

A Guide for Families of Children with Cancer



MassGeneral Hospital
for Children[™]

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We dedicate this booklet to our patients and their families. It is their continued strength and courage that have inspired us.

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introduction

THE DIAGNOSIS OF CANCER is a crisis for a family. It is normal to feel shocked, numb, worried, angry and helpless. In a short period of time there is much to learn and many decisions to be made.

It is our hope that this booklet will provide you with important information about childhood cancer and its treatment. You may find it helpful throughout the course of treatment to keep your own notes or journal in order to help you remember blood test results, appointments, medications and questions you need answered.

In the days ahead, you will be confronted with new procedures and new words. This book explains the procedures and defines the words. Please take a minute to leaf through the text before you begin reading. Most of the new words are explained and there also is a glossary starting on the last pages. Other information, such as types of treatment plans or advice about home care, is placed in sections to allow quick use of the booklet.

You should read through the entire booklet at least once to be aware of what it contains, but you do not need to remember everything. Instead, the sections of the book will allow you to find the information as you need it.

The staff in the hospital and in the oncology clinic are always willing to answer questions, share information and lend support.

Parents' Role

You, as a parent, know your child better than anyone else. MassGeneral Hospital for Children practices family-centered care. You are an integral part of the treatment team. We encourage you and other family members to be involved as much as possible in your child's care.

the health care treatment team

YOU AND YOUR FAMILY are part of a team. The goal of the team is to work together in planning treatment and caring for your child. It is important to ask questions and share your opinions and feelings. The professionals who will help care for your child are listed below:

Pediatric oncologist This doctor specializes in caring for children with cancer. He/she will coordinate your child's overall treatment plan and will care for your child in the outpatient unit and in the hospital. He/she will work with all care or treatment team members to insure safe, comprehensive care.

Pediatric oncology nurse practitioner The pediatric oncology nurse practitioner is an advanced practice nurse who will assess and manage your child's progress during and after treatment. He/she will guide you throughout the process with a focus on health promotion and disease prevention. The nurse practitioner works closely with the physicians and nurses to insure optimal care of you/your child.

Primary nurse Your child will have a primary nurse while he/she is in the hospital. He/she will set up a daily plan of care for your child and work with the other care or treatment team members. Your primary nurse will support you and your child during hospitalizations. Other nurses will care for your child when the primary nurse is not on duty; they will follow the overall plan of care.

Pediatric oncology nurses Your oncology nurse will care for your child while he/she is in the outpatient unit. In this setting you and your child will continue to receive treatments, education and support. Your oncology nurse will also follow your child during hospitalizations and be available to answer questions regarding your child's care.

Social worker A social worker is available to help your child and family cope with the stress that can occur when a family member has cancer. He/she lends support by listening, helping with financial and insurance issues and can direct you to other resources. The social worker is available to you throughout the course of treatment, both in the hospital and in the clinic.

Psychiatrist

The psychiatrist can provide support for children, adolescents and parents who are dealing with the stress of cancer. Often it is helpful for your child and you to have someone to talk with other than family. The psychiatrist can see your child/you in the hospital and as an outpatient.

Dietician

The dietician monitors your child's nutritional needs and provides dietary guidance. Chemotherapy often causes loss of appetite and the dietician can suggest helpful ways to increase calories and maintain good nutrition.

Physical therapist

The physical therapist will work with your child to help gain function and strength, and to help him/her learn how to walk with assistive devices if necessary. The physical therapist works closely with the treatment team and follows your child's progress throughout the time of treatment.

Orthopaedic surgeon

This doctor specializes in surgery of the musculoskeletal system. He/she works with the medical team in planning treatment for children with bone tumors.

Pediatric surgeon

He/she works in partnership with the other physicians in making decisions about surgery, biopsy or placement of a central venous access device.

Neurosurgeon

This doctor specializes in surgery of the brain and its related tissues, such as the spinal column. He/she works with medical team in planning treatment for children with brain tumors.

Radiation oncologist

This doctor specializes in treatment with radiation therapy. He/she plans the type, dose, and duration of radiation, and works together with the other physicians to coordinate the care of your child.

- Interns and residents** These are doctors who are undergoing training in a medical specialty, such as pediatrics or surgery. They work with your child's oncologist and other senior physicians to provide the day-to-day care while your child is hospitalized.
- Patient care assistants** This member of the team works under the direction of your nurse and assists the staff in providing care to your child.
- Child life specialist** The child life specialist provides recreational activities and play therapy to help your child understand and cope with medical procedures, illness and hospitalization. The child life specialist has special training in growth and development and will help your child continue to progress developmentally through social activities, projects and entertainment. The recreation or playroom is a safe place for children to play, relax and socialize during hospitalization. Diversion through music, crafts and cooking helps reduce stress.
- Chaplain service** Each chaplain serves as a member of the health care team, working closely with others who care for your child and you. Spiritual care is available to people of all faiths and to those of no religious affiliation. Chaplains are available 24 hours a day for pastoral emergencies.

Please refer to the *The A, B, C's of Hospitalization—A Parent's Guide to the MassGeneral Hospital for Children* for more information about other professionals and services in the hospital.

family changes

THE DIAGNOSIS OF CANCER in a child affects every member of a family. Routines are often disrupted and separations occur because of hospitalization or clinic visits. Parents feel worried, especially at the time of diagnosis, and children in the family sense this. It is stressful to maintain work schedules and usual family obligations while caring for a sick child. However, it is important to maintain as much of a normal family routine as possible.

OFTEN, PARENTS CAN GET SUPPORT BY:

- talking with a social worker
- accepting help from relatives and friends for baby-sitting, cooking or helping with other children
- parent's Support Group—ask primary nurse or social worker for information
- taking breaks together—parents are an important source of support for one another

Siblings of a child with cancer often have worries and concerns that they may or may not verbalize to you. Changes in family routines, separation from parents, and worrying about their sick sibling are difficult. Often, they feel angry, jealous or guilty. These are normal feelings. Sometimes siblings act out their distress by becoming more demanding, getting into trouble, failing in school or developing physical symptoms like stomachaches or headaches.

Families may find it helpful to include siblings in family discussions about what is happening to the sick child, and also to let them help if they choose to do so. It also is helpful to help siblings understand their feelings.

OTHER WAYS TO HELP BROTHERS AND SISTERS TO COPE INCLUDE:

- Inform the school guidance counselor about what is happening in the family.
- Set aside time (even 1/2 hour each day) just for the sibling, in order to help them feel included in your life.
- Help siblings keep a balance between helping at home and maintaining their normal schedules.
- Get assistance from the social worker, child psychiatrist or child life specialist.

growth and development

THE TREATMENT OF CANCER and hospitalization will affect each child differently.

INFANCY

Infants experience the world through sight, smell and touch. The infant can distinguish parents from others. The hospitalization experience need not interfere with your parenting and bonding with your child. We encourage parents to support infants in the following ways:

- Hold and soothe the infant.
- Participate in feeding and bathing.
- Bring in familiar items from home, such as toys, pictures or a blanket.
- Continue to support development by playing with your child.

TODDLER

The toddler continues to build skills as he/she moves out of infancy. Verbal skills and understanding are more evident. From about 9 months of age until 2-3 years, separation becomes an issue for the hospitalized child. The child becomes selective towards mother and father and shuns strangers. Separation from parents often results in crying and tantrums. You can support your child by doing the following:

- Participate in bath time and meal time.
- Bring favorite/familiar toys such as blanket, toy, pictures, sippy cup.
- When leaving, go quickly after telling your child you will return/
Prolonged goodbyes do not lessen anxiety or crying.
- Bring favorite snacks/finger foods if unavailable in the hospital.
- Continue with home routines and roles.
- Continue with toilet training if possible.
- Continue to support independence through walking and playing.

Your child masters many developmental tasks during this period. Because of the stress of hospitalization, you may see regression. Regression can be seen in the following ways: crying, thumb sucking, bedwetting if previously toilet trained, dependency on parents and baby talk. These are usually temporary behaviors that will stop when stress decreases. Children in this age group sometimes feel that illness is a punishment for something they have done or thought was wrong.

PRESCHOOL AGE

It is important to remind the child that they did not do anything wrong to cause their illness. Preschool age children can be supported in the following ways:

- Remind them that they are not bad.
- Do not present nurses and physicians as punishers, but rather as people who care about them and are here to help them get well.
- Be honest about leaving and reassure them that you are coming back. Leave something of yours to remind them that you are coming back.
- Remain consistent with discipline whenever possible.
- Prepare your child for procedures just before they are performed.
- Play is often a helpful way for your child to work out feelings, especially after a procedure.

SCHOOL AGE

The major developmental tasks for the 6-12 year old are the mastery of skills such as building, doing, being independent in caring for oneself, dressing, forming friendships and developing control over emotions. Hospitalization and illness interferes with this process by separating the child from classmates and by making them dependent on others to care for them. When stressed by hospitalization and illness, the school age child may demonstrate regression in behavior. Your child may become more dependent on you to do things he/she normally does for him/herself. Also, hair loss and changes of body image can be very distressing at this time.

You can support your school-age child by doing the following:

- Bring school work to the hospital if the hospitalization will be an extended stay.
- Be honest about procedures to help build trust.
- Allow your child to participate in his/her care.
- Support normal routines.
- Allow your child to verbalize his/her feelings.

ADOLESCENCE

Having cancer is stressful for a teenager who is already struggling with normal teenage issues such as identity, gaining independence from parents, peer acceptance, body image and sexuality. Adolescents struggle for control in their lives. Cancer makes life unpredictable for teenagers, and this can be very frustrating.

Adolescents can feel supported in these ways:

- Keep them informed and offer them choices and a part in decision making—it is their right.
- Respect their needs for privacy and individuality.
- Changes in body image due to hair loss and surgery are stressful and may make adolescents self-conscious. Respect their need for wigs, scarves or personal style of dressing.
- Peers are crucial to the adolescents' self esteem. Encourage contact with friends.
- Ask your teenager if he/she wants you to stay during chemotherapy or procedure. Some adolescents struggle with trying to maintain their independence while feeling vulnerable and needy.
- Compliance may be an issue. Let your child make decisions as appropriate, but keep in mind the overall goal of treatment.
- Encourage continued progress toward future goals.

PROMOTING NORMALCY

Although your child has a serious illness, he/she is growing and developing and has needs similar to healthy children his/her age. It is important to maintain some sense of “how things used to be” within your family as you experience treatment. Some important areas to consider are discipline and returning to school.

Discipline

It is normal to want to overprotect your child as he/she goes through treatment. However, even though your child is sick, he/she still needs to have limits set. Limits and discipline offer children a sense of security. For example, if your child had the job of setting the table for dinner, it is important to still expect this when he/she feels well. Your

child will feel that he/she is contributing to the family and will feel a sense of “sameness” despite having cancer. If a toddler is allowed to act out with no discipline, it may be difficult for him/her to respond to rules or limits later in life when he/she is well and off treatment.

SCHOOL RE-ENTRY PROGRAM

School is very important for the child with cancer, not only for the academics but also for socialization and normalcy. Sometimes a child has lost hair since he/she last saw their classmates and is worried about returning to school. At first, it can be scary returning to school looking and feeling different. Children, especially teenagers, worry about being accepted by their peers. He/she may be able to return to school but may be behind in school work. He/she may worry about being asked to do too much in physical education class or about attending a different school. The transition to school can be easier if the child has a chance to talk about his/her feelings, and if the school personnel and students are prepared with information.

If your child is school aged, your child’s primary nurse or clinic nurse will send a referral to the school nurse with helpful information about your child’s treatment. Phone calls and school visits may be made by the nurse to help transition your child back to his/her classroom. Please speak with your nurse for further information about our school re-entry program.

Children are absent from school far less than in the past. They usually want to continue friendships and the feeling of being part of a group. If your child has missed several days of school because of surgery or chemotherapy, it is important for you to be in contact with your child’s school. Many cities and towns will provide tutors for children with extended absences. Speak with your child’s social worker regarding school issues.

It is helpful to encourage visits and phone calls from classmates and to ask for homework to be sent to the student. Homework helpers are available in the hospital by asking the child life specialist. Some schools will tape lectures or video classes to enable the student to keep up with the class. Returning to school after treatment will be easier if he/she has maintained contact with his/her peers. Please know that you are not alone in planning how to best meet your child’s educational as well as medical needs. We are all here to help.

How can educational laws help my child?

There are two particular laws that can apply to children diagnosed with cancer. Because of the diagnosis, children can be eligible for extra help. Ask your child's social worker how these laws apply to your child.

IDEA ("Individual with Disabilities Act") is federal legislation designed to help children proceed at an acceptable rate in school.

Section 504 of the Rehabilitation Act is a written plan that explains what changes are necessary in your child's education program.

Massachusetts General Law, The Comprehensive Special Education Law—Acts of 1972; Chapter 766 is a written multidisciplinary plan that explains what modifications may be needed to assist your child's education. See pamphlet "Understanding the Beginning Process of Chapter 766."

diagnostic tests and scans

THESE TESTS ARE PERFORMED TO HELP determine a diagnosis, to check the progress of treatment and to determine changes in status.

X-ray

X-rays are done to detect any changes in normal anatomy, to locate and determine the size of a tumor, to check the condition of the lungs and insure proper placement of a central IV line.

CT scan

CT is an abbreviation for Computerized Axial Tomography. The CT scanner is a large machine, which takes very detailed images of the body. Your child will be placed on a stretcher and the area of the body to be scanned is advanced into the machine. If your child becomes frightened or agitated, it may be necessary to give your child a small amount of medicine to relax him/her. Sometimes a dye will be given through an intravenous catheter before the CT scan is performed. For a CT scan of the abdomen, he/she may be given a special dye mixed in juice to drink.

Ultrasound

The ultrasound machine takes images of the body by bouncing sound waves over the part of the body that needs to be imaged. Ultrasound can be done on any part of the body.

Cardiac echo

This is an ultrasound examination that can test the strength of the heart. This test may be done prior to and after administration of certain chemotherapy drugs that can affect the heart.

Audiogram

The audiogram is a hearing test. The audiogram will be done prior to and after administration of certain drugs which can affect hearing.

MRI

MRI is an abbreviation for Magnetic Resonance Imaging. The MRI is a large machine, which takes very detailed images of the body. It does not involve any exposure to radiation or X-rays. It takes pictures that are similar to a CT scan, but it is more sensitive in detecting certain types of swelling, bleeding, tumors and infection. It is used in helping to make a diagnosis, to determine the exact location of a tumor and to determine progress during therapy. Your child will be placed on a stretcher inside the MRI machine. Your child may need to be medicated if he/she is restless or frightened.

Urinalysis

A small amount of urine will be tested for red blood cells, white blood cells, bacteria, protein and sugar. If your child is not toilet trained a small plastic bag will be placed in the diaper area to collect urine.

Complete blood count (CBC)

A CBC determines the red blood cell, white blood cell, and platelet counts. It is done many times during the treatment. It also will be done if your child has a fever or has any change in condition. A small amount of blood will be taken by a fingerstick, venipuncture or from a central line.

Bone scan

This is a nuclear medicine test done to look at the bones for tumors, metastases, fractures or infection. A small amount of a radioactive dye is given through an intravenous line about 2 hours before the scan. The bones are then examined by a special camera.

Lumbar puncture (spinal tap)

The spinal cord and brain are surrounded by clear fluid (spinal fluid). A spinal tap involves the insertion of a needle between the third and fourth lumbar vertebrae of the spine at the base of the back into the spinal fluid. A lumbar puncture (LP) may be done as part of the diagnostic process. Spinal fluid is carefully collected in a test tube and sent to the lab for analysis to test for cancer cells. After diagnosis, an LP might be used to give chemotherapy into the spinal fluid (intrathecal/IT). This procedure allows the chemotherapy to act directly on the surface of the brain and spinal cord. The need for intrathecal chemotherapy (IT) will depend on the type of cancer.

Bone marrow aspiration/biopsy

Bone marrow is spongy material found inside bones. The primary function of the bone marrow is to manufacture red blood cells (RBC), white blood cells (WBC) and platelets. A bone marrow aspiration involves the insertion of a needle into the back of the hip (pelvic bone) and the aspiration (pulling back) of liquid bone marrow into a syringe. A bone marrow biopsy is done in the same spot as the aspirate only using a different needle. A small core of bone marrow is taken and, along with the aspirate, sent to the lab for analysis. Bone marrow aspiration/biopsy are initially done as part of the diagnostic process. The bone marrow will be examined under a microscope to

determine if cancer or leukemia cells are present. After diagnosis, a bone marrow aspirate might be used to confirm remission and response to therapy. The need for bone marrow aspiration/biopsy will depend on the type of cancer.

Although lumbar punctures and bone marrow aspiration/biopsy are quick procedures, they may be painful. Your caregiver will order sedation and or general anesthesia to minimize any discomfort. The patient should have nothing to eat after midnight or up to six hours before the procedure; clear liquids are allowed up to two hours before a procedure. Your caregiver will tell you the approximate time of the procedure. Both these procedures, whenever possible, are done in the operating room or other specially designated areas. We welcome you to stay with your child until the procedure actually begins. However, only hospital personnel are permitted in the operating rooms during procedures. Please be assured your child will be safe and cared for in your absence. When the procedure is finished and your child is recovering, you will be welcomed back to his/her side to offer support.

After the procedure

Please check the bandaged area(s) before bedtime. Remove bandages within 24 hours of the procedure.

Please call the clinic if your child experiences any of the following:
(617-726-2737)

- pain or tenderness
- fever 100°F or above
- bleeding, drainage or swelling
- or if you have any questions or concerns

DO NOT give medication for pain unless it has been approved by your physician.

treatment plans

DIAGNOSIS

The initial evaluation by the doctor includes a careful health history, a physical examination, a complete blood count, and several other tests, depending on the location and the type of cancer. In addition to blood tests, a bone marrow aspirate and a lumbar puncture may be done. For solid tumors, a small sample (also called a biopsy) of the cancer tissue must be studied before a specific diagnosis can be made. Often X-rays, computed tomography scans (also called CT scans or CAT scans), MRI's (Magnetic Resonance Imaging), or other images are made.

These studies allow the doctor to tell you what kind of cancer your child has and how much it may have spread (also called the stage of the cancer) from the location in the body where it first started. Knowing both the type of cancer and stage of development are necessary for proper treatment. The treatment plan will be based on the specific diagnosis and on all of the current information used for treating that type of cancer.

TREATMENTS

There are several methods of treatment for cancer that include surgery, radiation therapy, and chemotherapy. Treatment plans may combine two or more of these methods.

CLINICAL TRIAL/TREATMENT PROTOCOL

A clinical trial is a research study conducted with patients. The study will tell the doctor whether a new treatment or a slight change in treatment will be better for patients with a specific type of cancer.

Clinical trials are based on the best known treatment with changes or additions that may produce a higher cure rate or fewer side effects. These changes or additions in treatment are the results of studies done in the laboratory, and/or in a small number of patients with the disease, before being used in a larger treatment protocol. Clinical trials help us find out if a promising new treatment is safe and effective for patients. Standard treatments, the ones now being used, are often the base for building new, hopefully better treatments. During a trial, more information is gained about treatments, risks and how well they work.

Patients taking part in a clinical trial are treated according to the clinical trial's treatment plan (protocol) and checked carefully for the desired effect and the side

effects of the treatment. If your child's treatment is based on a clinical trial, you will receive the schedule of treatments and tests that will be done. The schedule is called a "road map." Whether or not your child is participating in a clinical trial, your physician will follow a treatment plan that details both tests and treatments.

The road map outlines what tests and treatments are scheduled in the weeks and months ahead. Ask your child's doctor for a copy of this road map. Most tests and treatments are done according to this map, but minor changes may be made to better serve your child and your family.

How does a clinical trial affect treatment?

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

Before your child begins therapy, you will be given an informed consent to read. This document describes the treatments, the possible benefits, and the known possible side effects. After reviewing this information with the treatment team, you will be asked to sign the informed consent document giving permission for your child to be enrolled in the study. If your child is old enough to understand, he/she will be asked to review and also sign the consent form. Make sure that all of your questions have been answered fully before signing the consent form.

The results of the research being conducted in clinical trials will not be known until all the patients have completed the treatment. Records are reviewed during each study, and if important new information is discovered, it will be shared with you.

If during the course of the clinical trial, information about a better treatment for your child's disease becomes available, the improved treatment will be offered. To make decisions about how to proceed in the best interest of your child, you should feel comfortable asking to review any part of the clinical trial with the treatment team.

Once your child is entered into a clinical trial, you and the treatment team still have choices. If the treatment proves to have too many side effects for your child, the treatment can be altered or your child can be removed from the study. You or your child can choose not to continue treatment in the clinical trial at any time.

Common concerns regarding clinical trials

1. Clinical trials are research studies that involve people. Each study tries to answer scientific questions and to find better ways to prevent, diagnose or treat disease.
2. In cancer research, a clinical trial is designed to show how a particular anticancer strategy—for instance, a promising drug, a gene therapy treatment, a new diagnostic test or a possible way to prevent cancer—affects the people who receive it.
3. A clinical trial is one of the stages of a long and careful cancer research process. Getting results from testing a new drug on mice, for example, is a preliminary step to human research studies. Treatments that work well in mice do not always work well in people.
4. People can benefit from clinical trials. In treatment trials, for example, participants receive high-quality cancer care—and will be among the first to benefit if a new approach is proven to work.
5. New treatments under study are not always better than, or even as good as, standard care; and they may have unexpected side effects. Through a process called informed consent you will learn about a study's treatments and tests, and their possible benefits and risks, before deciding whether or not to participate.
6. Who is eligible to participate in a clinical trial? Each study has its own set of guidelines for who can participate. Generally, participants are alike in key ways, such as the type and stage of cancer, age, gender and other factors.
7. Many treatment trials are designed to compare a new treatment with a standard treatment, which is the best treatment currently known for a cancer, based on results of past research. In these studies, patients are randomly assigned.
8. Where do clinical trials take place? They are underway all over the country in cancer centers, other major medical centers, community hospitals and clinics, physicians' offices and veterans' and military hospitals in numerous cities and towns around the United States.

Where to go for more information

For information about clinical trials, log onto the Internet at <http://cancertrials.nci.nih.gov>. This is the National Cancer Institute's (NCI) comprehensive clinical trials information center for patients, health professionals and the public. It includes information about understanding trials, deciding whether to participate in trials, finding specific trials, plus research news and other resources.

Information can also be found in *Taking Part in Clinical Trials: What Cancer Patients Need to Know*. NCI's new easy-to-understand brochure designed for cancer patients and their families. Call the NCI's Cancer Information Service at **1-800-4-CANCER (1-800 422-6237)** to request a free copy or download it from the cancer trials web site.

treatment

CHEMOTHERAPY

Chemotherapy refers to many drugs that are used to treat cancer.

Usually combinations of drugs are more effective against cancer than a single drug. Chemotherapy may be given in various ways, including pills or liquid taken by mouth, injections into a muscle or injection under the skin. The most frequent way in which these drugs are given, however, is into a vein. Some drugs can be given over a few minutes, while others require a several hour infusion with lots of intravenous fluid be given. Some treatments will be given in the Pediatric Hematology-Oncology Clinic, but others will require admission to the hospital for a few days. Also, some drugs may need to be given directly into the spinal fluid (the fluid surrounding the brain and spinal cord) through a spinal tap.

Multiple courses of chemotherapy are usually required to cure cancer. The time between treatments varies among different treatment plans, from a few days to three to four weeks. The total duration of treatments also varies from a few months up to as much as two and a half years. To determine how effective the treatment has been, your child will undergo periodic diagnostic tests such as blood tests, X-rays, CT scans, etc. Your child also will need to have blood tests done before each course of chemotherapy to make sure his/her body is ready for more treatment. Sometimes chemotherapy must be delayed because of complications such as low blood counts, infection or other side effects.

If your child is on a protocol that requires frequent administration of intravenous chemotherapy, a central venous access device (see explanation below) may be recommended by your physician. These devices are semi-permanent and are placed by the pediatric surgeon into a large vein. The types primarily used at this hospital are called Broviac catheters, Port-a-Caths and PICC lines. If it becomes necessary for your child to have one of these, your primary physician and nurse will explain in detail the benefits and risks of these devices.

Chemotherapy drug doses are calculated according to your child's height and weight, and are designed to provide the maximum effect on the cancer cells while affecting the normal cells of the body as little as possible. If severe side effects occur, the dose of the responsible drug may need to be readjusted. There is no need to worry if your child cannot tolerate the usual dosage or if there are minor delays in treatment. This does not mean that there will be an unfavorable change in your child's prognosis.

CENTRAL VENOUS LINES (CVL)

A central venous line is a long, soft tube or catheter. It is inserted into a large vein that leads to the heart. This device is inserted in the operating room using general anesthesia. Central venous lines may be used for giving chemotherapy, blood products, IV fluids and nutrition. They also may be used to take blood samples for lab work.

A Broviac catheter is an external central venous device that extends outside the skin. The exit site of the catheter requires a bandage. You will be taught to change the bandage at home to prevent infections. You will also be taught to flush the line with heparin to prevent the line from clotting.

A Port-A-Cath or Implanted Port is an internal central venous device that is placed under the skin. Ports are made of stainless steel or titanium and silicone rubber. To give medicine or take blood, a special needle must be inserted into the port. This device does not require a bandage unless the needle is in the implanted port. The port will need to be accessed and flushed at regular intervals.

A Peripherally Inserted Central Catheter (PICC Line) is a long soft catheter that is externally placed into a large vein in the arm using local anesthesia. The catheter is threaded or tunneled into a larger vein that leads to the heart. This device provides a different way to provide IV access for the child who may be unable to have a central line placed or who needs an immediate and reliable IV site. The entrance site requires a dressing, and the catheter requires flushing as well as cap changes.

Your child's diagnosis, treatment protocol and specific needs determine the type of device to be used. Your treatment team will discuss with you which central venous device will be best for your child. Please refer to the pamphlet "Care of Your Child's Central Venous Catheter."

Showering, bathing, and swimming when you/your child has a central venous line (CVL)

There is no published medical literature regarding the safety of swimming when a CVL is in place. It is known, however, that moisture promotes the growth of micro-organisms (bacteria). If the CVL site or caps become wet, there is a risk of developing a blood-stream infection. **We do not recommend swimming but** offer the following guidelines to insure the safety of your child.

General guidelines:

- *Hand washing, hand washing, hand washing.*
- Keep CVL dressings and caps dry at all times.

- No swimming during the first month after line placement or after a bone marrow/stem cell transplant.
- No swimming when white blood cell count is low (neutropenic).
- No swimming if Port-a-Cath is accessed or CVL is infusing fluids/medications.
- Never swim in lakes or in ponds. Do not use a hot tub or spa.
- When outdoors, use a sunscreen with a sun protection factor (SPF) of at least 15. Stay out of direct sunlight from 10:00 AM to 3:00 PM. Wear a hat to protect scalp.

When showering/bathing/swimming:

- Wrap/coil the line and place on top of CVL existing dressing.
- Place gauze on top of wrapped/coiled line.
- Cover with a large Tegaderm. Make sure all the gauze is covered, so it does not get wet.
- When in the water, check the dressing frequently to insure that it is still dry. If the dressing is wet, get out of the water and change the dressing and caps.

After showering/bathing/swimming:

- Change the dressing when finished showering/bathing/swimming.
- Wipe the line, which is not covered by the dressing. Wipe line from the end of the dressing toward the cap with an alcohol wipe.
- Change caps. Do not flush the line until after you have put on new caps.

To minimize the exposure of the CVL dressing to water:

- If your child swims in the ocean or a chlorinated pool, keep the CVL site as dry as possible by limiting the time spent under the water.
- If a “kiddie pool” is used: a) buy a new pool at the beginning of the summer; b) fill the pool just before use; c) empty the pool and clean it after each use; and d) do not allow children with diapers to use the pool.
- If a sprinkler is used, buy a new hose and sprinkler at the beginning of the summer.
- If a tub bath or shower is used, clean the tub with a household cleaner every day before use.

Call the Pediatric Hematology-Oncology Unit (617-726-2737):

- If the CVL dressing is not staying dry while showering/bathing/swimming.
- If your child develops a fever or chills.
- If the CVL site looks infected (red, tender, swollen, hot or there is drainage).

SURGERY

Surgery is performed to completely or partially remove a tumor or to obtain a biopsy for diagnosis. Prior to surgery, the surgeon will discuss the planned procedure with you. At this time you will be given an opportunity to have your questions answered.

A pediatric anesthesiologist will be administering the anesthetic agents and pain medications.

Chemotherapy and/or radiation may be started prior to or following surgery depending on your child's condition and diagnosis.

RADIATION THERAPY

Radiation is a type of treatment prescribed for many different types of tumors. Radiation therapy uses high-energy X-rays to kill tumor cells. Normal cells also are affected by radiation but usually are able to recover.

Your child may be seen by a radiation oncologist who will examine him/her and make treatment recommendations. He/she also will answer any questions that you might have concerning the radiation therapy.

Some radiation treatment areas may require the use of an immobilization device. This insures accurate positioning each day during the treatment. A simple cast or mold specially designed for your child will be fashioned and only used during the actual treatment.

Simulation

This is a radiation planning session. The physician designs the area to be treated and the angles from which to treat. Your child will be lying on an X-ray table while the

therapist positions the machine around him/her. There will be a series of X-rays and measurements. At the conclusion of the simulation, marks will be placed on your child's skin with a blue magic marker. There may also be a few freckle-sized tattoos placed, which will require a small needle stick. These blue marks designate the treatment areas and should not be washed off. This session may take up to one hour. It is very important for your child to remain very still during this planning session. For very young children, it may be necessary to use a sedative or anesthesia during this session and subsequent treatments. After the planning session is completed, the radiation oncologist will discuss the potential side effects and ask you to sign a consent form. You also will be given an appointment for your child's first treatment.

TYPES OF RADIATION THERAPY

External beam treatment

Using the blue marks, the therapist will set up the daily treatment according to the physician's plans. The actual treatment and the equipment resemble the simulator. After positioning your child, the therapist will leave the room. However, they can see and hear your child at all times via a monitor. It is important for your child to remain still during the treatment. Remember, a sedative or anesthesia may be needed for some children. Your child will not feel anything during the treatment itself. It is similar to having an X-ray. The treatment lasts for several minutes. Occasionally, X-rays will be taken to verify treatment position. When the treatment is done and the machine is turned off, there is no radiation left in the room. After your child's first treatment session, the radiation therapists will set up a time for you to come for the rest of the treatments, usually the same time every day.

Total body irradiation (TBI)

For bone marrow transplantations, a type of radiation treatment called total body irradiation or TBI may be given. The treatment planning, delivery, and daily schedule are different from conventional external beam radiation therapy and will be discussed with you in detail if your child is scheduled for this type of treatment.

Proton beam treatment

For certain tumors, a different radiation beam is needed. The proton beam has the ability to deliver radiation in a very sharply defined manner. This treatment is sometimes indicated for tumors of the eye, brain and spine. Again, for very young children, anesthesia may be required. These treatments are given on an out-patient basis.

Status check

Each week, you and your child will meet with your radiation oncologist and nurse, either before or after treatment, for what is called a “status check.” These meetings are an opportunity for your physician and nurse to see how you and your child are doing, examine your child and ask about side effects. At this time, medications will be reviewed, skin care advice given and other recommendations discussed. It is also a time for you to ask questions or express concerns that you might have. Of course, the physician and/or nurse always are available should questions or problems arise.

Skin care

Side effects of radiation treatments are limited to the area being treated. The physician and nurses will outline specific side effects that your child may encounter during the course of treatment. Here, we will discuss general skin care considerations.

After several weeks, the skin in the treated area may become red, dry and tender (like a mild sunburn). Do not put anything (creams, powders, lotions, deodorant, perfumes or cosmetics) on the skin in the treated area unless discussed with your physician or nurse. Wash the area daily with mild soap and warm water. Pat skin dry rather than rubbing. Cornstarch applied three to four times a day has proven beneficial and soothing. Avoid extremes in temperature to the treated area, as well as heating pads, straight razors, sun exposure and tanning booths. While under treatment, and for several months afterwards, treated areas exposed to the sun should be covered and/or a #15 sun block applied.

NUTRITION

A balanced diet is important during treatment for proper nutrition and healing. A dietician is available for advice concerning adequate caloric and protein intake.

Please remember, this is general information regarding radiation treatment and is not intended to replace in-depth discussion between you and your child’s medical team. We urge you to direct all questions and concerns to the physician and nurses.

RADIATION ONCOLOGY PHONE NUMBERS

Emergency calls – Daytime(617) 726-8650

**Night/Weekend/Holiday ask for
ON-CALL doctor for Radiation Oncology**.....(617) 726-8650

Social Service(617) 726-8187 or 726-7664

Physician Appointments(617) 726-8662

frequently asked questions about radiation treatment

How does radiation therapy work?

By stopping cell multiplication in tumors, healthy cells recover and tumor cells die.

Can my child be given too much radiation?

There are many safety checks built in to prevent an overdose.

Will my child become radioactive?

No.

Will my child feel the radiation?

No.

Can my child engage in physical activity/sports during the course of radiation treatment?

The level of physical activity or playing of sports will be determined by the area being treated. This should be discussed with your child's oncologist and/or orthopedic physician.

Can my child bring a friend or sibling in to watch the radiation treatment?

Yes. It is frequently very helpful for a sibling or friend to see the department and treatment machine.

How long do the side effects from radiation last?

Acute effects, such as red, tender, dry skin can take up to several weeks to subside.

What happens if my child misses a treatment?

The total number of treatments will stay the same. Missed treatments can be added to the end of therapy.

What is the difference between radiation and chemotherapy?

Radiation acts only on the tissue in the beam while chemotherapy reaches all parts of the body.

Will my child become tired while undergoing radiation therapy?

Yes, probably in the latter part of treatment.

side effects of cancer treatment

MOST CHEMOTHERAPY MEDICINES and radiation therapy kill cancer cells during their reproductive cycle. Normal body cells and cancer cells reproduce by dividing: One cell grows, divides and becomes two cells; the two grow and divide to become four cells and so on. The reproduction of new cells is how a cut or scrape heals and hair grows.

When cancer cells cannot reproduce themselves, they die. Luckily, normal cells repair themselves much more effectively than cancer cells. It is when normal cells that rapidly reproduce are destroyed that we see many of the side effects of chemotherapy or radiation therapy.

Chemotherapy is a chemical way of treating cancer. Special medicines are given either by mouth (orally) or by injection. An injection can be intravenous (into a vein), intramuscular (into a muscle), subcutaneous (under the skin) or into the spinal canal. Once in the body, the chemotherapy acts on cells that divide rapidly.

The normal cells most affected by chemotherapy include those in the:

- digestive system (mouth, stomach, bowels or intestines and the rectum)
- hair
- bone marrow (where blood cells are made)
- reproductive system

Many of the side effects caused by destroying some of these normal cells are almost always temporary.

Call your child's physician or nurse right away about any of the side effects described here. Please call if you have questions regarding these side effects.

Our goal in treating your child is to rid him/her of cancer. At the same time, we want you/your child and family to live as normal a life as possible. We can work together to care for the side effects of treatment, give emotional and physical support when needed, and encourage independence and a return to normal life as soon as possible.

BONE MARROW SIDE EFFECTS

Bone marrow cells make blood cells that are released into the bloodstream when they are needed. Cells of the bone marrow, because they reproduce themselves rapidly, can be injured by chemotherapy and by radiation. A major side effect of chemotherapy is blocking blood cell growth also known as bone marrow suppression. This results in low blood counts.

Blood counts during therapy

Your child's blood counts will be checked by your treatment team frequently while receiving chemotherapy. This close checking will assist the medical team in taking care of your child, monitoring his/her progress and hopefully avoiding severe complications. However, you should be prepared, because your quick action will help prevent serious injury to your child.

Most of the time, your child's blood counts will be at a level that allows him/her to fight infection, maintain normal play levels, and prevent uncontrolled bleeding without special precautions and treatments. During the times when blood counts are normal, it is very important that your child be allowed to take part in play 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 sports.

Of all side effects of chemotherapy, bone marrow suppression will cause your child the most treatment delays, therapy changes and unscheduled trips to the hospital. You will not begin to notice the effects of the chemotherapy on the bone marrow until five to 14 days after the medicine was 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 the treatment team.

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

- red blood cells (RBCs)
- white blood cells (WBCs)
- platelets

Each of these cell types have different jobs, and it is when your child's blood counts, or the number of the different blood cells, are low and not able to do their special jobs, that he/she may have harmful effects.

Red Blood Cells (RBCs): Red blood cells carry oxygen for energy to all the organs of the body. The number of red blood cells in the blood stream is measured by the hematocrit and hemoglobin levels. When these are low, your child is said to be anemic. You may notice that your child tires easily and looks pale when the hematocrit is low. If it drops below a certain level or your child develops symptoms of a lower red blood count, your doctor may order a red blood cell transfusion. Usually, the red blood cell counts will recover on their own.

White Blood Cells (WBCs): White blood cells fight infections, and when their count is low, your child will be more likely to get sick from a bacterial or fungal infection.

There are different kinds of white blood cells, and it is the neutrophils that are most important in fighting bacterial infections. Other names for neutrophils are granulocytes, segs, or polys. When your child's absolute neutrophil count (ANC) is low (also called neutropenia), and a bacterial infection is suspected or a fever (greater than 100) develops, he/she may need to be admitted to the hospital and treated with intravenous antibiotics. The white blood cell count will recover on its own. A neutrophil count of less than 500 is considered to be low. To learn how to figure out the absolute neutrophil count (ANC), see the box below. Please remember you are not responsible for calculating your child's ANC.

Multiply the white blood cell count (WBC) by the percent of polys and bands

WBC x polys + bands = ANC

WBC 2,300 x (60%polys + 3% bands) = 1,449

Guidelines to follow when your child's white blood count is low

- Stay away from large crowds and people who are sick.
- Good hand washing by all family members, while always important, is especially necessary when your child's white blood cell count is low.
- If your child runs a fever (temperature of 100 or higher), you should contact your physician. Admission to the hospital for observation or antibiotic therapy may be necessary.
- Do not take rectal temperatures or use rectal suppositories. Anything pushed into the rectum may irritate the lining of the rectum and let bacteria from the stool enter your child's bloodstream. If your child cannot cooperate for an oral temperature, then his/her temperature should be taken under the arm.
- Do not schedule dental procedures or teeth cleaning when the ANC is low (less than 1,000). He/she also may need to be placed on an antibiotic prior to dental treatment. Please call the clinic before making dental appointments.
- If your child is "just not acting right," with or without a fever, you should contact us to decide if it is necessary for the child to be examined.

Platelets: Platelets are needed for the blood to clot normally. When your child's platelet count is low (also called thrombocytopenia), he/she may be more prone to bleeding.

- Signs of a low platelet count are increased bruising, red freckles (including red, pinpoint bruises called petechiae), a nosebleed that is difficult to stop, gums that bleed easily, or bleeding from a small cut or scrape that is hard to stop.
- If you suspect that your child's platelets are low, a platelet count should be done. When the platelet count drops below a certain level or if there is active bleeding, the doctor may order a platelet transfusion.

Guidelines to follow when your child's platelet count is low

- Avoid high risk sports (such as football, soccer or skateboarding) that could cause physical injury.
- Use a soft-bristled toothbrush, a tooth sponge, or a clean soft cloth to gently clean the teeth. Anything harder may cause irritation and bleeding. Do not schedule dental procedures or teeth cleaning when the platelet count and/or white blood count is low. Please call the clinic prior to making dental appointments.
- Do not take rectal temperatures or use rectal suppositories. Anything pushed into the rectum could tear the lining of the intestine and cause bleeding.
- If your child is constipated, the physician may order stool softeners because hard bowel movements can cause rectal bleeding (see the section on Constipation).
- If bleeding does happen while the platelet count is low, it may be hard to stop. Any time bleeding occurs you should call us.

The following guides will help you know what to do in specific situations:

Nosebleeds

Keep your child in a sitting position. Instruct your child to breathe through the mouth. Apply pressure by gently, but firmly, pinching the nostrils closed across the bridge of the nose. Continue this pressure for 10 minutes. Once the nosebleed has stopped, do not allow your child to sniff hard, blow the nose, or pick at the nose. The blood clot will break off and the nosebleed will start again.

Bleeding of the gums or mouth

If the bleeding is in an area that is easy to reach, apply gentle pressure until it stops. If you cannot apply pressure, have your child hold ice water in his/her mouth until the bleeding stops.

A cut that does not stop bleeding on its own

With a clean dry cloth, hold gentle but firm pressure over the cut for at least 10 minutes. If possible, lift the body part that is injured above the level of the heart. If the bleeding continues, call your treatment team. Do not apply a tourniquet to control bleeding because this could cause permanent tissue damage. If a cut is deep and the blood seems to be coming in spurts, apply pressure by pressing a cloth over the cut and take your child to the hospital at once.

Bleeding under the skin that is spreading or swelling

Hold gentle but firm pressure with a soft cloth or an ice pack over the area for at least 10 minutes. Lift the area above the level of the heart, if possible. If bleeding does not stop, call the treatment team.

Sudden, severe headache or collapse

This could be caused by bleeding inside the head. This is rare, but if it occurs, you should keep your child in a sitting position and call us immediately or call 911.

DIGESTIVE SYSTEM SIDE EFFECTS

Mouth sores

The cells that line the inside of the mouth divide rapidly to repair the damage done by the teeth, rough food and other normal wear and tear. Chemotherapy temporarily prevents this repair, and the mouth lining can break down. Mouth sores are the result. This may also occur with radiation therapy to the head and neck. Let us know if your child develops red or white areas or open sores inside the mouth. This can be a site for infection.

If your child develops mouth sores, there are a few practices that may help him/her to be more comfortable:

- Good mouth care should become a daily routine at the beginning of treatment.
- Good mouth care is essential. Teeth should be brushed with a soft brush after each meal. Infants' and toddlers' teeth should be cleaned with a soft cloth wrapped around your finger.
- If your child cannot brush his/her teeth, the mouth should be rinsed before and after each meal. Your physician may order a mouthwash, or you can use a mix of 1/4 teaspoon salt, 1/4 teaspoon baking soda, and 1 cup of water. Do not buy mouthwashes that have alcohol because they will sting and burn the mouth sores.
- If mouth sores become painful, your physician may order medicine to numb the sore areas. This medicine is most effective when swished around in the mouth right before a meal, because the numbing effect wears off quickly. However, if your child gargles with this medicine to ease throat pain, he/she should wait at least 30 minutes before eating or drinking, because it can numb the gag reflex at the back of the throat and cause choking.
- Feed your child soft, non-spicy foods, such as mashed potatoes and gravy, yogurt, soup, ice cream, Jell-O, custards and scrambled eggs. Cut foods in tiny pieces or puree them in the blender.
- Stay away from foods with sharp or rough edges, such as chips, toast or tacos. It is a good idea to avoid acidic foods, such as tomatoes, orange juice, or pickles that may irritate the tender areas.

- Foods served cold or at room temperature feel better to the sore mouth.
- A straw is helpful for directing fluids away from the mouth sores.
- If your child refuses to drink fluids or is unable to swallow saliva, contact the treatment team.
- If mouth sores are painful, call the clinic. If your child has persistent mouth pain, your physician may prescribe a medication for him/her.

Nausea and vomiting

Nausea and vomiting are caused by irritation of the stomach lining or by direct stimulation of the vomiting centers of the brain.

Chemotherapy induced nausea and vomiting may begin 30 minutes to one hour after taking a medicine and can last minutes or hours. Some chemotherapy drugs cause delayed nausea and vomiting that can continue for several days after the chemotherapy is completed. Episodes of severe nausea and vomiting lasting longer than two to four hours should be reported to the treatment team. Some chemotherapy medicines do not cause nausea or vomiting, others are only mildly annoying, and some can cause intense nausea and vomiting. Reactions are different for each patient, and your child may not act in the same way as another child receiving the same medicine.

Sometimes older children and adolescents develop what is called anticipatory nausea and vomiting. The child becomes nauseated and may even vomit at the thought of chemotherapy. The child may begin to get sick the night before chemotherapy or whenever you get close to the hospital. Remember, your child cannot control this reaction and needs your support and understanding. If your child develops this type of anticipatory nausea, discuss it with the treatment team.

There are a number of medicines used to treat nausea and vomiting caused by chemotherapy. We will work with you to find the medicine or medicines that are most effective for your child.

Most of your child's problems with nausea and vomiting will occur in the hospital or clinic, but if there continues to be a problem at home, here are some ideas to increase comfort:

- Serve meals in a well-ventilated room that is as free as possible from cooking and other smells. Feed your child small, frequent meals.
- Stay away from fried, spicy or very rich foods and foods with strong odors.

- Try not to serve your child's favorite foods when he or she is nauseated because your child may later connect this food with feeling sick.
- Rinse your child's mouth well after each episode of vomiting because stomach acid left in contact with the teeth and mucous membranes will cause tooth decay and irritate an already tender mouth.
- Give your child only sips of cool, clear liquids, such as Jell-O, or grape, apple and cranberry juice, until tolerated. Then try full liquids, such as sherbet, vanilla ice cream or vanilla pudding, and then move slowly to solid foods.

If your child has received a chemotherapy treatment that is likely to cause prolonged vomiting, your physician may order antiemetics/anti-nausea medicines while your child receives chemotherapy. If the medicine wears off and your child starts vomiting, your treatment team may order more medicine or another anti-nausea medicine.

Diarrhea

Some chemotherapy can cause diarrhea. Radiation therapy that includes the stomach or intestines also can cause diarrhea. If your child has problems with this, we will need to know about the color, size and number of diarrhea stools per day.

Here are some ideas for easing bowel irritation:

- Keep your child quiet after meals with quiet play or a nap. This will decrease bowel action.
- Feed your child small amounts of food frequently instead of large meals all at once.
- Stay away from spicy, hot, fried or fatty foods, juices and milk products when your child has diarrhea.
- Stay away from foods high in fiber, such as fresh fruits and vegetables.
- Feed your child a soft, bland diet that is high in potassium. Foods high in potassium that do not cause diarrhea include bananas, potatoes, and apricot or peach nectar.
- For the first six to 12 hours after diarrhea has started, it may be helpful to feed your child only clear liquids, such as tea, caffeine-free soft drinks or Gatorade. Then slowly begin bland, low-fiber solid food, such as mashed potatoes, toast, bananas, canned fruit, and saltine crackers.
- Do not give an anti-diarrheal agent without talking to your treatment team first.

Constipation

Constipation can be caused by drinking less fluid, eating less fiber, exercising less, or getting chemotherapy such as vincristine.

These changes can correct the problem:

- Give your child a warm drink, such as hot cocoa or hot apple juice around the time of day that he/she usually has a bowel movement.
- Increase the amount of fiber in your child's diet by choosing fresh fruits and vegetables, dried fruits, whole grain cereals and breads and oatmeal cookies. Add bran to casseroles, cookies and bread before baking.
- Encourage your child to drink more fluids, especially water and juice.
- Encourage your child to get more exercise through play.
- Call the treatment team if constipation lasts two days or more.
- If none of these changes help, let us know. Sometimes a stool softener will be ordered to prevent constipation. Do not give your child a laxative or suppository unless it is ordered by the physician.

PAIN MANAGEMENT

Your child may have pain from the cancer itself before diagnosis. This pain is often caused by pressure of the tumor on nearby tissues and organs. Some of the side effects of treatment, such as mouth sores or digestive problems, may also cause pain or discomfort. Ways to control pain have been suggested in other sections of this booklet.

A mild pain medicine may be needed for pain control. However, you should not give your child medicines that contain aspirin because aspirin can increase bleeding problems and irritate the stomach. Read labels of over-the-counter medicines carefully, and if they list aspirin or salicylates, do not give them to your child. Pepto-Bismol is one example of an over-the-counter medicine that has aspirin in it.

As a general rule, you should check with your treatment team before giving your child any medicines not ordered by the doctor.

If your child has severe or lasting pain, a stronger pain medicine may be needed. Call your treatment team at once if your child has:

- severe pain
- pain with fever
- severe headache during times of low platelet counts
- stiff neck with fever

Vincristine, a common chemotherapy medicine, may cause muscular aches in the arms or legs and jaw pain. This kind of jaw pain may feel like an earache. A very young child, who cannot tell you about jaw pain, may just refuse to chew food or drink. If your child has been getting vincristine and has this kind of pain, let your treatment team know.

Medicines for sedation and pain control are given before procedures, such as bone marrow and spinal taps. An anesthetic cream called EMLA numbs the skin and can be administered at least one hour before a painful needle poke. If you choose to use this cream, you should place it on your child's skin before coming to the treatment area. Please talk to your physician or nurse for instructions.

BODY IMAGE CHANGES

Changes in physical appearance may be the most upsetting side effects of chemotherapy for your child. Hair loss, excessive weight gain or weight loss and rashes are all physical changes that your child may experience. With the support of family members, close friends, and members of the health care team, your child will finish therapy with a positive self image. Each child is different, and it is impossible to predict exactly what changes your child will have. We can give you some idea of what to expect, however, based on your child's medicines and treatment plan.

Hair loss (alopecia)

Hair loss secondary to chemotherapy will almost always grow back. In fact, many children will regrow a full head of hair while still on treatment. Do not be surprised if the new hair is lighter, darker or curlier than it used to be.

Not all children will become completely bald; some will only have thinning. Patterns of hair loss differ. Some kids seem to lose their hair overnight, but others will lose it over a period of days or weeks. Sometimes there is very little hair loss and sometimes there is permanent or severe thinning.

The loss of your child's hair, while not life-threatening, can be the most traumatic part of receiving cancer treatment. If your child wants to wear a wig, you may shop around before hair loss becomes very noticeable and so that hair color and style can be copied. Wigs are made of natural or synthetic hair. Either type can be styled by a beautician to match your child's hair closely. Synthetic wigs are usually less expensive and easier to care for. Let us know if you need assistance in this area. Some insurance plans may require a prescription for a wig.

Some children may choose to wear a hat, scarf or bandana. These can be attractive and comfortable head coverings when worn alone or with wigs. There are creative ways to wear these head coverings. Ask for ideas and pamphlets on the subject.

A bare head is beautiful, but loses heat in the winter time and gets sunburned in the summer time. Encourage your child to use proper head protection in the form of a hat, wig, scarf or sunscreen during these times.

Excessive weight gain or loss

Steroids, such as prednisone or decadron, may cause increased appetite, excessive weight gain (particularly in the face and abdomen) and fluid retention. These effects will disappear after the steroids are stopped. Stretch or knit clothes can be more comfortable during weight changes.

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

Your child's weight and nutritional status will be checked and monitored closely. Your physician will discuss all nutritional options available should supplementation become necessary. It is important not to let anxiety about your child's illness and recovery turn the issue of eating into a conflict. Children can control very little of what is happening to them and will often try to control what they will eat. By offering nutritious and tasty foods and expecting your child will do his/her best to eat them, you can avoid conflict and keep meal times pleasant.

If excessive weight gain or loss causes problems with friends and schoolmates or makes your child self-conscious, your acceptance, support and understanding will be very important to your child. Discuss any of these problems or issues with your physician. With your permission, we can assist you by talking to your child's school nurse or teacher, asking that they explain to the class any changes in your child's appearance. This kind of understanding by classmates may help to decrease teasing.

Skin changes

Some chemotherapy medicines 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 necessary.

Some chemotherapy and radiation may cause a skin darkening or discoloration. This is not a cause for concern and will disappear as these skin cells grow.

Occasionally, chemotherapy medicines can cause tissue damage 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) drugs your child receives are vesicants. Extravasation can occur even when a central line is used, although it is very rare.

Effects of an 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 he/she has received a vesicant medicine within the last two to three days, an extravasation may have occurred. Please contact your treatment team for special care instructions if this occurs.

TREATMENT AND SEXUALITY

Parents may have questions about their child's fertility after cancer treatments. One of the first questions asked is whether or not their child will be able to have children. It is important to realize that this is also a concern for adolescents, although they may not verbalize this fear. Fertility after cancer depends largely on the treatment protocol. Anticancer treatments may cause infertility by lowering sperm count in men and affecting ovulation in women. During treatment, a woman's menstrual period may stop or become irregular. Chemotherapy-related infertility is less common in women who receive chemotherapy before puberty. Cancer therapy also may lead to early menopause.

Adolescent males may want to discuss sperm banking with their physician before the start of treatment. Unless you have been specifically informed by your physician that your child may be infertile, you should assume that your child is capable of having children in the future. Your physician will advise and discuss all the options with you and your child.

It is not advisable to become pregnant while receiving treatment since most chemotherapy drugs and radiation can cause birth defects in the developing fetus. Please inform your treatment team if you think your child might be pregnant or having unprotected sexual intercourse.

Going through cancer treatment may initiate feelings for your child about their body, themselves and their relationships. Sexuality can often be a difficult subject to discuss. We want you to know that we treat each patient and their family with respect and

dignity, honoring privacy and confidentiality. We encourage open communication. Your doctor and nurses are always available to talk with you or your child about this issue or any other concerns. These conversations are always private.

Reminders for you and your child to consider

It is important to use some form of birth control if you are having sex.

To decrease the risk of infection and sexually transmitted diseases a condom should always be used.

Learn more about sexually transmitted diseases. Painful urination, blisters, sores and discharge in the genital area are indications that sexual activity should be avoided, and your physician should be notified of these symptoms.

Maintaining a single partner decreases the risk of sexually transmitted diseases.

Taking steroids, such as prednisone or antibiotics, may increase the risk of yeast infections. Report any signs such as white discharge or an itchy sensation to your physician.

LONG-TERM EFFECTS OF TREATMENT

During the past 20 years, there have been many advances in the treatment of childhood cancer. As a result, the growing population of childhood cancer survivors continue to teach us about the long-term effects of cancer treatment in children.

Children who are successfully treated for cancer may in later years develop abnormalities or “late effects.” These late effects can include psychologic or social problems, learning disabilities, various growth and developmental problems, organ damage, reproductive problems and the development of secondary cancers.

These are obviously difficult issues to consider when your child is first diagnosed and treated for cancer. 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 preventable side effects from taking place. We want you to feel informed and comfortable discussing these aspects of cancer treatment with your child’s treatment team.

When your child has completed treatment, it will be recommended that he/she receive follow-up examinations into adulthood. It is therefore, important to understand what possible late effects of your child's treatment are and what can be done to monitor and minimize the effects. Your physician can discuss these issues with you and explain the types of long-term follow-up that will be necessary.

INFECTION

Cancer and its treatment reduce the ability of a child's immune system to fight infections. Our goal is to help your child have normal relationships with other children, which is possible by taking certain steps.

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 during the time of therapy. Infections can occur even if you do everything possible to protect your child. Neither you nor other children, especially brothers and sisters, should feel guilt or responsible if an infection develops.

There are steps you can take to help prevent certain infections from occurring:

- Good hand washing is the most important way to prevent infection.
- Your child should wash his/her hands before meals, after going to the bathroom, after blowing his/her nose and throwing away the tissue and after playing with other children. All who care for your child (parents, doctors, nurses, 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 or symptoms of an infection, such as fever, cough, sneezes, sore throat or a rash. People who must be around your child with these symptoms should wear a mask and practice good hand washing.

Unless your treatment team asks you to, do not separate your child from brothers and sisters who are sick. It will not work, and it will make the other kids feel worse. Use common sense to prevent spreading infection in the family:

- Do not share spoons, forks or cups.
- Wash your hands.

If your child has an implanted catheter, follow instructions carefully for dressing changes and care. Always wash your hands before handling the catheter.

Contact your treatment team at once if you find signs or symptoms of an infection, even without a fever. Keep a close eye on your child's mouth, rectal area, biopsy or surgery sites, and areas of injury such as cuts in the skin (especially the fingers and toes) or burns. Watch for redness, fluid drainage, heat or an unusual degree of pain at the site of a wound.

Contact your treatment team at once if sisters, brothers, or anyone else your child has had close contact with are suspected or diagnosed to have chicken pox, measles or mumps.

Even when reasonable steps are taken ahead of time, your child may still develop fevers or infections. This is no one's fault. It is a risk of treating your child for cancer. If fever or infection develop, your most important job is to quickly contact the treatment team for further instructions. Keep the names and telephone numbers of your treatment team near the phone at all times, in case an emergency arises.

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 may infect a child whose blood counts are low. Children with implanted catheters or ports run a higher risk of bacterial infections, but infections can occur in any child during cancer treatment.

If your child develops a fever or other signs of infection during treatment, it may be necessary to use 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 may not be known for 48 hours, but antibiotics will be started even 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 cover the most likely and most serious sources of infection. Antibiotics will be continued until blood counts have increased and/or all signs of infection are gone.

Opportunistic infection

There are organisms that do not cause infections in healthy children, but that can cause serious infections in people whose immune systems are affected by cancer or its

treatment. These infections are called opportunistic infections. They include fungal infections, such as thrush or yeast infections, and pneumocystis carini 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 blood counts are low or when intravenous antibiotics are required for long periods. Your child may be put on a medicine called Bactrim to prevent pneumocystis carini pneumonia.

Viral infection

Viruses usually cause relatively minor infections, such as the common cold, but certain viruses can cause serious infections in a child receiving cancer treatment. Viruses are very hard to identify, and they cannot be treated with antibiotics. Minor viral illnesses are allowed to “run their course” in a child with normal blood counts. Because the source of infection is so hard to find in a child receiving cancer treatment, children with low blood counts and signs of infection (such as fever) may be treated with antibiotics even if a virus, rather than a bacteria, is suspected.

If your child develops any kind of rash, talk with your treatment team right away, because this rash may be caused by the chicken pox or shingles virus.

Chicken pox

Chicken pox 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, which can cause treatment delays and even death.

The treatment team can help prevent or treat chicken pox infection at the time of exposure if we know the child has been exposed. Therefore, it is very important that you are informed by teachers, friends, etc., when your child has been exposed to chicken pox.

If your child is in school, you and your treatment team can work with the school personnel to identify when exposures have occurred. Tell the parents of your child’s playmates to contact you at once if their child develops chicken pox or a suspicious rash. The fear of chicken pox is no reason to keep your child out of school or away from other children.

A medicine called VZIG (varicella zoster immune globulin) can be given to prevent most cases of chicken pox from developing. This medicine is given as a shot and is only effective if given within 96 hours of exposure. If you find out your child has been exposed, contact the treatment team right away (even on a weekend) so that we can decide if VZIG should be used.

Signs of chicken pox can start showing up 9 to 21 days after exposure. Usually chicken pox starts with one to two days of flu-like signs, including fever and sometimes vomiting. Then the rash appears, usually with small red spots on the face or head, spreading to the trunk and then to the arms and legs. After a few days, the red spots will turn into little blisters that then dry up and form crusts. The rash is often very itchy. Children are contagious up to 48 hours before the rash appears.

If your child develops chicken pox, there is a very effective medicine called Acyclovir, which controls the infection and reduces the risk of serious added problems. We also will encourage drinking lots of fluids and giving comfort for the itching. Oatmeal baths or special lotion can lessen itching. Hospitalization may be required.

Although chicken pox can be a very serious infection in a child on cancer treatment, we can protect children from added problems if we know about exposures and check carefully for the signs of chicken pox.

Shingles

Shingles is a type of infection caused by the chicken pox virus. After having had chicken pox, the virus will remain dormant in certain nerve cells of the body. If the immune system becomes stressed as can occur with cancer treatments, your child could possibly have an outbreak of shingles. Shingles usually occurs as patches of red or blistered spots that look like chicken pox along a line of skin on the back or chest but can occur in other parts of the body. It can be painful, with a deep burning feeling along the nerves injured by the infection. There can also be a fever, chills and flu like symptoms as the rash develops.

During cancer treatment, the signs of varicella infection can be different from the usual infection, especially if the child has been treated with VZIG. If your child develops any rash or other suspicious signs, contact your treatment team at once.

A word about AIDS or HIV infection

There has been much publicity and concern recently about AIDS (Acquired Immunodeficiency Syndrome). Because your child has been diagnosed with cancer, you may have questions or fears about your child's risk for developing this infection.

AIDS is an infection caused by a virus called HIV (human immunodeficiency virus). This virus is transferred by contact with bodily secretions from an infected person. This contact can occur during sexual intercourse, by sharing infected intravenous equipment or by transfusion with infected blood products. The virus also can be transferred to an infected mother's child during pregnancy, delivery, or breast feeding. Infection does not develop from community or household contacts, such as sharing food, playing together at school or kissing.

Having cancer does not increase the risk of developing AIDS. Children who receive transfusions of blood products during the course of treatment run a very small risk of contact with undetected viruses in the blood they receive. Children are transfused only when it is absolutely necessary. All human blood products used for medical purposes are screened for the presence of HIV and other viruses. The risk of infection through transfusions is extremely rare.

Talk with your treatment team about any concerns you, your family or your community have about blood transfusions and AIDS. The AIDS issue should not affect your child's treatment for cancer, but because of publicity and misunderstandings, fears may arise and cause stress for your family. By talking about these fears and answering your questions, we hope to keep this from becoming an added worry for you.

common questions asked by parents

1) What should I tell my child about cancer?

It is important to be honest with children and teenagers. Even young children are capable of understanding their illness if explanations are given at an age-appropriate level. Children need to understand what their disease is and how it will be treated. Your child will benefit from preparation before procedures and from your support during procedures. Your child will cope better if they can understand why, for example, they must take medicine or have blood drawn.

2) Should I go into the treatment room with my child?

Parents are welcome to be with their child. Some parents, however, prefer to wait outside and comfort the child after the procedure. Your primary nurse can help you decide which may be best. Adolescents often appreciate being asked if they want a parent with them.

3) Should my other children visit in the hospital and clinic?

It is important for parents to keep siblings informed about what their sick brother or sister is experiencing. Preparing them prior to a hospital visit can help them to deal with seeing their brother or sister hooked up to an IV or going through a test.

4) Can we travel during the time my child is getting treatment?

It is advisable to check with the oncologist beforehand and to plan a trip when blood counts are not at their lowest. The oncologist can arrange to speak with a pediatric oncologist near the area where you are traveling in case your child becomes ill or requires medical care.

5) How will having chemotherapy affect my child's ability to have children later in life?

Chemotherapy can cause infertility. The option of sperm banking is available. Please discuss this issue with your oncologist and primary nurse if you have concerns. If your child is sexually active, birth control options should be discussed.

6) What if my child needs a blood transfusion?

Because chemotherapy can cause decreased blood counts, it may be necessary for your child to have a transfusion of blood, platelets or plasma. The blood bank tests all blood and carefully matches it to your child's blood type, as well as screening for infectious diseases such as hepatitis or AIDS. There is a designated donor program available. Feel free to discuss this option with your treatment team.

7) Will my child lose his/her hair?

Many types of chemotherapy cause hair loss. Each child will respond to the chemotherapy differently. Your child's hair will grow back once treatment has stopped. In the meantime, hats, scarves and wigs sometimes help, depending on your child's wishes.

8) What if my child won't eat?

While in the hospital your child may not feel like eating. Encourage foods your child likes and cater to food preferences. Try not to make eating an issue. Your child will eat when he/she wants to. The dietician may have some helpful suggestions.

9) Should my child visit the dentist?

Yes. Inform the dentist that your child has cancer and is on chemotherapy; he/she may wish to consult with your oncologist before performing any procedures. Consult your oncologist to determine the best time to see the dentist. Generally, the best time for your child to undergo dental work is just before a course of chemotherapy, when his/her blood counts are going to be at their highest and the risk of infection is minimized. Ideally, your child's absolute neutrophil count should be over 1000 and his/her platelet count over 100,000 for dental work. All children with bone grafts or central lines will need to be protected with antibiotics prior to visiting the dentist. Please call your child's physician for advice.

10) Can my child play sports?

You should consult with your oncologist, because sometimes contact sports should be avoided because of low blood counts and central venous lines.

11) Can my child continue with his/her immunization schedule?

Immunizations must be postponed until your child finishes chemotherapy. In particular, the polio, measles, mumps and rubella vaccines should be avoided. Usually, immunizations can be given starting six months after chemotherapy finishes. Vaccination schedules for your other children may need to be changed as well. Please refer to the immunizations section for further details and check with your pediatrician.

12) When should my child return to school?

School should be resumed as soon as your child feels well enough to return. A school reentry program is available to help your child's transition back into school. Your child's nurses can organize the school reentry program.

going home

GOING HOME CAN BE BOTH AN EXCITING and frightening time for your family. You have gone through many changes and learned a great deal of new information about your child's disease. There is so much to understand, you still might not feel ready to go home and care for your child. Your child's discharge from the hospital will be coordinated by the entire team, and every effort will be made to support your transition home. Home support services such as visiting nurses will be arranged based on your family's individual needs. The nurses in the hospital and from the home health agencies will provide you with information and teach you the skills you need to learn to continue to care for your child at home.

Planning your next admission

Following your child's discharge from the hospital, you will need to arrange for your child's follow-up care. This care may include additional inpatient admissions, outpatient clinic visits or further diagnostic tests. We request that you make all of these arrangements through the secretaries in the Pediatric Hematology-Oncology Clinic, so that we can do our best to coordinate visits, tests, etc. In particular, any admissions for chemotherapy must be confirmed with the secretary in the Pediatric Hematology-Oncology Clinic. Although we try our best to keep track of each child's schedule, it is also your responsibility to help us make sure that admissions, scans, etc., have been scheduled. Also, the earlier we hear from you, the easier it will be to make more convenient arrangements for your child's care.

Blood tests are usually required one to two days prior to every admission for chemotherapy, and also for many outpatient chemotherapy visits. These tests can be done at the MGH, but it may be more convenient for you to use a local laboratory. We can help you find and use a local laboratory, and at the time we schedule an admission or clinic visit, we will also call the laboratory to make sure the proper tests are ordered. We ask that you call us after the tests are performed to make sure that the results are satisfactory for your child to get chemotherapy. If your child is not ready, we can reschedule his/her visit at that time. We also will be able to direct any questions or concerns that you may have to the physician or nurses.

The telephone number of the Pediatric Hematology-Oncology Clinic is **(617) 726-2737**. Regular clinic hours are Monday through Friday, 9AM to 5PM.

general information

PEDIATRIC HEMATOLOGY-ONCOLOGY UNIT

Location **Blake Building, second floor, room 255.**

Telephone number **617-726-2737**

Emergency Room telephone number **1-617-724-4113 (pediatrics).**

If there is no answer, call 724-4100 (the main emergency room number) and ask for pediatrics.

Clinic staff

The clinic is staffed by pediatric oncologists, oncology nurses and nurse practitioners, social workers, psychiatrists and secretaries. These individuals share their expertise to promote a holistic approach to caring for your child and family. Please feel free to call on the staff to answer any questions you or your child may have concerning his/her treatment.

Scheduling

To minimize your waiting, appointments are scheduled by the secretaries. Office hours are from 9AM to 5PM, Monday through Friday. Laboratory work (blood work) might be required prior to each visit. Laboratory work may be obtained at the MGH Laboratory or the laboratory at your local hospital. You will need to discuss this with your physician.

Emergencies

In case of an emergency during office hours, please call the clinic. If an emergency should occur after clinic hours or on holidays, a pediatric oncologist is available 24 hours a day. Please call the clinic number and the page operator will have a physician return your call. If for some reason the physician has not called you back in 15 minutes, please place the call again. If still no answer, call the Pediatric emergency room number at **617-724-4113.**

Taking your child's temperature

Fever is the most important sign of an infection and could be troublesome to a child receiving cancer treatment. Take your child's temperature if you notice tiredness or listlessness, chills or shakes, or skin that is warm to the touch.

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

Your child's temperature should be taken orally (under the tongue with the mouth firmly closed for 3 minutes) or axillary (left firmly in place under the arm for 3 minutes). A child on cancer therapy should never have his/her temperature taken rectally 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 100 or higher is reason to contact the treatment team at once. Although the fever can sometimes be treated at home, your child may need to be hospitalized for intravenous fluids and antibiotics. It is important to let the treatment team know at once about fever so that the best decision can be made for your child. Please check with your treatment team regarding fever and at what temperature you should call. Do not give Tylenol (acetaminophen) or Advil/Motrin (ibuprofen) for a temperature until you talk with the treatment team. Do not give aspirin or any aspirin products. The team will let you know whether or not to give any of these medicines to your child.

Medicines

Most medicines that are given orally for cancer therapy should be given one hour before meals or two hours after meals. However, prednisone should always be given with meals or milk.

If your child vomits 15 to 30 minutes after taking a medicine, you cannot assume it has been absorbed. Do not repeat a chemotherapy medicine without first talking with your treatment team.

Do not give aspirin. It may aggravate bleeding because it blocks the action of platelets. Aspirin-free medicines, such as Tylenol or Motrin/Advil may be used for pain, fevers or discomfort. Check with your physician before giving any medication.

Tylenol is also called acetaminophen. Aspirin is called acetylsalicylic acid. Read the tiny print on your medicine bottle and all other over-the-counter medicines. If you are still unsure about any medicines you have, you can always ask your physician or pharmacist.

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 also may 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. Know all of your child’s medicines and allergies. It is helpful to bring your child’s medicines with you to all of your clinic visits so you can review them with your physician. Keep your medicines organized in a small carry bag. Be sure to keep these and all other medicines away from small children.

Exposure to sun

It is a good practice for everybody to protect themselves from sun exposure. If your child has had radiation therapy or certain chemotherapy medicines, he or she may easily sunburn and should be protected from exposure by reducing the time in the sun, especially in the middle of the day, wearing protective clothes (especially hats), and using at least a SPF factor 15 PABA free screen lotion. It is important to apply the lotion before your child goes outside and reapply every two hours and/or after playing in the water.

when should I call the pediatric hematology-oncology unit?

PEDIATRIC HEMATOLOGY-ONCOLOGY UNIT

Blake 255: (617) 726-2737

- Temperature—100 degrees or higher. (Do not take Tylenol unless first speaking with the oncologist. Never take aspirin)
- Infection—redness, tenderness or drainage anywhere on the body.
- Bleeding—persistent nosebleed (longer than 5 minutes) or bleeding gums; blood in the urine or stool (stool that is red or black); bruising or petechiae (tiny red/purple flat dots).
- Anemia—excessive tiredness, paleness, shortness of breath.
- Nausea and vomiting—lasting more than six hours in an infant or toddler; lasting more than 12 hours in an older child or adolescent.
- Dehydration—decrease in usual urine amount; dry mouth; no tears when crying; sunken eyes; irritability; dizziness that continues more than a minute after changing position (standing up).
- Diarrhea or constipation—lasting more than two days.
- Headache—severe or persistent.
- Pain—severe or persistent; when urinating or with bowel movement, mouth sores, sore throat.
- Difficulty breathing—coughing that does not stop; rapid breathing.
- Exposure to infection—anyone with chicken pox, shingles, measles or other infectious diseases.
- Difficulty with central venous line (CVL) or port-a-cath—chills after line flush; line won't flush; line leaking blood or body fluid; line falls out.
- Change in vision, hearing or sense of balance.
- Anytime your child does not feel or look right.
- Anytime you are worried about your child.

MGH Emergency Department: (617) 724-4100

immunization

IMMUNIZATIONS ARE AN IMPORTANT PART of health care. They are given to help protect children from certain infectious diseases. However, children who are receiving chemotherapy should not receive most of the usual childhood immunizations. In particular, live virus vaccines should not be given to children receiving chemotherapy because of the possibility of serious adverse effects, which can include developing the disease for which the vaccine is given.

The following is a list of vaccines that your child should not receive while on chemotherapy:

- MEASLES
- MUMPS
- RUBELLA
- VARICELLA

Siblings

There is also a risk that your child might develop a disease from a vaccinated sibling.

We do not recommend that siblings receive the varicella vaccine while your child is receiving chemotherapy. There is a risk that your child might develop chicken pox from the sibling that has received the vaccine.

Measles-Mumps-Rubella vaccine (MMR) can be given to siblings, because transmission of these vaccine viruses usually does not occur.

As of January 1, 2000, the oral polio vaccine (live Sabin vaccine) was discontinued. It was replaced by the injectable polio vaccine (inactivated Salk vaccine). This is important for immunocompromised patients and their families. There is no longer a risk that your child might develop disease from a sibling vaccinated for polio.

Once the chemotherapy is finished for six months, all regular immunizations can be given to both patients and their siblings.

Schools often require immunizations prior to attendance. Ask your physician to give you a letter advising the school of your child's condition and waiving the requirements.

Your treatment team will advise your pediatrician about immunizations and safe administration to your child, household contacts and playmates.

glossary

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| Allogeneic stem cell transplant (Allo) | The use of another person's bone marrow or stem cells. |
| Allograft | The cancerous portion of a bone is removed and replaced with a bone from the bone bank. |
| Alopecia | Loss of hair, baldness. |
| Amputation | Surgical removal of a diseased limb or organ. |
| ANC | Absolute neutrophil count. |
| Anemia | An abnormally low number of red blood cells in the blood. |
| Anorexia | Loss of appetite. |
| Anticipatory nausea | Nausea or vomiting that happens before, rather than after, a treatment. This happens when someone expects to be sick from the treatment. |
| Anti-emetics | Medicines that can decrease or prevent nausea and vomiting. |
| Autologous stem cell transplant (auto) | The use of a patient's own bone marrow or stem cells. |
| Axillary (temperature) | Temperature taken by putting the thermometer under the arm. |
| Benign | Not cancerous. A benign tumor does not invade neighboring tissue and does not spread to other parts of the body. |
| Biopsy | A small tissue sample taken from the body and examined under a microscope. |
| Blast | A "primitive" or immature form of blood cell. Blast is another name for leukemic cells. There are normal blasts that are made by the bone marrow and grow to form mature white blood cells. Leukemia blasts are abnormal because they stay immature and do not mature to form white blood cells. |
| Blood counts | The number of red cells, white cells and platelets in a specific amount of blood. This is usually referred to as a complete blood count or CBC. |
| Bone marrow | The "blood cell factory" inside the center of the bones. The marrow produces all of the body's blood cells. |

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| Bone marrow aspiration | Taking a sample of bone marrow (see page 17). |
| Bone marrow biopsy | Taking a sample of bone (usually from the hip). |
| Bone marrow transplant (BMT) | Transplantation of bone marrow from one individual to another that is a treatment for some kinds of cancers and blood disorders. |
| Cancer | A general term for diseases that involve uncontrolled growth of abnormal cells. It also is called malignant neoplasm or malignancy. |
| Cells | The smallest unit of an organism. |
| Cellulitis | Infection of the skin and its underlying tissue. |
| Central venous | A type of intravenous line used to deliver fluids and medications into a large access line: vein. |
| Cerebrospinal fluid (CSF) | The fluid around the brain and spinal cord. A lumbar puncture (spinal tap) may take a sample of this fluid. |
| Chemotherapy | The class of medicines, also called anti-neoplastic agents, used to treat disease, especially cancer. |
| Clinical trial | A research study in which patients are treated according to a “protocol” or study guidelines. This is how treatments for diseases are improved and refined. |
| CNS | Central nervous system, which includes the brain and spinal cord. |
| Consent form | A written description of a treatment and/or medications to be used. A child’s parents or guardian must understand and agree to a treatment before it is given. Signing the consent form shows that they give their permission. |
| Consolidation | The second phase of chemotherapy, following induction. |
| Dehydration | Inadequate body fluids caused by decreased intake or losses (diarrhea or vomiting). |
| Edema | Swelling or an accumulation of fluid within the body’s tissues. |
| Electrolytes | Minerals in the body necessary to maintain a proper functioning of cells and organs, i.e. sodium, potassium, magnesium, calcium. |
| Emesis | Vomit or “throw up.” |

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| Extravasation | When a drug leaks out of the vein into the surrounding tissue. |
| Febrile | Having a fever, a person has a temperature that is above normal. |
| Fungus | A group of micro-organisms that may cause infection; different than bacteria or virus (example, yeast or thrush). |
| Hematocrit (Hct) | A measure of the percentage of red blood cells in the blood. |
| Hemoglobin (Hgb) | The part of the red blood cells that carries oxygen. |
| Hemorrhage | Loss of blood. |
| IM | Intramuscular, meaning “in the muscle.” For instance, an injection may be IM or subQ (subcutaneous), meaning in the fatty tissue just below the surface of the skin. |
| Immunosuppression | Inability of the body’s immune system to fight disease. The immune system includes the spleen, white blood cells and lymph nodes. Temporary immunosuppression is often a result of chemotherapy and radiation. |
| Induction | The first phase of chemotherapy treatment. |
| IT | Intrathecal, meaning within the fluid surrounding the spinal canal. |
| IV | Intravenous, meaning in the vein. |
| Lumbar puncture (LP) | May also be called a spinal tap. A technique to remove a small amount of the fluid that surrounds the brain and spinal cord. |
| Lymph system | Vessels or glands that are linked together and carry lymph, a fluid that makes and stores infection-fighting cells. |
| Lymphomas | Cancers of the lymphoid organs, (such as the lymph nodes, spleen and thymus) which produce infection fighting cells. These cells also occur in almost all tissues of the body. Therefore, lymphomas may develop in a variety of organs. |
| Maintenance | The last phase of chemotherapy. |
| Malignant | In cancer, this implies the ability of the cells to invade, spread, and actively destroy normal tissue. |

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| Metastasis | The spread of cancer from its original site to other parts of the body. |
| Mucositis | Irritation of the mucous membranes. “Mouth sores” or red/white patches or ulcerations may be seen in the mouth. Also called stomatitis (irritation of the stoma or mouth). |
| Neutropenia | An abnormally low number of neutrophils (one type of white blood cell) in the blood. |
| NPO | Nothing by mouth, a Latin abbreviation. This means the child must not have anything to eat or drink. |
| Oncology | The study and treatment of cancer. |
| Petechiae | A rash characterized by tiny red or purple spots on the skin. Petechiae may be caused by low platelets. |
| Platelets | A component of the blood that helps with clotting. |
| PO | Abbreviation for “by mouth.” This means that a medication may be given orally. |
| Prophylaxis | Something done to prevent diseases or complications. |
| Protocol | A document that details tests and treatments. |
| Relapse | When cancer returns after it had been removed or induced into remission. |
| Remission | When all tests show no signs of cancer. (Some cancer may still be present, but it cannot be detected by the tests.) |
| Resectable | A tumor that can be surgically removed, totally or partially. |
| Sedation | Medicine that is given to your child to help him/her relax or sleep, particularly before diagnostic tests. |
| Shingles | Localized form of chicken pox resulting from re-activation of varicella zoster virus in the nerves. |
| Sibling | A brother or sister. |

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| Spinal tap | Same as lumbar puncture. A technique to remove a small amount of the fluid that surrounds the brain and spinal cord. |
| Spleen | An organ that filters blood, makes antibodies and lies next to the stomach. Often it is enlarged in people diagnosed with leukemia and lymphoma. |
| Stem cell | The building block or seeds of bone marrow and blood formation. |
| Stomatitis | Sores in the mouth. |
| Tissue typing | Special blood testing to find a donor match for a stem cell transplant. |
| Toxicity | Side effects caused by treatments. |
| TPN (total parenteral nutrition) | One way to meet a child's nutritional needs with solutions containing vitamins, minerals, sugar, electrolytes, lipids and proteins. It is usually given through a central venous catheter. |
| Transfusion | Giving blood or blood products through an IV. |
| Tumor | An abnormal growth of cells that may be benign or malignant. |
| Varicella-zoster | The virus that causes chicken pox and shingles. |

sources of information

IF YOU WANT MORE INFORMATION about cancer and related topics, this list may be helpful to you. Many of these societies have monetary resources available to meet your needs.

American Cancer Society—Massachusetts Division

247 Commonwealth Avenue
Boston, MA 02116
(617) 556-7400

Association for Brain Tumor Research

3725 North Tolman Avenue
Chicago, IL 60618
(312) 286-5571
e-mail address: info@abta.org

Camp Sunshine

RR #1 Box 712
Casco, ME 04015
(207) 655-7948

Cancervive

6500 Wilshire Boulevard
Suite 500
Los Angeles, CA 90048
(213) 208-9232

Candlelighters Childhood Cancer Foundation

Suite 1001
1901 Pennsylvania Avenue NW
Washington, DC 20006
(202) 659-5136

Children's Oncology Camps Association (COCA)

Deborah Stephenson, Executive Director
1622 Ashley Hall Rd.
Charleston, SC 29407
(803) 571-4336
(803) 571-4337

Provides addresses and information about camps that are available to children who have cancer.

Leukemia Society

733 Third Avenue
New York, NY 10017
(212) 573-8484

Make-A-Wish Foundation

50 Milk Street - 15th Floor
Boston, MA 02109
426-4112
web address: www.wish.org

National Coalition for Cancer Survivorship

323 Eight Street SW
Albuquerque, NM 87102

National Handicapped Sports and Recreation Association

1341 G Street NW No. 813
Washington, DC 20005

National Hospice Organization

1901 North Moore Street
Suite 901
Arlington, VA 22209
243-5900

National Marrow Donor Program (NMDP)

3433 Broadway St., NE
Minneapolis, MN 55413
(800) 654-1247
Website: www.marrow.org

Starlight Foundation

75 St. Alphonsus Street
Boston, MA 02120

Cancer Resource Room at the MGH

HOPES Program (Helping Our Patients and Families through Education and Support)
Cox 1 Lobby at Massachusetts General Hospital
Blossom St.
Boston, MA 02114-2696
(617) 724-1822

SELECTED WEBSITES

American Cancer Society

www.cancer.org

American Society of Clinical Oncology

www.asco.org

The Genetics of Cancer

www.cancergenetics.org

National Comprehensive Cancer Network

www.nccn.org

National Institutes of Health (NIH) CancerNet

www.cancernet.nci.nih.gov

Oncolink

www.cancer.med.upenn.edu

Click on “Disease Oriented Menus,” then “Pediatric Cancers.”

Massachusetts General Hospital

www.mgh.harvard.edu

The Never Ending Squirrel Tale:

Practical tips & encouragement for the parents of kids with cancer.

www.squirreltales.com

PED-ONC MAILING LIST E-MAIL

listserv@medinfo.org

E-mail support group for parents of children with cancer. To subscribe, leave the subject line blank and in the body of the message, type: subscribe PED-ONC (your) first name and last name.

For example:

subscribe PED-ONC Sally Smith.