

PEDIATRIC ONCOLOGY HANDBOOK

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PEDIATRIC ONCOLOGY HANDBOOK

Dear Parents:

This notebook has been written to provide you with practical and helpful information as you try to cope with childhood cancer.

All members of the pediatric oncology team have contributed information relating not only to their special training in this field but also drawn from their own experiences over years of working with other families in similar situations.

Most information is general but each book has been individualized with information about your child's disease and treatment plans.

We acknowledge the outstanding work of the Nursing Committee of the Pediatric Oncology Group in producing much general information in these pages.

We hope this notebook will be a source of information for many of the questions which arise and encourage you to ask questions of any of us during our partnership in the treatment of your child.

No handbook can provide answers to all questions and we want you to feel free to ask questions to any of us at any time.

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PEDIATRIC ONCOLOGY HANDBOOK

PEDIATRIC ONCOLOGY GROUP PARENT HANDBOOK

Your child has cancer. This is a time of confusion and distress. You probably have many questions about the disease and fears about the future. You may feel overwhelmed by the information you are given at the time of diagnosis and worry that you won't be able to care properly for your child.

The nurses of the Pediatric Oncology Group (POG) provided the basis for this handbook. Your physicians, nurses and social workers at this Medical Center have modified it to better describe our service. By using this guide for understanding your child's cancer diagnosis and treatment, your whole family can become more comfortable with the changes in your lives that result. You are a vital part of your child's health care team: for that and other reasons we want you to be as well informed as possible.

In the days ahead you will see many new procedures and hear new words. This book explains the procedures and the words. Please take a minute to look through the book before you begin reading. Although most of the new words are explained in the handbook, there is also a glossary in the back of the book. Other information, such as types of treatment plans or advice on good home care is placed in sections to allow quick use of the handbook.

You should read the entire handbook at least once to learn what it contains, but you do not need to remember everything. Instead, the sections of the book will allow you to find the information when you need it.

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WHEN TO TELEPHONE THE TREATMENT TEAM

(Urgency/Emergency)

This list is so important that we put it right up front for you!

* **FEVER** -- temperature of 101 F or higher (oral--never take rectal temps; if your child is too young for oral temps discuss with us)

* **BLEEDING** -- unusual bleeding that you and your child can see:

*Nose or gum bleeding that does not stop with gentle pressure

* Blood in urine or bowel movements

* Easy bruising or tiny red spots ("blood blisters" - petechiae) on the surface of the skin

* **EXPOSURE to chicken pox, shingles, measles, German measles or other contagious diseases.** (If your child has had chickenpox do not worry about exposure to chicken pox or shingles)

If your child breaks out in chicken pox or shingles notify us immediately.

* **Headaches** that occur in the morning and/or don't go away with Tylenol.
Never use aspirin or aspirin-containing products.

* **Unexplained drop in appetite or fluid intake**

* **Rash** -- or change in skin color, or becoming pale.

* **Change in vision, hearing, sense of balance or energy level.**

* **Constipation** -- no bowel movement in 3 days

* **Pain** -- especially with urination or bowel movements.

* **Coughing** -- that does not stop--or **rapid breathing.**

Anything else that worries you or you have questions about.

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PEDIATRIC ONCOLOGY CLINIC OPERATIONS

Clinic is open on Monday, Tuesday, Thursday and Friday from 8:00-1:00 PM. Appointments are scheduled every 15 minutes from 8:00 until 10:30. In order to best serve our patients we ask that you arrive at your scheduled time so that we do not have patients waiting to be seen. Clinic is located in the pediatric area on the ground floor of the ambulatory care building.

Our patient assistant will generally greet you upon arrival and check your child's height, weight and temperature. Your first visit will take more time (usually several hours) as we will need to have you registered with the receptionist so we have your insurance and other general information.

It is **VERY IMPORTANT** that if your address, phone number, insurance information, etc. ever changes you inform the receptionist and a member of the oncology team so we can update our records. It is generally helpful to bring special snacks, a stroller and favorite toys to clinic.

Once you have checked in your child may be sent to the lab for blood work (usually a fingerstick to check blood counts) and/or to Pediatric Radiology for scheduled procedures. After this your child will be put into an exam room where clinic personnel will see you.

Dr. Chauvenet, Dr. Wofford, Dr. McLean, Diane Samelak or Debby Cohen will examine your child. Our pediatric oncology nurses Nancy Smith and/or Diane/Debby or one of the physicians will see your child and administer chemotherapy as needed. Marti Hicks, our social worker will see you to help address coping strategies, crisis management, and other school and home issues. A clinical psychologist will be in clinic to assist you and your child as needed. **We are all here to help you and urge you to ask us about any problems or concerns you have.**

Please note that **if your child is scheduled for hospital admission we want you to come to clinic first!!**

FEVER/SICK: If your child has a fever or is otherwise sick, please let us know immediately upon arriving in clinic (even better, by phone as soon as you recognize this). **If your child has not had chicken pox and has been exposed or has broken out in chicken pox or shingles WE NEED TO BE TOLD IMMEDIATELY!**

APPOINTMENT CHANGES: If you cannot make your appointment for any reason or need to change an appointment, PLEASE let us know as soon as possible by calling at our telephone times. We will gladly work with you to reschedule your child's appointment.

If illnesses or injuries occur that require medical attention, a phone call can inform us of the situation. We can then guide you toward the appropriate course of action. This could result in coming to clinic, the emergency room, visiting your pediatrician or family doctor or being admitted to the hospital. A phone call allows us to notify appropriate personnel and have available our patient's chart, thus saving valuable time--your child's, yours and ours.

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TREATMENT PLANS

DIAGNOSIS

The first things to be done by the physicians are to talk with the patient and parents, perform a physical examination, and draw blood for various tests. In addition, several other tests that depend upon the location and type of suspected cancer would be done. A bone marrow aspirate is done if leukemia is suspected and in selected other cases. Sometimes a sample (biopsy) of the cancer tissue must be studied before the diagnosis can be made. Often x-ray films or special studies such as CT (CAT) scans, bone scans, ultrasound tests or other images are needed.

All these studies allow us to tell you what kind of cancer your child has and how much it may have spread (also called the stage--note that leukemias are not "staged" in this way) from the location in the body where it first started. Both the type of cancer and the stage are necessary for a complete diagnosis. The treatment plan depends upon both the type of cancer and the location(s) in the body.

TREATMENTS AND TREATMENT PLANS

Treatment for most forms of cancer may include surgery, radiation and chemotherapy. Treatment plans may combine two or more of these methods. The order in which these are used to fight the disease may vary, but usually surgery is first to prove a diagnosis (except patients with leukemia).

Then as much of the solid tumor as safely possible is removed. Radiation therapy may be used to destroy cancer cells in the area nearest the tumor while chemotherapy is used to destroy both the local tumor and tumor at distant sites in the body. Sometimes radiation or chemotherapy may be used first to shrink a tumor so it will be small enough to remove by surgery.

There are many kinds of chemotherapy used for treating solid tumors or cancers of the blood (leukemias) or lymph system (lymphomas). Usually several chemotherapy drugs are used to destroy cancer cells.

Radiation therapy is used to treat cancers located in areas of the body that cannot be reached by surgery, to shrink large tumors, and to destroy cancer cells that might remain after a tumor is removed by surgery.

Because we are always looking for ways to improve the chances of survival you may be asked to give consent for (allow) your child to take part in a treatment protocol.

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WHAT IS A TREATMENT PROTOCOL?

A protocol is a plan of treatment for a specific type of cancer. Most treatment protocols are clinical trials which are research studies conducted with patients. The study will tell us if a new treatment or slight change in treatment will be better for patients with a particular disease.

Protocols are based upon the best-known treatment (learned from earlier studies on other patients) **with changes or additions that may produce a higher cure rate or fewer side effects.** These changes or additions in treatment are based upon the results of studies done in the laboratory or in a small number of patients with the same disease before being used in a larger treatment protocol.

Patients taking part in a protocol are treated according to the protocol's treatment plan and checked carefully for improvement and any side effects of the treatment. We will give you a copy of the schedule of tests and treatments your child will receive. This is often called a "**road map.**" We can also give you a "modified" or simplified road map in checklist form. The road map tells you what tests and treatments are coming up in the weeks and months ahead. Some changes will be made to meet the needs of your child and family and allow for any major side effects or other problems. We will discuss these with you as they occur.

Sometimes a protocol compares two or more similar treatment plans (may also be called study arms) in groups of patients with the same type of disease. One group of children will be given the best known treatment for the disease while the other group will receive that treatment with slight changes or additions. These changes may result in fewer side effects, more side effects, fewer cures or more cures. Clearly the objective is to develop improved treatments.

Whenever a protocol compares two or more treatment plans, you will be told and informed why we recommend entering your child on this protocol. The actual choice of a treatment group is made randomly (by chance) by a computer method.

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HOW DOES A PROTOCOL EFFECT TREATMENT?

Whether or not your child is enrolled on a treatment protocol, every attempt will be made to provide the best known treatment in the safest way possible.

Before your child begins treatment, you will be given a form to read that describes the treatments being tested, the possible benefits and the known effects. After discussing this information with us, you will be asked to sign a document giving permission for your child to be enrolled on the study. This is called informed consent. If your child is old enough to understand, he or she may be asked to review and sign the form also. **Make sure that your questions are answered before you sign the consent form.**

If your child is not offered treatment on a protocol the reason will be explained. A consent form will be used that requests permission for the specific treatment being suggested for your child.

All the information about the benefits of a treatment plan will not be known for several years. However, we pay attention to all the children on the protocol; if important new information is discovered it will be shared with you. This could lead to changes in the treatment to make it better or easier to take.

If we learn about a better way of treating your child's disease, the improved treatment will be offered to you. **Please ask us questions about your child's treatment anytime you have them.**

Once your child starts on a protocol you and the treatment team still have choices. **If we see that the treatment plan of the protocol is not best for your child it can be changed and/or your child can be removed from the protocol.** You or your child can choose at any time not to continue on the protocol without fear that we will stop caring for and about your child.

You may not want to have your child to take part in a protocol. **This choice will not change how the treatment team feels about you and your child.** Every effort will be made to give your child the best treatment for his or her disease, using the treatment proven to be the best in the past.

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BLOOD COUNT INTERPRETATION AND BONE MARROW SIDE EFFECTS

The bone marrow cells make several kinds of blood cells that are released into the bloodstream as needed. Cells of the bone marrow, because they divide rapidly, can be injured by chemotherapy and radiation therapy. Since chemotherapy works by blocking cell (tumor) growth, one of the most common side effects is to slow the growth of cells in the bone marrow. This causes bone marrow suppression, also known as **"low blood counts."**

GENERAL COMMENTS ABOUT BLOOD COUNTS

Your child's blood counts will be checked at least every other week while he or she is on chemotherapy and more often when necessary. This will usually be done by a **"finger stick."** Close checking of blood counts should help keep us from being surprised by severe problems. However, you need to be prepared and educated because your quick action can help prevent serious problems for your child.

Most of the time your child's blood counts will be at a level good enough to fight infection and play normally. During the times when blood counts are normal it is very important that your child play and enjoy normal activities with other children. We will be glad to discuss any questions that you may have about the safety of your child's play and specific sports.

Of all the side effects of chemotherapy, bone marrow suppression will cause your child the most treatment delays, therapy changes and unscheduled trips to the hospital. **The effect of chemotherapy on the bone marrow will usually not be seen until 5-14 days after the chemotherapy is given.** Your child will **probably be at home** when the blood counts reach their lowest point, **so it will be necessary for you to know what to look for, what to do, and when to call us.**

There are 3 important types of cells made in the bone marrow and checked in your child's blood count. They are:

- PLATELETS**--stop/control bruising or bleeding
- RED BLOOD CELLS (RBCs)**--carry oxygen and carbon dioxide
- WHITE BLOOD CELLS (WBCs)**--prevent and fight infections

Each of these cell types has different jobs. It is when your child's blood counts are low that he or she may have the problems as described on the next few pages.

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PLATELETS

Platelets are needed for the blood to clot normally. When your child's platelet count is low (also called THROMBOCYTOPENIA) he or she may bruise or bleed easily. We interpret the platelet count and thus bleeding risk as shown in this table:

Normal Platelet count: 150,000 - 360,000
Adequate count: > 100,000
Low risk group: 50,000 - 100,000
Moderate risk: 20,000 - 50,000
High risk group: <20,000 especially <10,000

If the count is over 100,000 then clotting is normal. If over 50,000 normal activities except contact sports or elective surgery are allowed. We would not expect any serious bleeding when the platelet count is above 50,000.

In the moderate risk group there is seldom spontaneous bleeding but minor trauma may lead to unusual bleeding. We suggest that your child avoid contact sports or activities where they might be injured such as jungle gyms or bike riding.

In the high risk group there is often some bleeding, most commonly nosebleeds. Spontaneous bruises or small spots (petechiae) may appear on the skin.

If bleeding occurs, the best treatment is to apply pressure. If bleeding does not stop when pressure is applied you need to call us and we will need to check a platelet count and consider giving a platelet transfusion. Even if the bleeding stops we should be notified for anything more than a brief trivial amount of bleeding.

Never give aspirin or aspirin-containing products to your child while he or she is on chemotherapy--aspirin may prevent blood from clotting normally. **Ibuprofen** and related drugs may have similar effects. If you are unsure whether a medication is safe for your child please ask any of the pediatric oncology nurses or physicians.

To decide if a child needs a platelet transfusion, we consider the child and the platelet count. Also, we look to see if the platelet count is going up or down. Platelets live only 10 days after being made, so a count that has been steady at 30,000 for 5 days shows that some platelets are being made in the bone marrow. A count that is rising will show us that this problem is behind us until the next cycle of treatment.

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RED BLOOD CELLS

Red blood cells carry oxygen for energy to all organs of the body and remove carbon dioxide. The most common measures of the red cell number are the **HEMOGLOBIN** level and the **HEMATOCRIT**. Hemoglobin is the protein in the red cells that actually carries the oxygen and carbon dioxide. We will talk with you in terms of **HEMOGLOBIN** which is measured as the amount of the protein in a standard volume of blood. If someone uses Hematocrit just remember the equation: **HEMOGLOBIN X 3 = HEMATOCRIT**. **Hemoglobin will be abbreviated Hgb or Hb**. While the normal Hgb varies with age, race, sex and the altitude at which one lives, the following normal values for hemoglobin may be used:

	Boys	Girls
Infants/Children	11-13	11-13
Teenagers	14-16	12.5-15

Low hemoglobin represents **ANEMIA** (sometimes called "low blood"). Anemia has many causes. Your child may first be anemic from his or her disease and later from the treatments.

Since red cells live about 120 days anemia develops more slowly than drops in platelets or white cells. When your child is anemic s/he may be pale, irritable, have less energy or tire easily. Your child will usually restrict his/her own activities. We may give your child a blood transfusion if s/he has very low energy, very low hemoglobin or the hemoglobin is dropping rapidly. Many children go through chemotherapy without red cell transfusions.

While good nutrition is important, there is no special diet that will protect your child against anemia or prevent the need for blood transfusions.

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WHITE BLOOD CELLS

White cells fight infections; when their count is low your child will be more likely to get sick. In addition, there are some infections (called "opportunistic") that are more common and/or more serious in children on chemotherapy even when the white cell count is normal.

Unlike platelets or red cells, there are several types of white cells which play different roles in fighting infection. Thus a statement of the white count alone does not provide us with the necessary information about your child's blood counts. A "**differential**" (called **diff**) count must be done which provides the percentages of the different types of white cells. While there are many types of white cells, the most common and important are:

SEGS (POLYS)--fight bacterial infections
BANDS--junior segs--will mature to segs
Monocytes (Monos)--secondary fighters of infection
Lymphocytes (lymphs)--fight viral infections

SEGS and BANDS are also called **NEUTROPHILS or GRANULOCYTES**. It is the number of these cells that best predict the risk of serious bacterial infection. We are interested in knowing the **ABSOLUTE NEUTROPHIL COUNT** or the **ANC** (can be called **AGC**) which we calculate as follows:

$$\text{ANC} = (\% \text{ SEGS} + \% \text{ BANDS}) \times \text{white cell count}$$

Thus, if the white count is 5,000 and the diff shows 45% Segs, 5% Bands, 15% Monos and 35% Lymphs the ANC would be 2,500 (45% + 5% = 50% and 50% of 5000 is 2500). Then we can make the following table:

ANC > 1000 -- essentially normal risk of bacterial infection

ANC 500-1000 -- mild increased risk of bacterial infection

ANC 200-500 -- moderate increased risk of bacterial infection

ANC < 200 -- major increased risk of bacterial infection

(A copy of your child's blood count will be used to teach this.)

When the ANC is less than 1000, and especially when less than 500, there are precautions we urge to reduce the risk of bacterial infection. Fever is the most common sign of infection and should not be treated with Tylenol but should lead to calling us. It is vital that you review the pages later in this book dealing with infection and discuss this with one of us.

The most effective ways to reduce the risk of infection are good handwashing and avoiding sick persons who may be contagious. We do NOT believe facemasks reduce the risk of infection.

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BODY IMAGE CHANGES

Changes in how your child looks may be the most upsetting side effect of treatment for you and your child. **Hair loss, weight gain or loss and rashes** are physical changes that your child may have. With support of family members, friends and members of the health care team your child will finish therapy with a positive self-image. **Each child is different**; it is impossible to know exactly what changes your child will have, if any. It is important, however, that possible changes be planned for by you and your child so they will not be frightening. Based on your child's medications and treatment plan, we can give you an idea of what to expect.

HAIR LOSS (Alopecia)

Hair that is lost because of chemotherapy will almost **always grow back**. Some children will regrow a full head of hair while still on chemotherapy. Sometimes the new hair differs in texture, color or curliness. Not all children will become bald; some have only thinning. Patterns of hair loss differ. Some children lose their hair rapidly while others lose it over weeks to months. At times there is very little hair loss; sometimes (especially with radiation to the head) there may be permanent severe thinning.

The **loss of hair**, while not dangerous, **can be upsetting**. You know your child and the emotional effect that hair loss may have. Many young children will be just as happy without hair because they do not have to comb, brush or wash it. In fact, it may upset the parents more than the children. Older children, who do not like to be different from others, will need help in dealing with hair loss. A haircut may ease the transition.

If your child wants to wear a wig, you may want to shop around before hair loss becomes easily seen; this also allows hair color and style to be copied. Boys as well as girls may want to wear wigs. Wigs may be made of natural or artificial hair and either type can be styled by a beautician to match your child's hair closely. Artificial hair wigs are usually less expensive and easier to care for. **Some insurance policies cover all or part of the cost. Let us know if you need any help in this area.**

Some children may choose to wear a scarf or bandanna. These can make very attractive and comfortable head coverings when worn alone or with wigs. You may find that there are many creative ways to wear these head coverings. Your local American Cancer Society sponsors a program for teen-aged girls called "**Look Good, Feel Better**" that teaches how to use cosmetics and fashions to minimize changes in appearances caused by chemotherapy.

Finally, one word of medical caution. A bare head loses heat in the winter and gets sunburned in the summer. Encourage your child to wear some head protection like hat, wig, scarf or sunscreen during these times.

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EXCESSIVE WEIGHT GAIN OR WEIGHT LOSS

Steroids, such as prednisone or Decadron, will almost always cause increased appetite, excessive weight gain (especially in the face and abdomen) and swelling. These effects will disappear after steroids are stopped. Loose fitting stretch or knit clothes may be more comfortable than tight clothes.

It is important to realize that **children on steroids** are truly hungry and may **become very hungry without warning**. The weight gain from steroids is also from fluid retention. While taking steroids, your child should stay away from salty foods or foods high in sodium which will increase fluid retention (see section on Nutrition).

Because chemotherapy affects normal metabolism, your child may lose weight even while eating a well balanced diet. We will check your child's weight and nutrition status closely and make suggestions if necessary.

If your child gains or loses too much weight it can cause problems with friends and schoolmates or make your child self-conscious. Your acceptance, support and understanding will be very important to your child. Please let us know if your child is having problems in this area because we may be able to help.

SKIN CHANGES

Some chemotherapy drugs can cause rashes, such as acne or hives. These rashes can be side effects or allergic reactions to the medicine. Please show us any skin changes that your child develops so that we can decide what treatment (if any) is needed.

Some chemotherapy drugs can cause tissue damage (burns) if they leak outside a vein. These medicines are called vesicants and leakage into the body tissue is called extravasation. These medicines are always given intravenously and you should know which (if any) of the drugs your child receives are vesicants. One purpose of a port-a-cath or central line is to eliminate the risk of extravasation. However, extravasation can occur even when a central line is used, although it is very rare.

Effects of extravasation vary from mild tissue irritation or redness to serious tissue damage requiring hospitalization and surgery. Usually an extravasation is detected right away, but occasionally effects may be delayed. If your child complains of pain or burning in an area where s/he has received a vesicant medicine within the last 2 or 3 days, an extravasation may have occurred. Please call us if you suspect this situation.

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PAIN

Some of the side effects of chemotherapy and radiation, such as mouth sores or digestive problems, can cause pain or discomfort. You should not give your child medicine containing aspirin because aspirin can increase bleeding problems and irritate the stomach.

Read labels of over-the-counter medicines carefully, and if they contain aspirin or salicylates, do not give them to your child. If you are not sure please check with your pharmacists. As a general rule you should check with us and/or your local physician before giving your child **any** medicines not ordered by the doctors.

If your child has severe pain or pain that does not go away or pain and fever at the same time, you should contact us. Severe headache during times of low platelet counts or a stiff neck accompanying fever should be reported to us at once.

Vincristine can cause muscular aches in the arms or legs and jaw pain or a scratchy throat--usually 2-3 days after it is given; it can also cause abdominal pain from constipation. If your child has this kind of pain after getting vincristine please let us know.

OTHER SIDE EFFECTS OF TREATMENT

The side effects reviewed in the previous sections are those that occur most often in children receiving cancer treatment.

In addition, body organs, such as the kidneys, liver, heart or brain **may** be affected by certain drugs and radiation. These can be very mild, very serious or even life threatening in some children.

You will receive a list of the medicines that your child will be getting and their known side effects. We will explain to you how we can prevent some side effects and the tests we do to see if some side effects are beginning. If serious side effects occur, changes may be made in your child's treatment plan.

Not all children will have the same side effects with the same treatments. We will do everything we can to prevent problems and to give the medicines in the safest way possible.

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CHEMOTHERAPY HINTS FOR PARENTS

Your child is here for scheduled chemotherapy. Listed below is information that will help you and your child understand what will happen during this hospitalization. It will also tell you how you can help your child tolerate the treatment better and go home sooner.

- 1) Sometimes children get mouth sores after chemotherapy. Keeping the mouth and teeth clean can help prevent this. Encourage your child to brush his/her teeth (soft toothbrush) at least twice everyday. Gentle use of SOFT toothbrushes is probably better than sponge toothettes that do not adequately clean the mouth. If you need supplies ask your nurse for help. Always clean the mouth after any episode of vomiting. The stomach acids can damage tooth enamel and irritate the inside of the mouth.
- 2) Before most chemotherapy can begin, the urine must be checked. Ask for a container (or bag) so we can check the first urine. The sooner this is done, the sooner treatment can begin. Any staff person can help you with this.

Your nurse may ask you to save all urine (or diapers) during your hospital stay. Sometimes we need to measure only the volume. For some treatments we also check the urine for blood or sugar.

- 3) Before and during chemotherapy, it is important that your child stay well hydrated (lost of fluids). Sometimes extra IV fluids will be given, but if your child can tolerate fluids, encourage drinking.
- 4) We usually give an anti-nausea drug before any chemotherapy. If your child still has trouble with nausea or vomiting let your nurse know. Sometimes adjusting the anti-nausea medicine can help relieve this discomfort.
- 5) You should wear gloves when handling urine, stool or vomitus. This will protect you from chemicals that may be excreted in these body fluids during the time your child is receiving chemotherapy in the hospital.

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LONG TERM EFFECTS OF TREATMENT

During the past 30 years there have been many improvements in the treatment of childhood cancer. As a result, a growing population of childhood cancer survivors continue to teach us about the long-term effects of cancer treatment in children. This means that there are a lot of young adults who were successfully treated for cancer when they were children or teenagers.

Children who are successfully treated for cancer **may** develop problems years later. These "late effects" can include psychologic or social problems, learning disabilities, various growth and development problems, organ (heart, liver, lung or kidney) damage, reproductive problems (trouble having children) and the development of another cancer. There can also be problems with jobs or insurance. As with all side effects, these may not happen to your child. As research continues, advancements are made to improve treatments and lessen side effects.

These are obviously hard things to think about when your child is first diagnosed with and treated for cancer. However, children must first survive to have these problems. The treatment of cancer may include therapies with significant side effects and these risks must be weighed against the benefits we can expect to achieve with treatment. Your child will be carefully checked to keep any of the preventable side effects from taking place. We want you to feel very comfortable discussing these aspects of cancer treatment with your child's treatment team.

When your child has completed treatment, we will want to keep seeing him or her for many years. The schedule and the necessary testing will be explained to you by your treatment team and will depend on the type of cancer and the therapy given.

We have a "long term" clinic which meets at a separate time from our routine clinics and will generally try to schedule patients who are being seen every six months or once a year for this clinic. Then we can focus on late effects rather than immediate problems that may be seen during treatment.

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CARING FOR YOUR CHILD AT HOME

Activity and Rest

The child who has been hospitalized or who is receiving treatment for cancer may be more tired than usual and need added rest. When your treatment team says it is safe for your child to return to school, you may want to start by sending your child for half a day until you know his or her tolerance. However, it is important to encourage your child to return to school as soon as possible.

It is important that a normal bedtime and daily routine be resumed after hospitalization. A quick return to the normal routine reassures your child that he or she will recover and cope with their illness.

Some parents tell us that their children have surprising energy during treatment and can't be held back. If your child tolerates a usual daily routine without tiring, there is no need for extra rest. Other children may need more rest. Watch your child carefully and adapt to changes in their need for naps, etc.

DIET and NUTRITION

Unless you have been told that your child requires a special diet, the best diet is well balanced and includes items from the 4 basic food groups (grains, fruits and vegetables, dairy products, fish and meat). Your treatment team can give you several booklets that offer ideas and recipes for nourishing, tasty meals. During your initial period in the hospital a nutritionist familiar with childhood cancer medications will meet with you and your child.

Several aspects of cancer therapy may block your child's ability to take in an adequate and nourishing diet. Eating a normal diet can be difficult because some chemotherapy and radiation therapy can cause mouth sores, altered taste sensations, decreased appetite or nausea and vomiting.

Decreased activity levels and tiredness can decrease a child's appetite. Usually, these effects of cancer treatment are temporary and do not interfere with your child's growth or general health. Your child's weight and nutritional status will be checked regularly by the treatment team who will suggest changes in the diet if you child is undernourished.

It is important not to let anxiety about your child's illness and recovery turn the issue of eating into a conflict. Children who can control very little of what is happening to them will often try to control what they put into their mouths. By offering nutritious and tasty foods and expecting that your child will do his or her best, you can avoid a contest of wills and keep mealtimes pleasant.

LIQUIDS Encouraging a large intake of fluid is especially important just before and after in hospital treatment with methotrexate.

EXPOSURE to SUN

It is good practice for everybody to wear sunscreen. If your child has had radiation therapy or certain chemotherapy drugs he or she may easily sunburn and should be protected from exposure by reducing the time in the overhead sun, wearing protective clothes such as hats and shirts and using at least factor 15 sunscreen.

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MEDICINES

Most medicines that are given orally for cancer therapy should be given 1 hour before or at least 2 hours after meals. Prednisone is an exception and should generally be given with meals or a snack.

If your child vomits within 30 minutes after taking a medicine, you cannot assume it has been absorbed. Talk with your treatment team before repeating a chemotherapy medicine, however.

Do not give aspirin or any aspirin-containing medication. Aspirin can cause bruises or bleeding since it interferes with platelet function and thus with blood clotting. Aspirin-free medicine such as Tylenol may be used (but not to mask fevers).

Tylenol is one brand of acetaminophen. Generic acetaminophen or other brands are acceptable. Aspirin is acetylsalicylic acid. Children should never take aspirin unless specifically directed by a physician. Read the fine print on your medicine bottle and all other over-the-counter medicines.

For small children unable to swallow pills or tablets, use liquid medicines or crush the pills and add them to food or juice. Do not try to hide a pill or add it to a large amount of food or juice because your child may not finish the whole amount. **Frozen grape juice concentrate will mask the bitter taste of many medicines.** You may also use a small spoonful of applesauce, baby food, ice cream, yogurt or jelly, but try not to "burn out" all of your child's favorite foods by combining them with the taste of medicine.

TAKING YOUR CHILD'S TEMPERATURE

Fever is the most important sign of an infection and could be a sign of trouble for a child receiving cancer treatment. Take your child's temperature if you notice tiredness or listlessness ("just not himself"), chills or shakes or skin warm to the touch.

An accurate thermometer can be obtained at any drug store. Wash the thermometer after each use and store it in a dry place.

Your child's temperature should be taken orally (under the tongue with the mouth firmly closed for 3-5 minutes) or axillary (under the arm with arm firmly against side of chest 5-7 minutes). A child on cancer therapy should **NEVER have his or her temperature taken by rectum** because of the risk of bleeding or infection.

During chemotherapy, especially if your child's blood counts are low or suspected to be low, a temperature of **101 degrees F** or more is reason to contact the treatment team at once. Your child needs an immediate evaluation to determine whether hospitalization for IV fluids and antibiotics is necessary. It is important to call us or your local physician at once so that the best decision can be made for your child.

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IMMUNIZATIONS

Chemotherapy lowers the ability of the immune system to fight infection and to respond to immunizations. For these reasons, many children are not immunized while on chemotherapy. Live virus vaccines (oral polio and MMR) should NEVER be given to children on chemotherapy though they may be safely given 6-12 months after completing chemotherapy.

HOUSEHOLD CONTACTS or day care providers should be immunized. For example, brothers and sisters should receive the DPT (diphtheria, pertussis and tetanus), the conjugate Hib (Hemophilus influenza type b), the influenza (flu) vaccine, the MMR (measles, mumps and rubella) and the IPV (Inactivated Polio Vaccine).

OPV (Oral Polio Vaccine) virus can be transferred from person to person. Therefore household contacts as well as patients should NEVER receive this vaccine while the patient is on or within 6 months after stopping chemotherapy. Only the IPV (shot) should be given.

The MMR (measles, mumps, and rubella) can be safely given to any household contacts since these vaccine viruses are not transferred from person to person. Immunizing household contacts will protect the patient on chemotherapy. The child on treatment should NOT receive this vaccine; it is safe when given 6-12 or more months after treatment. Please review this information with us if you have any questions.

Please ask us if there are any other questions about vaccinations for the patient or other family members.

INFECTIONS

Cancer and its treatment reduce the ability of a child's immune system to fight infections. Infectious problems lead to more unscheduled hospitalizations than all other causes combined.

Preventing Infections

Because cancer and its treatment reduce the immune system's power to fight infection, your child will be at increased risk of infection for the time of therapy. Infections can occur even if you do everything humanly possible to protect your child. Neither you nor other children, especially brothers and sisters, should feel guilt or responsibility if an infection develops.

PEDIATRIC ONCOLOGY HANDBOOK

There are steps you can take to reduce the chances of certain infections occurring, most of which follow simple common sense:

- * **Good handwashing** is the most important way to prevent infection. Your child should wash his or her hands before meals and after going to the bathroom. All who care for or play with your child (parents, doctors, nurses and friends) should wash their hands before examining or treating your child.
- * When your child's blood counts are low, keep people away who have signs of an infection, such as fever, cough, sneezes, sore throat or a rash. People who have these symptoms and must be around your child should wear a mask and practice handwashing.
- * Unless we specifically ask you to, **do not separate your child from brothers or sisters who are sick**, UNLESS the siblings have been exposed to chickenpox. It won't work and will make the other children feel worse. Just use common sense to prevent spreading infection in the family:
 - * Do not eat or drink after each other
 - * Do wash your hands
- * If your child has an implanted external catheter (Hickman, Broviac, etc.) follow instructions carefully for dressing changes and care. Always wash your hands before handling the catheter.
- * When your child's blood counts are low, talk with us about whether or not your child should be in school. We can work together with you and your school staff to make school as safe as possible.
- * **Contact us at once if you find signs of an infection.** Keep a close eye on your child's mouth, rectal area, biopsy or surgery sites, and areas of injury such as burns or cuts in the skin. Watch for **redness, fluid drainage, heat or an unusual degree of pain** at the site of a wound.
- * **Contact us at once if you think siblings or classmates have or have been exposed to mumps, measles or chicken pox.** We should be called immediately if your child is exposed to measles or chicken pox (unless your child has definitely had chicken pox in the past).

Even when everything possible is done, your child may still develop fevers and infections. **This is no one's fault.** It is a risk of treating your child for cancer. If fever or infection develops, your most important job is to contact us for further instructions. Keep the telephone contact information near your phone at all times in case an emergency arises.

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BACTERIAL INFECTION

Bacteria can cause serious infections in children with low blood counts. There are bacteria that live in or on our bodies that do not usually cause infection but that may infect a child whose blood counts are low. Children with indwelling catheters or implanted ports run a higher risk of bacterial infections, but infections can occur in any child on cancer treatment.

If your child gets a fever or other signs of infection while his/her white blood cell counts are low, s/he may need intravenous antibiotics in the hospital to treat the infection. Before antibiotics are started, cultures will be obtained to try to identify the organism causing the infection. Results will usually not be known for 48-72 hours but antibiotics will be started before the results are known. **Because it can be hard to identify the source of infection in children with low blood counts, antibiotics are chosen to treat the most likely and most serious sources of infection.** Antibiotics will be continued until blood counts have increased and all signs of infection are gone.

OPPORTUNISTIC INFECTION

There are organisms that don't cause infections in healthy children but can cause serious infections in people whose immune systems are affected by cancer or its treatments. These infections are called opportunistic infections. This includes fungal infections (such as thrush or yeast infections) and pneumocystis pneumonia. It is difficult to prevent exposure to these organisms because they are all around us.

We will watch your child for these opportunistic infections during periods of increased risk, such as when intravenous antibiotics are required for long periods. Your child will usually be put on an antibiotic (Bactrim or Septra) to prevent pneumocystis pneumonia.

VIRAL INFECTION

Viruses usually cause relatively minor infections, such as the common cold but certain viruses can cause serious infections in the child receiving cancer treatment. **Viruses are very hard to identify and they cannot be treated with antibiotics** that are effective against bacteria. Minor viral illnesses are allowed to "run their course" in a child with adequate blood counts. Because the cause of infection can be so hard to find in a child receiving cancer treatment, children with low blood counts and fever are usually treated with antibiotics even if a virus is suspected.

If your child develops a rash, please contact us right away because the rash could be due to a serious viral infection: chicken pox or shingles.

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CHICKEN POX: This is a common childhood infection caused by the varicella virus. It is usually mild and serious problems are rare. However, children who are being treated for cancer and have never had chicken pox may develop added problems that can cause treatment delays and even death. **If we know that your child has been exposed to chicken pox we can reduce the risk by giving a shot (VZIG) within 96 (we prefer 72) hours of exposure. Therefore, it is very important that you have contact with your child's school and friends so that you may know when your child has been exposed.** We will be glad to supply you with a letter to be distributed to parents of other children in your child's classroom. If you suspect or know an exposure has taken place, please contact us immediately.

Signs of chicken pox usually develop 14-21 days after an exposure. A 1-2 day period of flu-like symptoms including fever and sometimes vomiting occurs before the rash in many cases. The rash usually starts with small red spots on the face, head or body that then spread to the arms and legs. After a few days the red spots will turn into little blisters which will then dry up to form crusts. New spots continue to appear for 3-5 days, sometimes longer in a child on chemotherapy. The rash is often very itchy.

If your child does get chicken pox during or within 3 to 6 months of finishing chemotherapy, we would admit your child to the hospital for intravenous acyclovir, a drug which can decrease the complications of chicken pox.

PEDIATRIC ONCOLOGY HANDBOOK

SUPPORTIVE CARE AND FINANCIAL SUPPORT

In the following section of this handbook, we have collected information relating to our parents support group, summer camps, school, financial assistance and other matters not directly tied to your child's medical treatment.

You should realize that **this section is no less important**. One goal in treating children with cancer is to allow these children to achieve the potential they had prior to the diagnosis of cancer. This can only be achieved through **supporting the child's return to school**, finding ways to overcome the sense of isolation common to children with cancer and their families, and making efforts to obtain the social and financial resources to assist families in need. Questions regarding specific areas in this section may be addressed to any of us, but we have tried to assist you by naming one or more individuals best able to help with specific problems.

Marti Hicks, our pediatric hematology/oncology social worker, can best assist you with social, emotional and financial concerns. Her job is described on the following page. The additional pages list individual programs and persons who are available for specific needs.

PEDIATRIC ONCOLOGY HANDBOOK

PEDIATRIC ONCOLOGY SOCIAL WORKER

As a member of the pediatric oncology team, our pediatric oncology social worker can help you and your family members with the many concerns, feelings and questions which arise when a child is diagnosed with cancer. These issues may relate to you, a family member, a friend, one of your other children or the patient.

The social worker works with the doctors and oncology nurses and can provide an additional communication link between the medical staff and the family. This continued presence might serve as a familiar link between your child and the hospital, which in turn can lessen the anxiety and fear of the unknown for both parent and child.

The social worker can also be of special assistance to the child and family in helping you pursue and benefit from appropriate community resources such as family services, school-related programs, counseling services, support or other community resources. The social worker is specially trained to provide services to you in these areas or make referrals to services closer to home if needed.

The social worker also co-facilitates the Parent Support Group with Jeff Ungetheim, the child and family counselor. If you are interested, contact Marti or Jeff (713-5984) and you will be put on our mailing list. The format is generally open discussion, though guest speakers or films may be used at times. Refreshments are also served.

In addition to the emotional support offered by the social worker, our family's practical needs are also addressed. A subset of financial aid resources and transportation assistance is listed on the following pages. Marti can provide a more extensive list if needed. Temporary housing including Ronald McDonald House information is also included in this section.

The social work offices are located on the main floor near the main lobby in Social Work Services. The telephone number is **336-716-6857 for Marti Hicks**.

CHILD AND FAMILY COUNSELOR

The Pediatric Oncology team includes a child and family counselor. This position is provided through The Children's Cancer Support Program to offer our children and families additional support throughout treatment and follow-up visits. Some of the services include: counseling for coping with diagnosis, post-treatment, and other related concerns; referral information for neurological and psychological testing help with school related problems in learning and behavior; and support through various programs such as support groups, parent to parent mentoring, annual events, and a resource room. For a complete list of services, see **OUTRAGEOUS COURAGEOUS KIDS: SERVICES OF THE CHILDREN'S CANCER SUPPORT PROGRAM**. The telephone number is **336-713-5984 for Jeff Ungetheim**.

PEDIATRIC ONCOLOGY HANDBOOK

OUTRAGEOUS COURAGEOUS KIDS **SERVICES OF THE CHILDREN'S CANCER** **SUPPORT PROGRAM**

Counseling Services (provided through private donations by groups and individuals.)

1. Counseling for coping with diagnosis, post-treatment, and other related concerns.
2. Individual, marital, and family counseling is available for patients and their family members, both during and following treatment.
3. Parenting consultations for behavior problems and school issues.

Peds Pals

This is a “big brother/big sister program” that matches medical students up with kids for them to have a buddy to visit with while they are in the hospital.

Arts for Life

Arts for Life is a non-profit organization that gives young cancer patients cameras, film, and recording devices to have fun with and to document their experiences. They also provide lessons in photography and related art projects. Contact the Support Program Director for details.

Referral Information

The support program counselor can help with referral sources for counseling and psychological services in Forsyth and surrounding counties.

Family Education Center (located across from the check-in rooms in the clinic). This room has brochures, handouts, and video tapes on a variety of topics related to coping with cancer. You can browse for yourself or ask Jeff Ungetheim for help.

Groups

1. Parent Meetings
If you are interested in meeting with other parents for mutual support and education, please let Jeff Ungetheim know so you can be on our mailing list (336-713-5984).
2. Adolescents' group
Meets periodically for special events and activities. Let Jeff Ungetheim know if you would like to be on the mailing list. See the teen section of the Brenner Children's Hospital website (www.wfubmc.edu/brenner/core.html).

Parent to Parent Linking

This program links parents and children (newly diagnosed) together with other parents who have been through treatment with their kids in order to provide additional support and perspective.

Teen to Teen Linking

Gives newly diagnosed teens a chance to talk with other teenagers who have experienced cancer and its treatment.

School Visitation Program

The staff of the Pediatric Oncology Department offers School visits to all school age children who request it. The staff member goes to the child's school, if requested, to discuss with teachers and the child's peers the nature of the illness and how they can be most helpful to the student.

Other Health Impaired Certification

Sometimes, as a result of the disease and the treatments, a child will have difficulty at school in various ways. The OHI certification entitles the child to special services in light of his/ her medical condition. The support program counselor can help initiate this process and can help with coming up with the appropriate services which the school could arrange.

Fall Fun Day

Mid to late September annually. Information will be provided in the clinic and through mailings.

Holiday Party

The first Saturday in December annually at Parkway Presbyterian Church in Winston-Salem. Information will be in clinic and in mailings.

Email listserv – jungethe@wfubmc.edu

This is a way for parents and kids to email Jeff and one another with comments and questions through an email address at the hospital. This way others who are on the list can learn from others with similar experiences.

For more information about any of the above, contact Jeff Ungetheim, the program director, at 336/713-5984, or email at jungethe@wfubmc.edu.

Web site: www.wfubmc.edu/brenner/den/CancerSupport/index.html

HOW TO COPE WITH YOUR CHILD'S SERIOUS ILLNESS

1. Educate Yourself.

At first, you may allow your doctors to make all decisions for your child as you adjust to the shock of diagnosis.

As time goes by, you will feel more confident taking an active role in your child's care. You are the "expert" on your child.

Understanding your child's illness and treatment will be easier if you read and ask questions.

Write your questions down as they come to you so you don't forget to ask!

Ask other parents about their experiences. **You are not alone.**

2. Make Peace With Your Guilt

You may feel responsible for your child's illness. Many parents experience this feeling.

There is no scientific evidence that anything parents did or didn't do led to their child's cancer.

Guilt places stress on parents, robbing them of their ability to cope and support the child effectively.

Make peace with your guilt, focusing on the present.

Good and bad people become ill. No one is to blame, the illness is not a punishment.

3. Tell Your Child The Truth

Be truthful, but gentle, when you explain the illness to your child.

Adjust the information to a level your child can understand.

Ask a health care professional how to tell your child about the illness if you are unsure.

Being honest with your child allows him or her to be honest with you about fears and concerns.

PEDIATRIC ONCOLOGY HANDBOOK

Because your child does not talk about cancer or death, do not assume he or she has not thought about it.

PEDIATRIC ONCOLOGY HANDBOOK

COPING SUGGESTIONS (continued)

3. **Tell Your Child The Truth (continued)**

Be prepared to deal with the child's anger or fear.

Ask your child's health care team how to cope with the feelings your child expresses.

4. **Be Your Child's Advocate**

You know your child better than anyone else.

Exercise your right to ease your child's stress and frustration.

Talk to other parents who have "been there."

Make doctors and nurses aware of what your child needs in order to cope with treatment.

Bring favorite toys and comfort objects from home.

If you feel mistrust of those caring for your child, discuss your concerns with those involved. Children will mirror your anxiety.

Realize you do have some control over your child's experience during treatment.

5. **Talk To Siblings (Brothers and Sisters)**

Begin conversations about the child's illness. Siblings will have questions they are afraid to ask.

Tell siblings cancer is not contagious.

Tell the siblings they did not cause the cancer.

Prepare siblings for their brother or sister's hair loss, weight gain or loss, changes in mood, upcoming surgeries or hospitalizations.

Try not to focus all your attention and love on the sick child.

Involve siblings in the child's treatment as appropriate.

Consider family counseling.

PEDIATRIC ONCOLOGY HANDBOOK

COPING SUGGESTIONS (continued)

6. Take Care of Yourself or Preparing for the Long Haul

Medical treatment often lasts several years.

The illness will become a focus of your life. Prepare for reduced work schedules, less vacation time, family separations, and **MORE STRESS**.

Try to treat your sick child as normally as possible, maintaining usual discipline.

Be aware of how your perspective changes as you no longer "take things for granted." These feelings may distance you from your friends.

It is not selfish to take care of yourself. Allow time to "recharge your batteries." Take time to be alone, to grieve, to relax.

Find a constructive outlet for your anger and fear. Prayer, gardening, exercise, being with a close friend help some people.

Make time for your spouse. Serious illness places serious strain on the marital relationship.

ASK FOR HELP from friends, family, and neighbors. If you can think of specific tasks all the better. (Ask a friend to bring a casserole over on a day you will be in clinic, to pick up your dry-cleaning, to baby-sit, to help you clean your house, to cut your grass, etc.)

Realize loved ones and friends may not react to a child's illness in ways you expect. They may withdraw completely or be over-involved.

Live day to day, enjoying the small victories.

Attend support groups, speak to a social worker, counselor or member of the clergy.

Plan small pleasures into each day. A phone call, good music, a long bath can all help you cope.

PEDIATRIC ONCOLOGY HANDBOOK

CANDLELIGHTERS

Candlelighters is an international organization serving children with cancer and their families by promoting education and support. There is a free quarterly newsletter (and a teen newsletter); they also have information on groups relating to specific diseases (ex: Histiocyte Society). The National address is:

Candlelighters Cancer Foundation
1901 Pennsylvania Avenue NW
Suite 1001
Washington, D.C. 20006

Phone: 202-659-5136 or 1-800-366-2223

For questions or more information contact the social worker.

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SCHOOL AND SCHOOL RE-ENTRY

Children with cancer always miss some school. One of our goals is for your child to return to school as soon as is safely possible. This is part of the overall effort to keep life for your family and your child as normal as possible. Thus we strongly encourage your child to attend and keep up with school.

There are two hospital school rooms located on our Pediatric unit: Reynolds Tower (grades K-5) and the Adolescent Unit (7 North; grades 6-12). For those patients who must stay in their room bedside teaching is available.

Students may begin receiving instruction as soon as the referral process is completed. The doctor's referral form and the parent permission forms may be obtained from the nurse's station or from the hospital teachers.

The educational model is as follows:

- (1) Hospital teachers initiate contact with the home school to obtain assignments.
- (2) Academic progress is reported at the end of hospitalization through a written summary.
- (3) If necessary, hospital teachers will communicate with the home school to facilitate homebound teaching as needed.

When admission to the hospital is planned, it is helpful to bring any books and assignments.

Teacher for ages 6-12: Erin Webster

Teacher for 12-18: Liz Clark

In addition to this in-hospital system, our home visitation program also extends to schools. **We will be happy to schedule a school visit by a pediatric oncology nurses and/or a social worker-**please feel free to discuss this with any of us. In addition, we will be glad to provide written documentation of illness, expected or necessary days in the hospital, and so on as needed on an individual basis.

PEDIATRIC ONCOLOGY HANDBOOK

HOME and SCHOOL NURSE VISITATION PROGRAM

We have supported a home visitation program for over 15 years. Through this program, for which there is no charge, one of our nurses, social worker and/or psychologist will visit with you and your child in your home and/or at your child's school.

The purpose of the home visitation program is to continue the support of the child and family once the child is discharged from the hospital. It is often very frightening to leave the security of the hospital and return home with a child who has just been diagnosed with cancer. Very soon after discharge, one of the nurses may come to your home to review what you have learned about your child's illness, answer any questions you have, talk with siblings and other family members and also to provide emotional support to both you and your child. On occasion, the social worker may also make home visits. She can help you not only with emotional issues but also with any financial difficulties you and your family may be experiencing.

Another aspect of the home visitation program is the school visit. **We strongly encourage all children who are physically able to attend school.** Many times the schoolteacher, classmates and other school workers may have questions about your child's illness and limitations, if any. Also, they're any many general misconceptions about childhood cancer. One of our nurses or social workers can work with your child's teacher and classmates to help make the transition back to school a smooth one. Either on your child's return to school or before the team members can go into the classroom and talk with the children and teacher. This is usually a fun and positive experience for the classmates, teacher and child.

PEDIATRIC ONCOLOGY HANDBOOK

FINANCIAL COUNSELING

The diagnosis of cancer in a child places great financial burdens on most families. We wish to assure you that your child will NEVER be denied care for financial reasons. Providing services for children with cancer is expensive; the payments for these services make it possible for us to maintain the level of excellence we believe we provide for all the children under our care.

We have financial counselors who work with our patients. They may call you at home to review your hospital insurance benefits. They will let you know what the estimated costs will be for your child's admission and let you know the estimated difference after insurance. You will be asked to pay this amount on admission for scheduled admissions. For emergency admissions, you will be asked to pay the difference upon discharge. Your child will never be denied care regardless of your ability or lack of ability to pay. If you are unable to pay amounts not covered by insurance, financial services will assist you in working out a payment plan. Financial services and the social worker will also assist you in determining your child's eligibility for various financial support programs.

If your child is not covered by any health insurance, Financial Services will work with you to determine your child's eligibility for Medicaid or other assistance programs. They will need to obtain financial information from you that will be used to determine financial eligibility for assistance.

Please call Financial Services at (336) 716-9055 if you need assistance to help with the medical expenses or understand your bills or benefits. You are welcome to stop by and see Financial Services any time between 8:00 am and 5:00 pm, Monday through Friday. They are located in the Financial Counseling Department located on the main floor of Reynolds Tower.

If you have questions about your outpatient bills (Wake Forest University Physicians bill), you should call the billing department. They can also tell you about special programs for which you may qualify. (WFUP Billing: 336-716-3988 or Toll Free: 877-938-7497)

Please inform Marti Hicks, our social worker, or Financial Services whenever and as soon as, your insurance status changes to avoid incurring large bills for which you may be held responsible. Also please let any of the staff in the clinic know of such changes.

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LEUKEMIA and LYMPHOMA SOCIETY

Patients with a diagnosis of Leukemia or Lymphoma (including both Hodgkin's and "Non-Hodgkin's" Lymphomas) are eligible for support from the Leukemia and Lymphoma Society. **They will provide some aid on a cost-per-mile basis of your travel** and will cover parking costs for clinic visits and admissions. They also provide some financial assistance for chemotherapy, blood transfusions and radiation. The maximum per year for one person is \$750.

The National address is:

Leukemia and Lymphoma Society
733 Third Avenue
New York City, New York 10017

Phone: 212-573-8484
WEB: www.leukemia.org

The North Carolina Chapter:

Leukemia and Lymphoma Society
5950 Fairview Road, Suite 250
Charlotte, North Carolina 28210

Phone: 704-998-5012 or 800-888-9934

The Virginia Chapter:

Leukemia and Lymphoma Society
Post Office Box 21
2101 Executive Drive
Hampton, Virginia 23666

Phone: 757-838-9351 or 800-866-4483

Marti Hicks can provide you with forms to complete for the appropriate chapter so that you will be eligible to receive this assistance. Be sure to let her know if you have any problems. The travel forms should be completed monthly and must be signed by a staff member. Please ask us if you have any questions about this and remember to bring the forms to clinic to be signed.

PEDIATRIC ONCOLOGY HANDBOOK

AMERICAN CANCER SOCIETY

There is assistance available to some children with cancer to cover transportation expenses, the rental of medical equipment or drugs. The Society is financed by public contributions. The ACS provides free educational literature and in some cases offers support groups.

The organization's regional office is in Atlanta but many counties have local chapters. To apply, contact your local chapter or ask the social worker for information about your local chapter.

American Cancer Society
Southeastern Division
2200 Lake Boulevard
Atlanta, GA 30319
Phone: 1-800-227-2345

American Cancer Society, Virginia Division
4240 Park Place Court
Glen Allen, VA 23060
Phone: 1-800-476-1289

SUPPLEMENTAL SECURITY INCOME (SSI)

Many children with cancer are considered disabled by the Federal Government. Supplemental Security Income for disabled children is a federal program which is administered through the Social Security Administration. **It provides extra income** for children with serious medical problems whose families have limited financial resources.

Application can be made by calling the Social Security office at 1-800-772-1213. A Social Security representative will arrange a phone interview for the application or may ask you to come to the office. It is helpful when applying to have the following: birth certificate of the child and siblings; proof of income; rent or mortgage receipts; checking and savings account statements; social security number; life insurance policy; address of physician who is treating the child, diagnosis of the child and information relating to the plan of treatment. Please ask any of our team if you need help with this information!

EMERGENCY/SPECIAL ASSISTANCE

Since other assistance programs exist which are not listed please check with the social worker when you need any kind of financial help. We have an emergency medicine, transportation and miscellaneous needs fund. Please keep this in mind and ask the social worker or a member of the team when assistance is needed. For greater financial needs there are foundations and special funds which may provide assistance--check with the social worker.

The hospital pastoral care office can often provide financial assistance for medications, meals and lodging. The Ronald McDonald House (see elsewhere) can waive the \$5 per night fee for those unable to pay.

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RONALD McDONALD HOUSE

The Ronald McDonald House located at 419 S. Hawthorne Road is a temporary lodging facility for out of county families whose child is receiving medical treatment at Brenner Children's Hospital, NC Baptist Hospital and other local hospitals. The house is conveniently located across the street (walking distance) from the Medical Center. The hospital van service will provide transportation to Ronald McDonald House, if needed.

It is owned and operated by the Board of Directors of Rainbow House of Winston-Salem, Inc. It is designed to offer a "home away from home" while your child is receiving medical treatment.

The house has 17 bedrooms, 18 bathrooms, kitchen, dining area, playroom and free laundry and parking. Sheets and towels are provided. The kitchen has some food supplies, however guests have to provide the bulk of their own food.

The following criteria are used to determine eligibility for admission to the Ronald McDonald House:

- (1) The family must be from outside Forsyth County
- (2) The child receiving treatment must be 18 years of age or younger.

Once a family has met the criteria for admission, their name is placed on a waiting list. The waiting list is operated on a first come, first served basis, with special priority given to cancer or long term outpatient families. Families can call in advance of admissions to place their names on the waiting list. Families can use one room per family. Families staying in the house for the first time go through an orientation that lasts about 35 minutes.

Families are asked to pay \$5 per night. Actual cost to operate the room is \$27 per night. Those for whom payment may be difficult are asked to discuss alternate arrangements with the Manager, as no one is turned away due to inability to pay.

Those who are interested in staying at the Ronald McDonald House should ask the nursing staff, social worker or physician. Or, for admissions information, call the Manager of the House at 336-723-0228.

PEDIATRIC ONCOLOGY HANDBOOK

CAMP CAREFREE

Camp Carefree is a facility built on a farm near Stokesdale, NC. It operates 5 or 6 week long camping sessions each summer. One week is always for children diagnosed with cancer and another for siblings of any children eligible for any of the weeks. The weeks start with a check-in Sunday afternoon and end with pick-up by the family the following Saturday. Children may come to the camp who are on treatment or who have completed treatment. One of our doctors is always present on Sunday for check-in and nurses from our hospital and others are there around the clock.

The age range is 5-16 years with older children sometimes able to come as counselors in training. The children sleep in dorm-like cabins with 1 counselor for every 3-4 children.

The camp has many of the things you associate with camps: arts and crafts, Ping-Pong, pool tables, a swimming pool, a small lake for boating and fishing, tennis, basketball, softball and horseback riding. Everything is well supervised. **THERE IS NO CHARGE** although donations are tax-deductible and always welcome.

Each spring we will have application forms for the camp. If your child has previously attended you should receive an application directly from the camp. Otherwise ask us in clinic or obtain the forms by writing directly to the camp:

CAMP CAREFREE
275 Carefree Lane
Stokesdale, NC 27357

Phone: 336-427-0966

