

HOME PLAN

“Ask the hospital for the chemo day to be the same weekly. Ask your job to reduce your schedule to have that one day off a week. I had the doctor write a letter for my job and I wrote a letter also. It helped my employer to know what set day I would be off. I did include that I may need to take time off for unforeseen reasons, ct scans, radiation, surgery’s, unexpected hospital stays and admissions.”

Keep useful phone numbers, your child’s latest blood counts and medication list on hand for when you need them. This can make emergency calls less stressful. When calling the hospital or doctor, the more information you can provide quickly, the better. You can fill in the relevant numbers on the “Emergency Numbers” sheet then laminate it so you can write on and wipe off weekly blood counts. Keep the sheet handy by the phone or hung on the fridge so you know where it is located at all times. It will also be in your best interests to purchase a good digital thermometer. There will be many times when you will need to be able to take a reliable temperature reading.

Try to keep life at home as regular as possible, except for the regular doctor visits life can mostly go on as usual. It is important that your child be encouraged to go to school and have play dates as long as they are well enough. Keep a list of fun activities you and your child can do on low energy or neutropenic days.

“Our close proximity neighbors were wonderful, as there were two in particular that we simply couldn’t have made it through without. When Lauren was hospitalized; Jennifer and I took day and night shifts. Basically, she took the days, I took the nights”.

– Scott and Jennifer

QUITTING SMOKING

As we all know stopping smoking is one of the best things we can do for our own health as well as the health of our children. Obviously the less your child is exposed to second hand smoke at this time the better. If you find it essential to smoke try to smoke outside or away from your children.

We understand that this is one of the most traumatic times in your life and you may need to rely heavily on smoking as an outlet for stress, but many people are inspired to cut down or quit smoking at this time. Please know that there are options available to assist you if this is a path you choose.

Your doctor can prescribe medicine to help you, or you can rely on support groups to help you quit. **Please see resources section for online assistance.**

SIBLINGS

The unfortunate reality of childhood cancer is that the entire family is affected. Adults have a much better grasp on what is happening to the family dynamic, as children have a much harder time adjusting. Wherever possible try to keep life as normal as possible for siblings. Ask for help to make sure that everyone can continue with their after school activities and sports.

Try to make sure that everyone knows what the weekly schedule will be, children thrive on routine.

Team up:

If you are a two parent team, try to make sure that it is not the same parent at the hospital every time; siblings need to spend time with each of you to minimize feelings of neglect. Try to involve other family members or trusted adults to devote special time and attention to siblings. Devote as much time as you can to well siblings, make sure that you hug them and reassure them constantly.

Educate everyone about basic cancer facts:

When the whole family is educated about cancer and cancer treatment, it makes it easier to talk about your feelings. It is sometimes more difficult for the siblings to cope with childhood cancer because their feelings can be confusing. They may experience feelings of fury, heartache, guilt, jealousy and vulnerability.

There are ways in which families can ease the burden felt by siblings. At the same time these techniques will help to ease the strain put on the family as a whole. Make sure to stress to everyone in your family that cancer cannot be caught and that nobody caused your child to have cancer. THIS IS NOBODY'S FAULT!

Everyone needs a role:

Give Siblings a role in taking care of the sick sibling. Everyone needs to feel that they are needed and that they have defined roles.

Children can be in charge of "cheering up" the unwell sibling. Explain to them that their role is to keep up the spirits of the child in treatment. Encourage them to make cards or write letters to their sibling during hospital stays. In return encourage the child in hospital to write thank you notes and cards to their siblings.

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Catch your children doing something good:

Make sure to acknowledge when your well children make efforts to raise their sibling's spirits. Make sure to thank them for their efforts. Cards, notes and small gifts from you to well siblings can reassure them that they are special and avoid feelings of abandonment. Celebrate small victories and occasions together as a family.

Talk about feelings:

It can be difficult for children to express their feelings, especially considering their limited vocabularies. Encourage them to express their feelings, even those of jealousy or resentment towards their sick sibling. Explain that although it is normal to experience those feelings, their actions towards the sick sibling need to be considerate and thoughtful. Let them know that you have feelings too, and that all of our feelings are natural. You may explain that you have fears, but that you know that the doctors and nurses are working as hard as they can to make their sibling well again.

Talk to sibling's teachers about your child's diagnosis. There may be changes in siblings behavior due to stress and unusual circumstances. The more caring adults that take time to understand how difficult this is for siblings, the better.

"We had 2 more boys to be taken care of and since they were only 2 ½ and 1 ½ it was VERY difficult but since it had to be done my GREAT family stepped up and took care of them for me. Of course at night they were at home with Dad".

– Kim

NUTRITION

It is likely that your child's appetite will change during treatment. This may mean that they crave new or different foods, their appetite may drop drastically or at certain times their appetite may be enormous. All of these changes are quite normal.

As a parent we are all concerned with making sure our children eat a balanced diet and get their nutritional requirements, however your doctor may encourage you to allow your child to eat whatever appeals to them to make sure they keep up their calorie intake.

If you find that your child has no appetite at all you should encourage them to drink milk shakes and smoothies as you can hide calories in them easily. Instant breakfast mixes are great for adding to milk, they tend to contain vitamins as well as calories. You can also slip in a little cream or ice cream to add even more calories.

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Use higher fat content foods such as butter and whole milk instead of lower calorie options when cooking for your child. Try not to worry too much, if your child's weight begins to drop slightly. Your doctor will suggest different options to supplement your child's diet.

You can help your child by encouraging them to eat when they feel like it, and slipping calories into food when they don't!

"Carnation Instant Breakfast works very well and can be used to make chocolate milk and milkshakes. It tastes much better than Ensure! It also doesn't feel as bad as many foods when they have mouth sores. Cook with whole milk, butter and oil. Make the calories count; if they want steak, feed them steak".

– Dianne

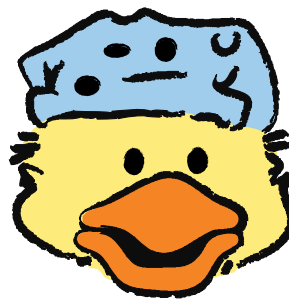
"My son was dx at 10 months old and had to go through chemo and radiation. I kept him on his formula for an extra year. Where does it say you must switch to milk on the 1st birthday. He was such a poor eater that I got a little comfort knowing he was getting his vitamins and iron".

– Cheryl

"Most of all, try not to stress too much. If all they want to eat is Pringles or Cheetos (always good back-ups it seems...) give it to them and remember this too shall pass"!

– Natalie

gabe's CHEMO DUCK PROGRAM



CALL 911 IF YOUR CHILD: CANNOT BREATHE • IS UNABLE TO WAKE UP • IS HAVING A SEIZURE

HOME PLAN

CALL THE DOCTOR IF YOUR CHILD HAS:

1. A Fever of 100.4 or above*
2. Signs of Infection*
3. Exposure to chickenpox
4. Difficulty breathing
5. Changes in behavior*
6. Vomiting or diarrhea
7. Severe headache
8. A break in his/her line
9. Excessive bleeding*

BLOOD COUNTS WEEK OF: _____

WHITE BLOOD COUNT: _____

CRIT: _____ **ANC:** _____

PLATELETES: _____

CURRENT MEDICATIONS: _____

EMERGENCY NUMBERS:

PEDIATRICIAN _____ **PHONE#** _____

ONCOLOGY CLINIC _____ **PHONE#** _____

RADIOLOGY _____ **PHONE#** _____

RADIATION ONCOLOGY _____ **PHONE#** _____

OTHER SPECIALISTS _____ **PHONE#** _____

1. Please check with your child's oncologist for the appropriate temperature to call your doctor.
2. Pain, redness or swelling. Sore throat, earache, stiff neck, pain when using the bathroom or pain or redness at line/port site.
5. Sleepy or irritable, making no sense when talking.
9. Nose bleeds or bleeding from the gums that does not stop with 5-10 minutes of pressure. Blood in urine or stool. Vomit or stool that appears black. Easy bruising or tiny red freckles on the skin.

REMOVE THIS SHEET, LAMINATE IT AND KEEP IT BY THE PHONE FOR REFERENCE.