all times, for those unexpected hospital stays. This bag should contain some comfort items from home such as a favorite blanket and pillow or stuffed animal.
- 2. Keep an activities bag packed with new books, coloring and crafts, or purchase a portable DVD player or Game boy to keep your child entertained during hospital time.
- 3. Keep a binder filled with all of their information ex. dx, chemo type, radiation dates, visits, blood counts. any med complications, and the size of the needle used to access his/her port-ocath line.
- **4.** Try to keep some of your child's favorite snacks that may not be available in the hospital.
- 5. Take advantage of the services offered by your hospital: child life, physical therapy, etc. as a caregiver you can use that time to slip out for a quick cup of coffee or a few minutes of walking the stairs for some physical activity. You need to keep yourself healthy and relaxed in order to care for your child in the best possible way.
- **6.** Remind your child that cancer is not caused by ANYTHING they did. Neither the disease nor the treatment is a punishment.
- **7.** Be as honest and open as you can about procedures and let your child know about changes that arise.

- 8. If you can walk outside Do it! Everyday!
- **9.** Do not expect to be able to answer every one of your child's questions; it's Okay to say "I don't know, I'll try to find the answer to that".
- **10.** Encourage your child to talk about their feelings and let them know that it's Okay to be sad, you are sad sometimes too.
- **11.** Help your child to stay in touch with friends and school mates, so they feel less detached.

## **Tips for Teens**

- 1. Keep a bag of clothes and toiletries packed in the car at all times, for those unexpected hospital stays. This bag should contain some comfort items from home such as a favorite blanket and pillow or stuffed animal.
- **2.** Remember that you do have choices, ask doctors to talk to you directly as well as your parents, if that is your preference.
- **3.** Try to keep an open dialogue with your doctors and parents about your concerns, some of them may be unfounded.
- **4.** It can be hard to cope with the lack of control over your life when coping with cancer. Try to take things one step at a time. Do not worry about too many things at once.
- **5.** Keep a binder of menus from restaurants in the hospital area. When you are ready to eat you will know what is available.
- 6. If you can walk outside Do it! Everyday!
- 7. Try to keep your sense of humor.
- 8. Try to relax using some of the following methods: Meditation, Relaxation Techniques, Prayer, Gentle exercise (if recommended by your doctor), Counseling, Art Therapy, Poetry, Writing/ Journaling, Reading and Talking with trusted friends.
- **9.** Try to be honest about your feelings with friends and family.
- **10.** Let people know what they can do to help.

- **11.** Let friends know that you want them to continue to call or visit: this is a new situation for both of you.
- **12.** Know your limits: Have friends call before visiting so you can let them know if you are too tired to talk or visit.
- **13.** Ask your social workers to recommend books or resources in your community to help you cope.