

Dear Parent or Caregiver:

The experience of a sudden diagnosis of cancer in a child is a deeply upsetting one. During this turbulent time, we extend our heartfelt support and care to you and your family.

As you begin to face the many challenges that cancer imposes, please know that the pediatric oncology team is fully available to your child and family to provide assistance in every way possible. Our combined years of experience in the practice of pediatric oncology provide a strong basis of support that, we hope and expect, can do much to ease your burden.

It is our goal to help parents and patients feel as comfortable as possible with the medical care that is required for treatment of childhood cancer. We want you to be able to understand your child's disease and treatment so that you can take part in the decisions and the care of your child while in the hospital as well as at home.

There is no easy way to absorb the shock, pain, and fear of being told that your child has cancer. This experience affects the entire family and confronts each caregiver with additional problems of everyday living. Feelings of helplessness, frustration, and loss of control impact parents as well as children and members of the extended family. These are all normal responses. We hope you realize that you are not alone. Many of the problems and emotions you are experiencing are shared by most people in your situation.

Again, we offer to you and your family the best of our support and care and will help you in all the ways that we can to cope with the journey that lies ahead.

This handbook contains information you will need to understand your child's disease and its treatment. Please read it over and refer to it frequently. We know it seems like a lot to learn, but our intent is for you to be informed in order to provide the special care your child needs.

Sincerely,

The Pediatric Oncology Staff

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Weekdays: Call during clinic hours, 8:30 AM to 5:00 PM Monday through Friday:
(510) 752-6592. The clinic is closed for lunch from 12:30 to 1:30 PM

Nights and Weekends: Call the page operator at (510) 752-1666. Ask for the
pediatric oncologist on call.

THE DISEASE

What Is Cancer?

Unlike normal cells, which grow at a normal rate, cancer results from the continuous, uncontrolled growth of abnormal cells. One theory states that normally the body's own immune system is capable of eliminating these cells, but when this system breaks down, and abnormal cells are not destroyed, they begin to grow out of control and a cancer is formed.

We believe that all cancer is genetic in origin. However, it is very rare that cancer is inherited from family members in the manner of hair or eye color. Rather, we mean that cancer results in part from changes in the DNA of the cancer cells, rendering them prone to rapid overgrowth.

Cancerous cells have two main traits. First, they fail to develop from young to mature cells, so they continue to reproduce immature cells. Second, they can separate and travel, by way of the blood stream or through the **lymphatic system**, to other places in the body, where they grow and reproduce more abnormal cells. For example, a liver cancer cell can travel to bone, reproducing liver-type tumors at the new site. This process is called **metastasis**.

Unrestrained growth and the spread of cancer cells to other parts of the body eventually lead to the growth of an abnormal mass (**a tumor**) which can interfere with the body's functioning, eventually leading to death.

A number of childhood cancers are routinely curable. Cure rates have increased with advances in basic research leading to improvements in chemotherapy, radiation, and surgery. It is encouraging that where once children were diagnosed, treated, and died, many are now diagnosed, treated, and are preparing for college, careers, marriage and parenthood.

TREATMENT

Children's Oncology Group

The Children's Oncology Group (COG) is an organization of pediatric oncology specialists from major pediatric medical centers in the United States and Canada. Established in 1955 under the auspices of the National Cancer Institute (NCI), the group works to increase the survival and cure rates of children with cancer.

Most children with cancer at Kaiser Oakland are registered and treated on COG studies. COG compiles data from large numbers of cancer patients in many different locations. This allows for joint research projects, sharing of information, testing therapies in large numbers of patients, and quicker advances in treatment than could be made by researchers working independently.

Programs (protocols) for diagnosis and treatment are used for each type of cancer and are continuously updated as new data is gathered. A computer at COG headquarters may randomly select children for one of two or more effective treatment regimens. If one regimen proves more effective than others, all children are then either switched or assigned to that regimen, until further improvements develop.

These research methods have provided excellent results over the years, improving the survival rates for children with cancer.

If your child or teen is eligible for a COG study, you will be asked if he or she can participate. All aspects of treatment will be explained to you, including the risks and benefits. If your child participates, you will be asked to sign a consent form. You will receive a sample copy and be given instructions on how to fill it out. These forms will be sent to data managers who collect information about each child's disease and treatment. The data managers will then send the consent forms to the COG Statistical Center for further evaluation.

TREATMENT CALENDAR

The calendar describes your child or teen's treatment plan. We will go over it carefully so you will understand it well. It outlines the following areas:

- Type(s) of chemotherapy your child will receive.
- Specific doses of chemotherapy or other drugs your child will receive.
- When certain procedures (i.e., blood tests, bone marrows, spinal taps) are due.
- When treatment should begin and how long it should continue.

The calendar will help you keep track of the treatments. **Please bring the calendar and this handbook to all your child's appointments.**

The calendar will look similar to the one displayed on the next page.

CHEMOTHERAPY

Chemotherapy is any medication that destroys cancer cells. These drugs can be given by mouth (pills or liquid), by an injection into a vein (**intravenous or IV**), just beneath the skin (**subcutaneous or SQ**), or deep into a muscle (**intramuscular or IM**). The drugs then travel by bloodstream to cancer cells anywhere in the body. Most drugs cannot get to the brain, so the best method for getting chemotherapy to attack cancers in the brain or spinal canal is by injecting the drugs directly into the spinal fluid (**intrathecal or IT**) during a spinal tap.

Chemotherapy is effective because it kills rapidly dividing cells -- which cancer cells are. However, chemotherapy can harm other rapidly dividing normal cells, resulting in side effects. Most side effects are temporary and will gradually go away after each treatment or after treatment stops altogether.

Depending on your child or teen's type of cancer, chemotherapy treatments usually last for several months to several years. The combination of drugs, the frequency of their administration, and the possible side effects will be outlined in detail by your doctors and nurses. You will also be given information sheets on each medication your child receives.

CENTRAL LINES: BROVIACS, PORT-A-CATHS AND GROSHONG CATHETERS

Central lines are necessary for many children requiring chemotherapy, radiation treatment and/or frequent transfusions. They provide access to the veins, to allow administration of IV fluid, blood products, and medications such as chemotherapy. These medications can cause damage to the skin and surrounding tissues if it is not administered directly into the bloodstream. IV access in children is not only painful, but can be challenging as they have small veins and children are very mobile, thus maintaining a working IV also presents challenges. Central IV catheters are surgically placed and are present for the duration of treatment, assuming there are no complications such as an infection requiring the removal of the catheter.

The Broviac and the Groshong catheters have an external tube extending out of the chest that allows us access for lab draws and infusions of fluid or medicine without the use of needles. The Broviac catheters require daily flushes of heparin and both catheters require weekly dressing changes. You will be taught how to care for these lines before your child is discharged from the hospital.

Port-a-caths are indwelling, meaning they are under the skin and do require a needle to access the port. This needle can be left in for one week at a time. Attached to this needle is a tube that can be used for I. V. access, or lab draws. This line does not require care at home. If you desire, we can teach you how to access the port if this will make blood draws easier for you and your child.

All central lines, while an excellent benefit in easing your child's treatment do have some risks. The primary concern is that of infection. **It is important to notify us of any fever, 101.5° or higher, so we can treat promptly with IV antibiotics. It is also important to notify us before any dental visits or planned surgical procedures,** as oral antibiotics are required 1 hour before the visit to help prevent any infection. It is important to contact the pediatric hematology/oncology clinic for these conditions for the entire time the catheter is in place.

Central lines require specialized nursing care and not all nurses are trained in this care. The pediatric nurses in the hospital, as well as the pediatric hematology and oncology nurses are proficient in this care. When it is necessary for your child to be seen in the Emergency Room or another area of the facility, the nurse caring for your child may not know how to care for the catheter. It is important to speak up and state your ability to care for this line. You are the expert with your child's line. Please bring your lab drawing supplies with you, they may hand you different

vials for blood collection but the technique for drawing blood is the same as you have been taught.

It is important to always carry with you a "blue clamp". This is a safety clamp in case there is a tear or leak in the tube of the Broviac or Groshong catheter. You would need to clamp above the tear, between your child's chest and the tear. This will help to prevent infection. If there is any problem with flushing or withdrawing blood from your child's catheter, you need to contact the pediatric hematology/oncology clinic immediately.

Supplies for your catheter will be delivered to your home from a Kaiser pharmacy located in San Francisco and referred to as "French pharmacy". You will be given an order sheet with the phone number to place orders, as you need supplies. Please call at least 1 week in advance, as it takes time to receive the order. The blood collection tubes, labels and lab slips will be supplied by the clinic. **It is important to always use the lab slips we give you in the clinic**, as they are marked so the labs are processed quickly and any abnormal results will be reported to us. Please let us know as you need additional lab slips, collection tubes and labels.

SUPPORTIVE CARE

Risk of Infection

Children with cancer are more susceptible to infections because both the cancer itself and the treatments lower children's resistance and impair their ability to recover from infection. The risk of infection is even greater in children with low white cell counts.

When infections occur they may be life threatening, so they require prompt attention. To assure the earliest diagnosis and treatment possible, you can help by learning to recognize early signs of infection. Notify your oncologist promptly if you suspect infection.

Signs of Infection

Fever, although not always present, is one of the most frequent signs of infection. Other signs include pain, rash, change in bowel or bladder patterns, irritability, listlessness, or fatigue. Swelling, redness, tenderness or pus around a wound may also occur. However, children with low white blood cell counts often cannot make pus.

If your child has a Broviac (central line) catheter, it is important to assess the site frequently for possible infection. Any redness, swelling, discharge or pain should be reported promptly to the oncology nurse.

Symptoms other than high fevers are often helpful in evaluating the seriousness of infections. You know your child best. If your child's behavior changes, check his or her temperature. Call the oncology clinic if your child develops any signs of illness or infection.

Checking for Fever

Use a thermometer, rather than guessing. Temperatures may be taken orally, tympanically (in the ear), or under the arm, but let your doctor know which method was used, because readings may vary with different locations. **Avoid taking a rectal temperature**, which increases the risk of infection from rectal tearing. **It is important to use the same method to obtain the temperature if you are monitoring the child for fever; different methods may result in different readings.**

What to do if Fever Develops

If your child has a **single temperature of 101.5 degrees Fahrenheit (38.3 degrees Centigrade) or greater, CALL THE ONCOLOGY CLINIC IMMEDIATELY**. If after hours, call the page operator and ask for the pediatric oncologist who is on call.

Do not give Tylenol unless it has been approved by your doctor. Giving Tylenol (acetaminophen) only "hides" a fever, delaying evaluation and treatment for a possible infection. This could be dangerous for your child.

If the fever occurs after clinic hours, you will be directed to bring your child to a Kaiser emergency room for evaluation. You can expect that your child or teen may need a complete physical exam, including laboratory tests ordered by your doctor. Blood may be drawn from both the central catheter and another site such as the arm or hand. This may be necessary in order to determine if an infection is present only in the catheter or is more widespread throughout the body. If the blood tests show that the neutrophil count is less than 500, and the temperature is 101.5 degrees F (38.3 degrees C) or greater, your child will be admitted to the hospital for IV antibiotics.

Chemotherapy and Fever or Infections

Chemotherapy is usually omitted or discontinued when fever or infection is present because some drugs inhibit the body's ability to overcome infection. Whether drugs are stopped depends on the severity of the infection and the white blood cell count. Brief interruptions of medication, when recommended by your doctor, will not jeopardize the welfare of your child.

Preventing Pneumocystis Pneumonia

Pneumocystis carinii is an organism that can cause an unusual form of pneumonia in people whose immune systems are weakened by disease or drugs. It is possible to prevent this pneumonia by giving either Bactrim TM or Septra TM twice daily (about twelve hours apart) for three days in a row each week. In our clinic, we place all patients on a Friday-Saturday-Sunday Septra schedule. Although there may be exceptions, we usually continue these drugs throughout the entire course of chemotherapy and until the immune system recovers after treatment is complete. These drugs contain sulfa, so give them with lots of fluid to help flush the medicine through the kidneys as it is excreted. These medications also increase the patient's sensitivity to sunlight; therefore it is recommended that patients wear sunblock when outdoors. Wearing a cap and long sleeves will also increase your child's protection.

Infectious Diseases

Don't bring your child to the hospital ward or clinic if he or she has an infectious disease such as chickenpox, which can be dangerous to other children with weakened immune systems. Instead, call the oncology clinic for instructions.

CHICKEN POX

Chickenpox is a common childhood disease caused by the varicella virus and spread easily by coughing, sneezing, or direct contact with moist lesions. In most children, it causes a mild reaction. However, children with cancer who have never had chickenpox can develop a more serious infection because their bodies' normal immune systems are depressed by cancer, drugs, and/or radiation.

Exposure

If you remember your child having had chickenpox, and this is confirmed by a positive blood test (**varicella titer**), then no special action is required at the time of a second exposure. However, if he or she has not had chickenpox, special treatment may be required under the following circumstances. If your child comes in close contact with another child one or two days before that child comes down with chickenpox, or while the chickenpox lesions are active (not dried and crusted over), then your child has been exposed and may develop lesions ten to 21 days later.

Treatment

If we are notified within 72 hours of an exposure, a medicine called Varicella Zoster Immune Globulin (VZIG) can be given. It may prevent or decrease the severity of the infection. Protection lasts for four weeks, so it may need to be repeated if exposure occurs again. This medication can only be given as an intramuscular (IM) injection.

If your child develops chickenpox, he or she will receive a medication called acyclovir. Generally, children are admitted to the hospital to receive this medication intravenously. If there are no complications, your child may be able to go home and complete the course using oral acyclovir.

Whether your child is treated at home or in the hospital, care will include extra fluids, controlling itching, attention to cleanliness, and medicines for fever and infection, if needed. Other treatment may be necessary if complications occur. Chemotherapy will be stopped until the infection is over. If your child is hospitalized, he or she will be isolated to prevent transmission to other patients.

Signs and Symptoms

- A slight fever, runny nose, fatigue, headache, and loss of appetite may occur one to two days before the rash appears. (This is the most contagious period, although chickenpox continues to be contagious until all blisters have crusted or dried.) An elevated temperature, along with the above symptoms, may persist for several days.
- Round blisters filled with fluid and encircled by a reddened area may appear first on the chest, back, and face, and then later on legs and arms. This rash is usually very itchy.

What You Can Do

- Tell teachers and parents to tell you immediately if a schoolmate or playmate develops chickenpox.
- Call your oncologist immediately if you think your child has been exposed to chickenpox. Call even if you're not sure.
- Check your child closely for signs of infection until the incubation period is over (21 days).
- If your child was exposed to chickenpox, collect as many facts about the exposure as you can, such as when and where it occurred and whether other children developed an infection.
- Keep separate from others who are susceptible to severe infections. Do not come to the hospital or clinic without notifying the nurse about your child's exposure to chickenpox.
- At the first signs of infection, immediately notify your doctor.
- Keep a written record of your child's progress, including temperature, number of new blisters each day, appetite, and any other aspects of the infection that concern you.
- Send a letter to the parents of classmates to educate them about the seriousness of chickenpox exposure for your child. This will help gain their cooperation in alerting you immediately should their children get chickenpox. See the sample letter on the next page.

Date: _____

Dear Parent:

Our child, _____, is a member of your child's class. He /she is currently receiving chemotherapy for treatment of cancer at Kaiser Permanente, Oakland.

The chemotherapy kills cancer cells in the body, but it also kills some normal cells. When normal cells are killed, lowered immunity becomes a problem. This means that it is more difficult to fight infections, especially viral infections like chickenpox.

PLEASE NOTIFY US (or the school, if we are not home) IMMEDIATELY IF YOUR CHILD BREAKS OUT WITH CHICKENPOX. Call us night or day as soon as you see the first spots. For a child with lowered immunity, medicine can help lessen the effects of the disease. But the medicine must be given within 72 hours of the exposure. Your child may be contagious as early as one to two days *before* lesions appear, and throughout the illness until the lesions have all dried out and crusted over.

If you have any questions, please do not hesitate to call us. Thank you for your help.

Sincerely,

(your name)
Phone #

SHINGLES

When children are infected with the chicken pox virus, the virus remains in the body even after the outward symptoms have disappeared. The inactivated virus is stored in the sensory ganglia (nerves). When the body is stressed (by illness, emotional stress, chemotherapy, radiation treatments, etc.), and the immune system is compromised, the virus can become active again.

The virus erupts in painful clusters of vesicles called shingles or herpes zoster. They usually develop in a characteristic "band" along the child's torso. Frequently, patients complain of tingling, itching and/or burning in the same area for a day or two prior to the eruption.

Shingles is contagious only if a person who has never developed immunity to chicken pox comes in contact with the fluid in the vesicles. It is not spread by respiratory infection (by breathing infectious particles).

Acyclovir is a medication that may be given to ease the symptoms or limit the length of the outbreak. Most children will be admitted to the hospital to start a course of intravenous (IV) acyclovir. If the symptoms are mild, the child may be discharged home to complete the treatment with oral acyclovir.

If your child develops a rash or blisters that concern you, please call our clinic and speak with the oncology advice nurse.

UNDERSTANDING BLOOD COUNTS

Knowing how blood is formed and how it functions may help you better understand your child's disease and its treatment. Understanding his or her treatment may help you feel more in control.

Blood cells originate in the bone marrow, a spongy network of tissue inside bone. Once blood cells mature, they are released into the bloodstream to protect against infections and provide nourishment, oxygen, hormones, and other chemicals necessary for the body to function properly.

There are three different types of blood cells: red blood cells, platelets, and white blood cells — each performing a specific task. Keeping an accurate record of your child's blood count will help you and your doctors to know when and how to be cautious with chemotherapy.

Red Blood Cells

Also called **erythrocytes** or **RBCs**, red blood cells provide energy and give the pink color to cheeks and gums. They contain a red iron protein (**hemoglobin** or **Hgb**) that binds to oxygen in the lungs and releases it in tissues and organs. When your child or teen is on chemotherapy, you can expect the hemoglobin to be between 8-10 gm/dl.

The **hematocrit** or **Hct** is the percentage of packed red blood cell in a given volume of blood. Normal values for children on chemotherapy are from 24 to 30 percent, depending on age. Normally, the hematocrit is about three times the value of the hemoglobin.

Certain chemotherapy agents can destroy immature red blood cells in the bone marrow and cause the hemoglobin or hematocrit to go down (also called anemia). The lowest point is generally seven to 14 days following chemotherapy. When your child's hemoglobin is below 7 gm/dl or the hematocrit is below 20 gm/dl, provide your child with adequate rest and make sure he or she avoids strenuous activities.

Signs and symptoms to watch for in your child include paleness, lack of energy, rapid pulse rate, and shortness of breath. He or she may also complain of dizziness or headaches, particularly when getting up from lying or sitting positions.

Contact your physician if any of these symptoms occur. Your child may need a **complete blood count (CBC)**. A blood transfusion is usually not necessary unless the hemoglobin falls below 7. (See page 23 for more on transfusions.)

Platelets

Also called **thrombocytes** or **PLTs**, platelets are pieces of larger cells, which aid in blood clotting by collecting at the site of an injury and forming a "plug." Normal platelet values range from 140,000 to 400,000.

You can expect a drop in the platelet count seven to 14 days after the start of chemotherapy and a possible return to normal by the 21st day. If the platelet count drops below 100,000, chemotherapy **may** be postponed until the count returns to a level of 100,000 or greater.

If the platelet count drops below 50,000, supervise your child's play, ruling out contact sports or activities that increase the risk of injury, such as skateboarding, horseback riding, or bike riding. Also, pay special attention to proper mouth care (see pages 28-29).

Signs and symptoms of a low platelet count include easy bruising, bleeding from the gums or nose, tiny freckle-like spots on the skin, called petechiae, or blood in the

urine or stool. Watch for these signs, especially if the platelet count drops below 50,000, and notify your doctor. Platelet transfusions are usually not necessary unless the platelet count falls below 10,000 or there is active bleeding. (See page 23 for additional information on transfusions.)

White Blood Cells

Also known as **leukocytes** or **WBCs**, white blood cells prevent and control infections. The WBC is the total number of white blood cells circulating in the body. Normal values range from 3,500 to 15,000. While on chemotherapy, the white blood cell count is lower, usually ranging from 1,000 to 3,000.

There are many different types of white blood cells, each with a different function. Doing a **differential count** tells how many of each type exist in the bloodstream. Found by taking the total WBC and dividing it into percentages of each type, the differential includes neutrophils or polys, lymphocytes, monocytes, eosinophils, and basophils.

Because neutrophils engulf and destroy harmful bacteria, their number is most important. It determines your child's ability to fight bacterial infection and whether or not it is safe to begin chemotherapy.

An Absolute Neutrophil Count (ANC) of 1,000 or greater is **usually** needed before starting chemotherapy. If your child's ANC is less than 500, special precautions should be taken because his or her body is less able to fight infection.

IF YOUR CHILD HAS A FEVER ABOVE 101.5° FAHRENHEIT AND AN ANC BELOW 500, ADMISSION TO THE HOSPITAL FOR IV ANTIBIOTICS IS NECESSARY.

When the ANC is less than 500, try to keep your child away from sick people and avoid large indoor crowds. Limit activities to small groups of children so you can screen for illnesses. Outdoor play is recommended for group play when the ANC is below 500 because illness is transmitted less easily outdoors. During this time, we recommend that your child not go to school.

Signs and symptoms of infection include:

- Fever above 38.3 degrees Centigrade or 101.5 degrees Fahrenheit
- Pain anywhere in the body
- Redness or swelling
- Ill appearance
- Bad cough
- Persistent diarrhea or vomiting

TRANSFUSIONS FOR PEDIATRIC ONCOLOGY PATIENTS

Some Frequently-Asked Questions:

1. **Will my child or teen definitely need to be transfused?** Most patients who receive chemotherapy will need blood transfusions. The chemotherapy harms the bone marrow, the place where blood is made. Patients with leukemia usually require the most transfusions.
2. **What type of transfusions will my child receive?** There are three components to blood:
 - a) red blood cells are needed to carry oxygen and give the body energy. If the level gets too low (patient is anemic), we transfuse packed red blood cells;
 - b) platelets are needed to help clot the blood and prevent bleeding. If the level gets too low, we transfuse platelets.
 - c) white blood cells are needed to help fight infection. We generally DO NOT transfuse these as they only last a few hours in the body, so it is not practical. (See page 21 for what to do when WBCs are low.)
3. **Where do the blood products come from? How are they tested?** All the blood products for Kaiser Oakland Medical Center come from the Red Cross. All donors are volunteers. All donors are tested for syphilis, HIV virus (which causes AIDS), hepatitis B and C viruses, and cytomegalovirus. In addition, donors must have normal liver function tests.
4. **Are there any risks to the transfusions?** There are always risks, but we believe they are outweighed by the benefits. Without transfusions, we could not give life-saving chemotherapy. For example, the chance of contracting hepatitis B is only 1 in 40,000. The chance of contracting the AIDS virus is close to 1 in half a million. Much more common problems with transfusions are allergic reactions (fever, chills, rash). These are usually controlled easily with medications.
5. **Are blood products covered by my Kaiser health plan?** Yes!

6. **What if I want my child to receive blood only from me or our friends and relatives?** This is called DIRECTED DONOR BLOOD. We generally do not recommend this for several reasons:
- a) statistically, directed donor blood is no safer than volunteer blood from our blood bank;
 - b) a parent should not donate blood to his or her child in case the child later needs to undergo a bone marrow transplant; and
 - c) the Red Cross supplies us very rapidly with blood and platelets. Your child will most likely need transfusions at unpredictable times. Once we determine that his or her count is low, we usually need to transfuse within 24 hours. It would be unmanageable for you to try on such short notice to get a friend or relative to donate. Platelets are the biggest problem. Once someone donates, the platelets are only good for 5 days. This means if you want to ensure that your child receives platelets only from DIRECTED DONORS, you would have to have someone donating every 5 days. We feel it is better for you to concentrate your time and energy on caring for your child, and leave the problem of finding blood to us.
7. **What if I still want to use DIRECTED DONOR?** Ask one of your doctors or oncology nurses. We will discuss it further with you and give you the proper forms to bring to the Red Cross to have this done.
8. **How can we estimate how many transfusions our child will need?** This depends on your child's disease and the type of therapy he or she is receiving. Often children need many transfusions in the first few months and much less later on.

MEDICATION

In general, it is best to avoid unnecessary medication, including non-prescription drugs, because they may lessen the effectiveness of chemotherapy. Read all labels of non-prescription drugs to make sure they don't contain aspirin.

If you are monitoring your child for a possible fever, check with your oncology nurse or doctor before giving cold preparations or pain medications that contain acetaminophen (Tylenol). Take your child's temperature before giving the medication. If you need advice, don't hesitate to call the oncology clinic.

Reordering Your Medications

When medication is prescribed for your child, you will usually be given more than is needed for that particular course, with several refills. This is because you will need many of the same medications at another time. We have found that is helpful to bring your current calendar, with the medications for that course, to your appointments. This will allow us to answer any questions that may arise regarding how and when to administer medications to your child.

When the patient's supply of medications starts to run low, additional medications may be ordered by utilizing the Kaiser EasyFill system. This system may be used even when there are no refills listed on the medication vial. If refills are already listed, the request will be immediately sent to the pharmacy. If there are no refills left, a message will be sent to your oncologist requesting a refill. These requests are answered daily, then immediately forwarded to the pharmacy. Some medications may not be in stock and will need to be ordered. For that reason, it is best to order refills when you still have at least a one-week supply of the medication(s) remaining.

The phone number to access the Kaiser EasyFill system is listed in the Kaiser Guidebook, in the pharmacy section under each Kaiser facility. You may also call the phone number listed on the medication vial. Medication refills can be mailed to you free of charge by calling the Kaiser refill recorder at 1-888-218-6245. Allow 5-7 business days to receive your prescription by mail.

If your family fills prescriptions outside of the Kaiser system, please speak with the oncology nurse about obtaining refills.

Aspirin and Aspirin Substitutes

Avoid aspirin, which is known to prolong bleeding and is not recommended for children. Carefully check the labels of medicines for aspirin, acetylsalicylic acid, or ASA content. If it is unclear whether a medication contains aspirin, ask a pharmacist. Some trade names for aspirin include Datril, Tempra, St. Joseph's, Liquid A, Liquiprin, and Valadol. Instead, use acetaminophen. Tylenol (acetaminophen) and aspirin substitutes can also mask symptoms, delaying an accurate diagnosis and prompt treatment of infection. **Do not** use acetaminophen if your child has a fever, unless your doctor has approved it. Before giving an aspirin substitute, always check your child's temperature. Avoid use of anti-inflammatory medications such as Advil (ibuprofen) or Naprosyn (naproxen sodium). These interfere with platelet function. Please check with your oncology nurse before giving these medications.

Antiemetics

Many chemotherapy drugs cause nausea and vomiting, so drugs controlling these symptoms (**antiemetics**) are sometimes used. Antiemetics work best if begun before chemotherapy begins, and are continued around the clock during the course of drug therapy. Antiemetics are less effective if given after vomiting begins. Your doctor and nurse will instruct you regarding these medications.

Suppositories and Laxatives

Try to control constipation with diet. Large amounts of fluids, fresh fruits, raw vegetables, and food high in bulk may ease constipation. Docusate Sodium (Colace) is a stool softener available over the counter or by prescription. Milk of Magnesia -- a gentle laxative -- or mineral oil may also be used. **Don't use rectal suppositories or enemas; they can cause a tear in the rectal tissue, which can lead to a serious infection.** Talk with the oncology nurse if your child has a problem with constipation or diarrhea.

Vitamins

If your child is taking methotrexate, avoid vitamins with extra folic acid, which may interfere with the effectiveness of the drug. Vitamins free of folic acid include Poly-Vi-Sol drops.

Normal multivitamins with folic acid are fine.

SPECIAL CARE

This section outlines important information about your child or teen's general care and special needs.

Immunizations

Many immunizations that your child needs will not be given during the time of treatment. Your oncologist will let you know when to resume the schedule of immunizations.

Siblings of the cancer patient who need a polio vaccination must be given the Salk (inactivated) vaccine, which is injected into the muscle. With the Sabin (oral) vaccine, the virus is shed for about 30 days in the stools and saliva, so the virus could be transmitted to the cancer patient.

Immunizations, such as those for diphtheria, pertussis (whooping cough) and tetanus (DPT) are not "live", so they are safe.

Generally, we do not recommend immunizations while the patient is on treatment or has recently finished treatment, as they may not be effective. Since the immune system is suppressed, the patient may not make a sufficient amount of antibodies. In that case the patient is still at risk for developing certain diseases and will need to be immunized again when the immune function has returned.

Sedation

It is necessary for children to lie very still for several minutes for procedures such as spinal taps, bone marrow aspirates and biopsies. For these types of procedures, children may need to receive medication to relax them and it may put them into light sleep.

If sedation is required for your child, we recommend that he or she not eat or drink for 8 hours prior to the appointment time. Prescribed medication may be taken with a sip of water. For medications that should be taken with food (such as prednisone or Decadron), bring the morning dose of the medication with you and a small snack to give to your child after the procedure.

Bleeding

For prolonged bleeding from a cut or wound, apply direct pressure until the bleeding stops. Press a towel, handkerchief, or clean cloth firmly over the area.

You can usually control nosebleeds by firmly pressing the sides of the nose together and maintaining constant pressure for 15 minutes. Do not have your child

lie down. Have him or her sit up or lean forward to prevent swallowing blood and to slow the rate of bleeding. Call your doctor if bleeding does not stop within 30 minutes (after two 15-minute compressions). See page 228 of your *Healthwise Handbook* for more helpful information on nosebleeds.

Dental Care

Your child should visit the dentist for preventive care at least every six months. **Before any dental work — including cleaning — blood counts should be taken** to assure that he or she has an adequate number of white cells and platelets to avoid risk of infection and excessive bleeding. Ask your oncologist about antibiotics, which may be used before dental work to prevent infection. **If your child has a central line, antibiotics must be given before any dental work.**

Avoid feeding your child a diet high in sugar to prevent dental decay and an increased risk of infection. If your child does eat sweets, have him or her rinse or brush soon afterwards. Avoid prolonged exposure to sweets such as hard candies, suckers, or sugared gum. For infants, limit bottles containing fruit juice to no more than 10 or 15 minutes.

Mouth Care

Chemotherapy may temporarily cause changes in the mouth, leading to mouth sores or infection. Bleeding may occur around the gums, especially if they're brushed too vigorously. Good mouth care can help prevent mouth sores and infections, and gentle cleaning can help prevent bleeding. If your child is having chemotherapy, follow these basic guidelines:

Brushing

- Brush the teeth after each meal and before bed.
- Use a toothpaste containing fluoride.
- Use a soft toothbrush. Soften the toothbrush further with hot water, if desired.
- **When ANC is 500 or less, use a sponge-like toothette or gauze pad.**
- Get a new toothbrush once a month and after any infections.
- If gums bleed, switch to a sponge toothette or just rinse the mouth with Peridex or a solution of one teaspoon salt and one teaspoon baking soda, mixed in one quart of warm water.
- Don't use toothpicks, dental floss, a firm toothbrush, or a Waterpik.

Peridex Mouth Rinse

For patients on chemotherapy that can cause mouth sores:

- Have your child rinse with Peridex (for 30 seconds, if possible) four times a day after brushing
- Have him or her spit out the Peridex after rinsing.
- Do not feed him or her anything for 30 minutes after rinsing with Peridex to maximize the effectiveness of the rinse.
- For children less than three years old, use a toothette soaked in Peridex to paint your child's teeth, gums and mouth.

"Magic" Mouth Rinse

If your child has mouth sores, Peridex mouth rinse may be too irritating to use. Discontinue the rinses with Peridex until the mouth sores have healed. "Magic" mouth rinse is a mixture of Benadryl, nystatin and Maalox (some pharmacies may use slightly different formulas).

It is very important to swish the Magic mouth rinse around and swallow it. Mouth sores can develop anywhere along the gastrointestinal tract and the Magic mouth rinse is soothing to any sores that your child may have. It helps to prevent and/or treat thrush (an overgrowth of yeast in the mouth).

Other Mouth Rinses

- It may be soothing for your child to rinse with a mouth rinse made up of one teaspoon salt and one teaspoon of baking soda in one quart of water.
- Do not use commercial mouth rinses because they're too harsh; most contain alcohol, which causes a burning sensation.

Call Your Doctor If:

- Any gum bleeding doesn't stop.
- White spots appear (these are the first signs of thrush, an oral infection).
- Pain or mouth sores prevent eating or drinking.

DENTAL PROCEDURES

We encourage regular, twice yearly dental examinations. Cleaning, scaling, fillings, or extractions should not be done if the child is thrombocytopenic (platelet count below 100,000/m²) or neutropenic (absolute neutrophil count of less than 1,000).

We recommend antibiotic prophylaxis as follows:

Standard Doses:

Amoxicillin 50 mg/Kg 1 hr. before procedure

If allergic to Penicillin:

Clindamycin 20 mg/Kg 1 hr before procedure

Cephalexin or Cefadroxil 50mg/Kg 1 hr before procedure

Azithromycin or Clarithromycin 15mg/Kg 1 hr before procedure

Maximum Doses — Do Not Exceed:

Amoxicillin 2.0 gm 1 hr before procedure

Clindamycin 600 mg 1 hr before procedure

Cephalexin or Cefadroxil 2.0 gm 1 hr before procedure

Azithromycin or Clarithromycin 500 mg 1 hr before procedure

NUTRITION

As a result of radiation or chemotherapy, your child may experience nausea, vomiting, stomach and intestinal disorders, or diarrhea. Try the following tips to assure adequate protein and calories, which are necessary to rebuild new and healthy tissues.

Smaller, more frequent meals and non-greasy foods may be more appealing if your child is nauseated. If your child is vomiting, cold foods such as popsicles, small amounts of fluids (7-up, juice, broth) taken frequently, and high-protein foods may be appealing.

A nutritionist is available to all families. Ask your doctor or nurse if you would like to set up an appointment.

Refer to your *Healthwise Handbook* for more information on home treatment of vomiting, dehydration, constipation and diarrhea. Always call the pediatric oncology nurse if you have any concerns about your child's health.

ADOLESCENTS AND CANCER TREATMENT

As children grow into adolescence, many changes begin to take place in their bodies. For the teen that is undergoing treatment for cancer (chemotherapy and/or radiation), some changes may be perfectly normal. Others may require prompt medical intervention.

It is very important that your teen be encouraged to discuss any unusual symptoms with you. Bleeding, excessive or unusual pain, vaginal or penile discharge, especially if foul smelling or irritating, are symptoms that require immediate medical attention. Please call the oncology clinic and speak with the advice nurse. You may be asked to bring your teen to the oncology clinic, or you may be able to see a local health care provider.

Preventing injuries and infections is as important as seeking prompt medical attention for them. Teens undergoing cancer treatment will frequently experience neutropenia (an absolute neutrophil count of 500 or less) and/or thrombocytopenia (a low platelet count). During these times, the teen is at particularly high risk for injury and/or infections.

For the teen that is sexually active, it is extremely important that steps be taken to prevent injury and/or transmission of infection. **Nothing** (including tampons, intrauterine devices, sexual objects, etc.) should be inserted in the vagina or rectum when blood counts are low. Indeed, nothing should ever be inserted in the rectum at all, as this very delicate tissue can easily tear and become infected. Sexual intercourse should also be avoided when the counts are low.

Body art and jewelry can be very popular in this age group, and special precautions should be taken. Body piercing and tattoos should only be done when the ANC and platelet count are at a sufficient level. Piercing and tattoos should only be done at a reputable establishment that is known for using sterile equipment. Please consult the pediatric oncology advice nurse before having these procedures done.

You may have been informed that some chemotherapy agents have been known to cause sterility. Whether your teen's ability to become pregnant (or cause someone else to become pregnant), is decreased or not, protection and contraception are still very important. Barrier devices, such as condoms, help to prevent the spread of sexually transmitted diseases. The use of contraceptives, such as Depo-Provera injections, birth control pills, contraceptive foams or gels, help to insure that an unplanned pregnancy does not occur. In addition, sexual intercourse should not take place when your teen has a low neutrophil and/or platelet count.

Smoking, alcohol and drug use are not healthy for any teen, but it is particularly important that the teen undergoing cancer treatment try to stay as healthy as possible. Treatment with radiation and/or chemotherapy places a tremendous stress on the body. In addition, the teen's body is undergoing significant growth and change. Putting toxins in the body only makes it much harder for the teen to feel good and recover from each course of chemotherapy. It can also intensify the potential side effects of the treatment. Encourage your teen to take an active part in maintaining his or her health by avoiding alcohol, tobacco and drugs.

GOING HOME

Making Adjustments

Going home from the hospital is the first step toward "getting back to normal." Now your family develops new ways of incorporating your child and the illness into your family life. Some of your concerns may be addressed below.

Activities

In general, children with cancer can participate in whatever activities they enjoy. We feel that each child should be encouraged to live as normal and active a life as possible. Expecting this from your child can encourage him or her to achieve it.

If your child feels well, there is no need to insist on extra rest. Some days, however, your child may tire more easily, especially on days when he or she is receiving tests or treatment. When platelet counts are decreased (below 50,000), restrict your child's activities to avoid knocks and bumps, which might cause excessive bruising or bleeding.

SCHOOL

Notify the school shortly after the diagnosis to help keep them informed. This may allow your child or teen to receive letters and support from teachers and classmates.

The social worker can provide guidance as you plan for your child's continued education during treatment. Some children may require home tutoring, because the treatment can often be quite difficult in the beginning.

Before your child returns to school, the social worker can collaborate with you to develop a plan to support your child's smooth transition. The child life specialist may be involved in this process. Also, the oncology social worker may be able to help facilitate the process to insure that your child's needs are met. Meeting with the principal, counselor, nurse or teacher can also help ease the transition.

Returning to school can improve your child's self-confidence and is a concrete sign of his or her return to normalcy. After we have given you the "okay," encourage your child to attend school as usual.

Encourage your child to participate as much as he or she feels able. Don't be alarmed if your child tires easily. Most schools are very understanding and would be willing to allow him or her to attend school part-time or to enroll in a modified education program. Talk with his or her teacher and/or principal if you have any questions or concerns.

Your child may be anxious about returning to school and uneasy about classmates' responses to his or her changed appearance. Don't dismiss these fears. Discuss with him or her how to handle them. Be firm and optimistic about the return to school. If the transition back to school is not going smoothly, or if you just want to inquire about school-related issues, please talk to the doctor, nurse, social worker or child life specialist.

LOCAL PHYSICIANS

We will make sure that your family physician has up-to-date information about your child's course and treatment plans. Keep in touch with your family physician, even though your child is receiving oncology care at Kaiser Oakland. Your local physician is the one who is closest to you and who will be responsible for your child's general health care.

It is very helpful to have a physician nearby who is familiar with your child. They may be able to see him or her for minor health concerns such as a suspected ear infection, cough or rash, and can help you avoid seeing the pediatric oncologist here in Oakland for very minor concerns.

If you have any questions about whether your child should be seen by his or her local pediatrician or a pediatric oncologist, please call and ask to speak with the pediatric oncology nurse.

SUPPORTIVE SERVICES

A close-knit team of caregivers within the pediatric oncology clinic is available to you and your child throughout the course of treatment. Among those you may look to for guidance and support are the clinical social worker, the child life specialist, and the pediatric psychologist. These specialists work together to provide your family with counseling and resource assistance to enable you, your child, and your family to cope in the best possible way.

The Social Worker

The clinical social worker on the team is here to assist you in coping with the many practical, psychological and social challenges arising from having a child with cancer. All families will routinely be seen by the oncology social worker, beginning at the time of diagnosis, to help you identify possible areas in your family life that may be affected by the diagnosis.

The social worker has been described as a counselor, resource-finder, problem-solver, communication helper, bureaucratic guerrilla, or just a "friend on the inside." Any concern related to the psychological, practical, financial or social well being of your child or family may be discussed with the social worker, who is an important member of the pediatric oncology team.

Short-term or in-depth counseling may be provided to families on an as-needed basis by the social worker or psychologist on our team. At times it is also helpful for individual family members to meet with a mental health professional for assistance during or after the treatment period. Involvement in support groups offered through the clinic or with the nearby community may provide an additional basis of help and guidance.

The Child Life Specialist

A child life specialist is available a) to promote your child or adolescent's growth and development while in a health care setting, and b) to help your child or adolescent cope with the stress and anxiety of the overall health care experience (e.g., clinic visits, hospitalization).

A child life specialist can help in the following ways:

- ◆ Prepare your child/adolescent for surgery and procedures using age-appropriate language. Provide support during procedures, as necessary and as requested.
- ◆ Provide therapeutic play and art-based activities to encourage free expression and normalize the hospital or clinic environment.
- ◆ Identify your child/adolescent's concerns and communicate unique coping mechanisms to other health staff to facilitate treatment.
- ◆ Provide emotional support to siblings, including therapeutic play and art-based activities.
- ◆ Meet with your child's classmates to explain your child's absence from school, treatment plan, side effects, etc.

In Oakland, call Kim Sherman, Licensed Clinical Social Worker, Pat Frasca, Certified Child Life Specialist or Jeanne Courtney, Licensed Clinical Social Worker at (510) 752-6592.

FAMILY SUPPORT

Because a diagnosis of childhood cancer affects the entire family, we extend our support to you, your other children, and to others who are closely connected to your child.

This section of your handbook shares information we have learned about the challenges, needs and strengths of families in similar situations. It includes:

- Suggestions on emotionally supporting your child or teen;
- Age-related issues and what you can do to help;
- Parental or Primary Care Giver Issues;
- Sibling concerns; and
- Grandparent Issues.

We hope this section helps you realize that, although each child and family are unique, many issues are common to families who have a child or teen with cancer. We encourage you to talk with the members of our team regarding your concerns.

EMOTIONALLY SUPPORTING YOUR CHILD OR TEEN

A diagnosis of a serious illness such as cancer brings up many issues for a child or adolescent. Questions such as "why me?" "what did I do wrong?", "what will happen to me?" are common. Your child or teen may experience times of disbelief, anxiety, fear, sadness and anger. These feelings are normal.

Children will often verbalize their concerns and should be encouraged to talk about how they feel. It is important to answer your child's questions as openly and honestly as you can. By giving your child accurate information at a level that he or she can understand, you are providing a sense of control. In addition, you are reinforcing your child's trust in you as a parent or primary caregiver.

Your child or adolescent may not be able to talk about his or her feelings, but may express them in subtle, nonverbal ways. Some children might have nightmares or resume behaviors they have previously outgrown, such as bedwetting. Others might show a decline in school performance or begin to have behavioral problems. Even though your child might not be able to talk about his or her feelings, you can still encourage self-expression. Play, drawing, and role-playing with puppets, for example, are comfortable ways for children to express themselves. These activities also may provide you with information regarding your child's understanding of his or her diagnosis and treatment plan.

Although cancer will change your child's life for a time, he or she will still have many of the same emotional needs as other young people. You can help by encouraging your child to continue a "normal" life as much as possible. Here are a few suggestions on ways to help your child during diagnosis and treatment:

- Be honest when describing procedures and treatments, making sure that your explanations are appropriate for your child's developmental age. Hiding the truth often results in a loss of trust.
- Acknowledge your child's feelings. Letting your child know that it is okay to feel sad and cry provides an outlet for his or her emotions.
- Tell your child or teen that cancer is not a punishment, and there was nothing he or she could have done to prevent it.
- Don't be afraid to ask your child questions. By asking, you are providing him or her with opportunities for expressing feelings or asking questions.
- When you don't know the answer to a question, it is okay to say something like "I don't know, but I will ask someone who might know the answer to your question".

- Continue to set limits. During this period, your child may challenge the limits previously set. Although a natural tendency is to let ill children “bend the rules”, this sudden change may make him or her more anxious and imagine that things are worse than they really are.
- Offer realistic choices, when possible. Choices allow your child to have a sense of control and grow in spite of necessary restrictions.
- Recognize that children, like adults, have good days and not-so-good days.
- Take some time each day to love and enjoy each other.
- Parental grief is a normal response when a child experiences a serious illness. Be gentle with yourself and your child and find ways to connect with hope and optimism.
- Remember that your health care team is available for support and questions.

In the event that a child life specialist or volunteer is not available to provide therapeutic play or art-based activities, please try to prepare for your visits to the clinic or hospital. For example, while a multitude of videos are available in the clinic, your child may prefer to play with something from home, read a special magazine, or even do some homework.

While a diagnosis of childhood cancer is serious and often overwhelming, please know that your child also may have some positive experiences, including becoming more independent, and developing new inner strengths and coping skills.

AGE-RELATED ISSUES

How your child reacts to the stress of a serious illness depends on his or her age and developmental level, as well as to your response to various actions and behaviors. Below is an overview of how children typically react at certain ages and what you can do to help.

Infants (birth to 12 months)

Infancy is a period of rapid growth. The infant progresses from instinctual reflexes to coordinated and controlled muscle movements. Infants are totally dependent on their primary caregivers (e.g. parents) for love and nurturance. An important task for infants is to learn to trust. In order for infants to grow and develop, they need to be able to explore their environment. Children progress developmentally by touching, feeling, tasting, hearing, and looking. In a hospital, for example, it becomes an important challenge to give infants enough variety so they can continue to grow and thrive.

Typical Reactions and Concerns

- Irritability
- Not eating or sleeping well
- Crying or clinging to parents
- Little tolerance of unmet needs
- Fear of strangers (starts at 6 months)
- Sensitive to abnormal stimulation (e.g. bright lights, loud noises)
- Not holding still for procedures

How You Can Help

- Hold and cuddle your child. Talk in a gentle and soothing manner.
- Play soft lullaby music.
- Use tactile stimulation (e.g. human touch, soft blanket) to comfort your child during and after procedures.
- When giving oral medications, hold your baby, restrain arms and legs, and use a syringe to squirt small amounts into the back of the mouth, close to the cheek.

If your child is hospitalized:

- Try to keep a consistent schedule for feeding, play time, and naps.
- Stay with your child as much as possible. If possible, take turns with other familiar caregivers.
- If you can't stay with your child, provide known tape recorded voices and pictures.
- Bring toys, blankets or other comforting objects from home.
- Offer stimulation during awake, alert times with calm, rhythmic movements.
- Participate in your child's care if you feel comfortable doing so.

Toddlers (1 to 3 years old)

In general, toddlers are active and very curious. They learn about their surroundings as they walk, run, and play. A sense of independence and autonomy awakens as they learn to do things for themselves. This struggle between independence and dependence on parents sometimes causes behaviors such as defiance and temper tantrums.

Typical Reactions and Concerns

- Increased need for autonomy
- More assertive
- Increased independence - saying "no"
- Understands more words than can express or speak
- Not holding still for procedures
- Loss of newly acquired skills
- Fear of strangers
- Fear of separation and abandonment
- Fear of the dark and loud noises
- Not eating or sleeping well.
- Crying and clinging to parents
- Likes rituals -- doesn't like changes

How You Can Help

- Try to keep your child's schedule as consistent as possible. Tell your child about upcoming clinic or hospital visits. Because young children live in the present, tell your child no sooner than the morning you are leaving.
- Provide opportunities for limited and simple choices when available (e.g. "would you like to take your medicine before your bath or after?")
- When giving oral medications, sit your child in your lap, restrain arms and legs, and use a syringe to squirt small amounts into the back of the mouth, close to cheek.
- Actively involve your child in treatment, when appropriate (e.g. press start button on blood pressure machine).
- Be honest about what your child will feel and what will hurt. Use non-threatening, familiar, and descriptive words.
- Provide brief details of what your child will hear, see, taste, smell.
- Help your child "practice" procedures using stuffed animal or dolls. Talk to your child life specialist or other members of the health care team for more information.
- Try distracting your child with songs, stories, or interesting objects.
- Let your child know when the painful or uncomfortable part of the procedure is over.
- Give positive reinforcement for trying and for cooperative behavior.
- Set limits and maintain discipline.
- Help your child maintain independence appropriate for his or her age.
- Invite the assistance of your health care team in your efforts to problem-solve on behalf of your child. Time-limited counseling with the clinical social worker or child life specialist may be useful.

If your child is hospitalized:

- Stay with your child as much as possible. Take turns with other familiar caregivers.
- Let your child know when you are leaving and when you are coming back. Use familiar events, such as a mealtime or bedtime to note your time.
- If you can't stay with your child, provide known tape recorded voices and pictures.
- Bring toys, blankets or other comforting objects from home to make transition easier.

Preschoolers (3 to 5 years old)

Children this age spend most of their waking hours at play, acquiring the ideas, skills, and values that are important for growing up. Preschoolers are working at gaining more control in their worlds. They are beginning to form an identity separate from the family as their intellectual abilities and social world expand. In general, they have an active imagination, ideas that are limited by their own viewpoint, and have difficulty distinguishing between fantasy and reality. Their ideas may be illogical, and they often believe two events are related because they happened at the same time.

Typical Reactions and Concerns

- Crying and clinging to parents
- Believing they became ill because they were "bad" and are being punished
- Loss of newly acquired skills
- Fear of unknown events
- Not holding still for procedures
- Ignoring parents, remaining silent and withdrawn
- Literal interpretation of language
- Fears loss of all blood (offer Band-Aids)

How You Can Help

- During procedures or pain episodes, try: 1) Distracting your child with songs, stories (real or imagery), or interesting objects; 2) Matching your child's breathing rate and then gradually slowing it down; 3) Counting or repetitive positive self talk.
- Help your child "practice" procedures using stuffed animal or dolls. Talk to your child life specialist or other member of the health care team for more information.
- Let your child know when the painful or uncomfortable part of the procedure is over.
- Give positive reinforcement for trying and for cooperative behavior.
- Reassure your child that he or she is not to blame for illness or hospitalization. Remind your child that treatment and procedures are not a form of punishment.
- Be honest about what your child will feel and what will hurt. Use non-threatening, familiar, and descriptive words.
- Provide opportunities for limited and simple choices when available (e.g. "would you like to take your medicine before your bath or after?")
- Actively involve child in treatment, when appropriate (e.g. press start button on blood pressure machine)
- Provide brief details of what the child will hear, see, taste, smell.
- Try to keep your child's schedule as consistent as possible. Tell your child about upcoming clinic or hospital visits no sooner than one or two days before for younger pre-schoolers.
- Set limits and maintain discipline.
- Help your child maintain independence appropriate for his or her age.
- Invite the assistance of your health care team in your efforts to problem-solve on behalf of your child. Time-limited counseling with the clinical social worker or child life specialist may be useful.

If your child is hospitalized:

- Stay with your child as much as possible. Let your child know when you are leaving and returning. Use familiar events, such as a mealtime or bedtime to note the time.
- If you can't stay with your child, provide known tape recorded voices and pictures. When you are gone, leave something of yours with your child.
- Bring toys, books, blankets or other comforting objects from home to ease transition.

School-Age Children (6 to 12 years old)

School-age children tend to define themselves through the eyes of their parents and family. During these first few years in school however, their friends are becoming increasingly important. Through friendships, children become more social and learn about competition and leadership. School-age children, generally, are able to focus their thinking on the facts they perceive in the world, and they are starting to think more logically and objectively. They are able to define illness as a combination of symptoms and understand the relationship between cause and effect.

Typical Reactions and Concerns

- Feeling out of control and dependent
- Loss of status in school or peer group
- Feeling different
- Compromised body- or self- image
- Being quiet and withdrawn
- Fear of surgery and anesthesia
- Feeling guilty about cause of illness
- Fear of disability and death
- Acting younger than actual age
- Hesitant to reveal fears

How You Can Help

- During procedures or pain episodes, try: 1) Distracting your child with music or videos; 2) Guided imagery (imagine favorite place); 3) Matching your child's breathing rate and then gradually slowing it down; 3) Counting or repetitive positive self talk.
- Help your child "practice" procedures using stuffed animal or dolls. Talk to your child life specialist or other member of the health care team for more information.
- Allow child to participate in own care.
- Encourage verbalization of thoughts and feelings.
- Communicate openly about illness, treatment, and prognosis.
- Give positive reinforcement for trying and for cooperative behavior.
- Reassure your child that he or she is not to blame for illness or hospitalization. Remind your child that treatment and painful procedures are not a form of punishment.
- Give honest and repeated explanations about procedures and other events. Use non-threatening, familiar, and descriptive words.
- Promote a sense of responsibility and independence.
- Respect - do not minimize - your child's fears.
- Protect privacy. Everyone needs his or her own physical and emotional space.
- Offer realistic choices.
- Use positive suggestions and non-threatening language.
- Encourage continuation of schoolwork and contact with classmates and friends.
- Set limits and maintain discipline.
- Invite the assistance of your health care team in your efforts to problem-solve on behalf of your child. Time-limited counseling with the clinical social worker or child life specialist may be useful.
- Consider involving your child in a peer support group or the specialized camp program for patients. Ask the clinical social worker for additional information about these resources.

Adolescents (12 to 18 years old)

Teenagers undergo dramatic physical and mental changes in a short period of time. At no other time in life are feelings about the self so closely tied to feelings about the body. The most important mental change is the growth in capacity for abstract thinking. At the same time comes the realization that choices need to be made in the spheres of education and relationships with friends. Identity problems, sexuality, and conflicts over independence complicate the problems of adolescents when they are ill. Adolescents want to be kept informed and need to understand their illness, prognosis, and treatment plan.

Typical Reactions and Concerns

- Feeling out of control and dependent
- Denial, refusing to discuss illness
- Non-compliance with medication
- Focusing on side effects of meds
- Separation or rejection of peer group
- Feeling of invincibility
- Loss of privacy
- Developing a poor self-image
- Strong but ambivalent ties to parents
- Worrying about the future
- Fear of failure in school
- Irritable, moody, impulsive, overreactive, unpredictable, withdrawn

How You Can Help

- During procedures or pain episodes, try: 1) Distracting your child with music, videos; 2) Guided imagery (imagine favorite place); 3) Matching your child's breathing rate and then gradually slowing it down; 4) Counting or repetitive positive self talk.
- Provide schedule to normalize environment.
- Encourage peer interaction (e.g. visits, telephone calls and e-mail).
- Involve your teenager in care decisions. Respond to long-term concerns.
- Respect autonomy and independence.
- Set consistent, reasonable limits.
- Encourage continuation of schoolwork.
- Reinforce issues of confidentiality.
- Offer realistic choices and control.
- Be honest about treatment and procedures. Be specific with details. Anxiety may prevent asking for information.
- Protect privacy. Everyone needs their own physical and emotional space.

- Strengthen feelings of uniqueness.
- Invite the assistance of your health care team in your efforts to problem-solve on behalf of your child. Time-limited counseling with the clinical social worker or child life specialist may be useful.
- Consider involving your teen in a peer support group or the specialized camp program for patients. Ask the clinical social worker for additional information about these resources.

Parents and Other Primary Caregivers

The diagnosis of cancer in a child comes typically as a profound shock to parents. Most all parents experience a flood of fear and other distressing emotions during this time. There may be a sense of disbelief with feelings of helplessness and trouble thinking clearly. You may have difficulty sleeping and eating, understanding what is said to you, or remembering what you're told.

Other common reactions in parents include denial, anger, guilt and grief. All of these responses are normal in such a time of crisis.

Because the sudden burdens with a diagnosis of this kind are so great, it is important that you exercise equally great gentleness and care with yourself. Invite the support of loved ones and friends, and look to the active guidance of your health care team.

Fear of the unknown can be paralyzing. Take action and become involved in your child's care. Learn about the disease and treatment. Realize your central importance as the primary caregiver of your child and have confidence in your ability to assist your youngster with the challenges ahead. You know your child best and can play a powerful role in affecting how all of you in the family cope through this crisis.

There are many resources available to you as your family begins to address the many challenges associated with this diagnosis. The pediatric oncology team can advise you on the wide assortment of services and support that may be helpful.

Single and Divorced Parents

Single or divorced parents face even greater challenges. In addition to the many new tasks required, the single parent often feels more alone than usual. For extra support, rely on relationships with friends, family, or counselors.

Although not unique, problems between divorced parents may be intensified by your child's illness. If you are both involved, you will need to cooperate on major decisions and tasks. For the parent without custody, cancer may be surprisingly difficult because of anger, frustration, or guilt about not being more involved. The pediatric oncology social worker is willing to discuss these issues and explore alternatives for resolving problems.

Siblings

Much of what is true for the sick child and the parents is true for brothers and sisters, as well. They also feel anger, fear, sadness, and a sense of loss. However, siblings have unique concerns related to their role as "healthy" brothers or sisters.

Some concerns revolve around the illness. Children or teens may feel they caused the cancer by fighting, wishing bad thoughts, or being jealous. Or, they may believe they can catch cancer like they catch colds. Give repeated assurances about these concerns and encourage them to ask questions. Explain the facts about cancer, keeping in mind the age and maturity of each child.

Other concerns involve changes in the family. Sometimes children are resentful or jealous over extra time and attention given the child with cancer. Even though they may understand the reason for these changes, they may still feel forgotten or less loved. At the same time, they may not want to burden their parents with their own needs. Being the healthy one may bring on guilt about complaining or fighting with the sick child.

Another stress may be a fear of the hospital. If your child is hospitalized and your other children are unable to visit for whatever reason, they may imagine what happens at the hospital and may experience related fears. Siblings are encouraged to visit if they are in good health and have not recently been exposed to chicken pox. No age restriction exists for visiting sisters and brothers at Kaiser Oakland. Other hospitals may have different visiting policies.

The best way to help your other children is to listen and talk with them about their conflicting feelings. Give frequent assurances that these feelings are normal -- that other brothers and sisters have similar feelings. Include them in the treatment as much as possible and praise them for their ability to understand and help their brother or sister. Try to set aside time that you can spend alone with the healthy siblings to help offset the extra time you spend with the sick child.

If your child is hospitalized, try to spend some time at home with your other children. If this is not possible, call the siblings daily at a regularly scheduled time. You can even send home art work or pictures of the sister or brother who is hospitalized, as well as other things at the hospital (e.g. patient room, playroom).

The pediatric oncology team has several booklets you may want to read with your other children. Feel free to talk with your doctor, nurse, social worker or child life specialist about your concerns. Also, during the summer there is a camp just for siblings. See the section below on Northern California Oncology Camp.

Grandparents and Other Close Family Members

Grandparents, no matter how near or far away, may share the intense feelings of helplessness. Try to keep them informed. Don't "protect" them by withholding information, which only adds to feelings of frustration. Giving them responsibilities such as child care or trips to the hospital may help them feel more in control. They may also wish to communicate with the doctor or staff.

Northern California Oncology Camp

One of the most enjoyable aspects of the pediatric oncology program is summer camp, developed in cooperation with other hospitals in Northern California. Children ages 6 to 18 have the opportunity to attend oncology and sibling camp at Camp Okizu, located 70 miles north of Sacramento at Berry Creek.

For Additional Emotional Support

A parent support network at Kaiser Oakland give parents the opportunity to talk things over with other parents in similar situations. If you wish to talk with others individually, be sure to ask any member of the pediatric oncology team for referrals.

Resources are available at your request.

COMPLEMENTARY TREATMENT

Many parents and caregivers of children or teens diagnosed with cancer become interested in the subject of complementary treatment. The term "complementary" refers to treatment approaches that historically have been considered to be outside the mainstream of conventional medical care. Examples of complementary or adjunctive therapies are acupuncture, herbal and specialized nutritional programs, yoga, massage, meditation and imagery.

The philosophy of treatment shared by members of the pediatric oncology team here at Kaiser embraces a broad-based approach to the goal of healing and recovery from cancer. While the best of conventional therapies, such as chemotherapy, radiation and surgery, is emphasized as the basis for treatment of childhood cancer, we believe that the health and well-being of patients are best served by an open dialogue with families that includes focus upon the alternative therapies as well.

The pediatric oncology physicians and staff encourage discussion of complementary approaches that you may wish to consider. In addition, the clinical social worker can advise you on sources of information and guidance on this subject.

The boom in information provided through computer on-line services offers plentiful references for parents to explore, as does a wealth of printed materials. In fact, such an abundance of information is available that parents can easily feel overwhelmed, and may experience confusion over what references or claims can be trusted. Again, our staff welcomes the opportunity to provide guidance to you in your efforts to support your child's recovery and long-term wellness, taking this area of exploration into full account.

Alternative or complementary treatment may interfere with efficacy of your child's treatment, therefore it is important to discuss any supplements you may be considering with your oncologist.

WHEN TO CALL US

Please advise us or your primary doctor if any of the following situations should arise. They may be emergencies.

- A fever of 101.5 degrees Fahrenheit (38.3 degrees Centigrade) or more. Your child will need to see a physician and have blood counts done.
- Exposure to chicken pox or measles, if he or she has not had the illness before.
- Persistent headaches, or pain or discomfort anywhere in the body.
- Difficulty walking or bending.
- Pain during urination or bowel movements.
- Reddened or swollen areas.
- Persistent vomiting with unusual frequency (unable to keep anything down).
- Blurred or double vision.
- Blood in the stools (red or black), in urine (pink, red, or brown), in vomit (red or brown, like coffee grounds).
- Nosebleeds or multiple bruises.
- Unusually severe side effects after treatment, such as severe mouth sores, constipation with abdominal discomfort or distention, persistent diarrhea, and easy bruising.
- Any problems with Broviac or Broviac site.
- Any incident of shaking and/or chills.

Also, notify us before any immunization or dental care.

For **emergencies** that come up after clinic hours or on weekends or holidays, one of the hematology/oncology doctors is always on call. The doctor on call can give you the necessary medical advice your child requires.

Please be advised, the doctor on call is **NOT** at the hospital or clinic. He or she does not have access to the computer or to your child's chart. This is normally a time the doctor would be off work, but to provide quality care to our patients, someone is available by pager for unexpected emergencies.

Do not call after hours or on weekends or holidays for routine issues like:

- Medication refills
- Laboratory results
- Appointment cancellation or re-scheduling
- Requests for letters, forms
- Routine pediatric care.

Please wait until the clinic re-opens and an advice nurse can assist you.

SOME RECORDS/CALENDAR

You are an important member of your child's oncology care team, so you must keep a brief record of your child's health history and treatments. You will have many dates, appointments, treatments, and observations to keep track of. Keeping a calendar with this handbook may make this task easier because you'll have it all in one place to be easily recalled and accurately dated. Because it's often difficult to remember things under stress, try to get in the habit of recording information in your calendar book as it occurs.

Please bring your calendar to every appointment. Come prepared to discuss the medication that your child is currently taking. Bringing a written record, or the actual medication vials themselves, is very important. This is especially important if you fill your prescriptions at a non-Kaiser pharmacy.

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It was revised in 2003 by Nomalanga Akintunde, RN, CPON and Laurie Chapman, RN, CPON, and the Pediatric Oncology team.

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