

Family Handbook for Children with Cancer

CureSearch

Children's Oncology Group

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We know that you are reading this Family Handbook because you've learned that a young person you care about has cancer. You are not alone. There are many young people and their families and friends facing this challenge, and there are countless doctors, nurses, psychologists, and other professionals working within the COG to treat the cancer and support young people and their families during and after treatment. In fact, their experiences have helped shape this Family Handbook.

Learning that a young person has cancer is scary and often overwhelming at first, but today nearly 80% of young people can be cured of their cancer if they are referred to established childhood cancer centers. Still, we understand that the "statistic" likely to matter most to you is just one: the child or teenager you love. This handbook can help you know how to take part in their care and manage their illness, its treatment, and the follow-up afterward.

Based on our experience and what parents have told us, we've done everything we can to make the Family Handbook useful, practical, and easy to read. It has information and concrete suggestions to deal with childhood cancer, and it can be custom-tailored for you. We encourage you to review the handbook and discuss it, along with any questions you have, with your doctor, nurse, or other members of the treatment team at your hospital.

We hope you find useful information and help in the pages of the COG Family Handbook. And we hope you'll let us know what you think of it, and give us your suggestions for future editions. That way, you'll be helping us help other families who are facing the challenge of childhood cancer.

Most sincerely,

A handwritten signature in black ink, appearing to read "Kathleen Ruccione".

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CHILDREN'S ONCOLOGY GROUP

FAMILY HANDBOOK FOR CHILDREN WITH CANCER

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INTRODUCTION

This handbook has been written by members of the Children's Oncology Group (COG) to help you learn about childhood cancer and how to care for your child. The handbook contains information about resources that are available to help you at your local hospital and in your community.

INTRODUCTION FROM YOUR HEALTH CARE TEAM

Disclaimer

Outlined boxes throughout the handbook indicate content that has been written by the health care team at your local hospital or clinic. The Children's Oncology Group does not assume responsibility for the opinions expressed or content in these boxes.

IMPORTANT PHONE NUMBERS

| | OPENS | CLOSES | PHONE NUMBER |
|----------------------------|-------|--------|--------------|
| Outpatient Clinic | | | |
| At Night/Weekends/Holidays | | | |
| Inpatient Unit | | | |

| YOUR TEAM MEMBERS | NAME | PHONE NUMBER |
|-------------------------|------|--------------|
| Doctor | | |
| Advanced practice nurse | | |
| Clinic nurse | | |
| Social worker | | |
| Child life specialist | | |
| Dietician | | |
| Chaplain | | |

CALL 911 OR EMERGENCY SERVICES RIGHT AWAY IF YOUR CHILD:

- Cannot breathe,
- Is not able to wake up, or
- Is having a seizure

CALL YOUR HEALTH CARE TEAM RIGHT AWAY IF YOUR CHILD HAS:

- Fever of _____.
- **Other signs of infection**
Pain, redness or swelling anywhere in the body (sore throat, ear ache, stiff neck, pain when urinating or having a bowel movement, pain or redness at the central line/portacath site), chills.
- **An exposure to chickenpox**
- **Bleeding**
Nose bleed or bleeding from the gums that does not stop with 5 - 10 minutes of gentle pressure. Blood in the urine or stool. Vomit or stool that looks black. Easy bruising or tiny, red freckles on the skin.
- **Difficulty breathing**
- **A change in behavior or level of consciousness**
Being very sleepy and being very irritable, or not making sense when talking
- **Vomiting, diarrhea, and not able to eat or drink**
- **Severe headache when he/she wakes up**
- **Break in the central line**

YOUR HEALTH CARE TEAM

As a parent, you are part of the team that will take care of your child. Depending on your child's needs and the staff at your hospital and clinic, any of the following people may be on your health care team.

Attending Physician

A doctor who specializes in cancer and supervises the medical care of your child.

Clinical Nurse Specialist/Nurse Practitioner

A nurse who has completed a master's program and specialty training in caring for children with cancer. He/she may coordinate the medical and nursing care of your child.

Child Life Specialist

A person who has special training in child development and how children react to illness and being in the hospital. A Child Life Specialist helps children to cope with cancer and its treatment.

Chaplain

A person who is trained to offer spiritual care, support and prayer according to each family's individual needs.

Fellow

A doctor who has completed medical school and a pediatric residency and is now receiving specialty training in pediatric hematology, oncology, or stem cell transplantation.

House Officer/Resident

A doctor who has completed medical school and is now receiving specialty training in pediatrics.

Nurse

A person who is trained to provide daily nursing care and teaching to children and their families in the hospital or clinic.

Nutritionist

A person who is trained to evaluate your child's nutritional needs and weight. The nutritionist also helps to provide teaching and support about eating and drinking when your child goes home.

Pharmacist

A person who is trained to prepare the medicines and nutritional support that your child will need.



Physical Therapist

A person who works with your child to maintain or restore a level of fitness through strength and endurance exercises.

Psychiatrist/Psychologist

A person who is available to help you and your child cope with feelings of anger, fear, depression, and hope that you or your child may experience. This person may also perform testing to see if your child has learning problems.

School teacher/Liasion

A teacher who works in the hospital to help your child keep up with school work during the hospital stay. The teacher can also keep in touch with your child's teacher at home.

Social worker

A person who is trained to help you and your child cope with illness and hospitalization through counseling, support groups, financial assistance, and resource referral.

Volunteer

A person who is trained as an unpaid helper with non-medical activities for your child.

OTHER TEAM MEMBERS AT YOUR HOSPITAL



WHEN TO CALL FOR HELP

Sometimes children with cancer will have symptoms that are warning signs of a serious condition. Your health care team considers these symptoms a sign of an emergency. An emergency means that you must take action right away.

Call 911 or Emergency Services

Some symptoms demand that you call 911 before you do anything else. These symptoms include:

- Your child is not breathing.
- You cannot feel your child's heart beating.
- Your child's skin and lips look blue.
- Your child is having a seizure.
- You cannot wake your child up (loss of consciousness).

Call Your Doctor Immediately

Other symptoms require that you call your doctor right away. Do not wait until the office or the clinic opens. Call the doctor's answering service and tell them to page your doctor immediately. These symptoms include:

- Your child has a fever.
- Your child has difficulty breathing.
- Your child has bleeding that does not stop within 5 - 10 minutes.
- Your child does not respond to your questions. Your child is awake, but seems "out of it."
- Your child has a change in vision.
- Your child has a severe headache that does not go away with Tylenol.
- Your child has vomiting or diarrhea and is not able to drink fluids.
- Your child has been exposed to chickenpox.
- Your child has a break in the central line (IV line in the chest).

Visiting the Emergency Room (ER)

If your child's central line breaks, your child has a fever, or another emergency, your doctor may tell you to go to the Emergency Room.

When you arrive in the ER, tell the nurse that your child is being treated for cancer and may have low blood counts. Tell the ER nurse what kind of cancer your child has, the date of the last treatment, and the results of the most recent blood counts. Make sure that the ER team knows that your child cannot have an enema, suppository, or rectal temperature. If your child has a fever, the team should give your child antibiotics as soon as possible.



DAILY ROUTINE AT YOUR HOSPITAL

- Vital signs** Your child's blood pressure, temperature, heart rate, and breathing rate will be checked every _____. In special cases, such as when your child has a fever or needs to get a transfusion, the vital signs will be checked more often. Vital signs help the health care team how your child's body is responding to cancer or treatment.
- Weight** Your child's weight may be checked as often as _____. Knowing if your child is losing weight is important. Weight loss may mean that your child is not eating or drinking enough. In some cases, your child may gain weight from too much fluid. In either case, the health care team needs to know when your child's weight changes during treatment. The dose of chemotherapy may also change if your child's weight goes up or down.
- Intake and Output (I/O)** Intake means how much fluid your child is taking in (by mouth and into a vein, also called IV). Output means how much fluid your child is putting out (urine, vomit, and stool). I/O may be measured every day to keep track of what your child drinks and how much your child puts out. If you change your child's diaper, do not throw it away. The diaper will be weighed to see how much urine is in the diaper. Even if your child uses the urinal or bedpan, do not flush the urine in the toilet until it is measured. Always remember to wear gloves for 48 hours after chemotherapy has been given when you are handling urine, vomit, or stool.
- Blood Tests** Your child will need to have blood tests done during cancer treatment. Blood tests are usually done very early in the morning so that the test results are ready when the doctors make the plan of care for the day.
- Rounds** Each day the health care team meets to discuss the plan of care for your child. This meeting is called *rounds*. The team looks at your child's blood tests, I/O, and talks about how your child is responding to treatment. The team will also come in the morning to examine your child and talk with you about the plan of care. Getting up and dressed before morning rounds is helpful. You want to be ready to talk with the team when they arrive. Write down questions you have before rounds to help you remember what to ask.
- Visitor Guidelines** You and your child may have visitors from _____ to _____. Check with the doctor or nurse if small children want to visit in the hospital or clinic areas. Anyone who has a fever, rash, diarrhea, vomiting, or other illness should not visit you or your child. Family and friends who may have been exposed to anyone with the chickenpox should not visit the hospital or clinic areas.

CLINIC GUIDELINES AT YOUR HOSPITAL

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Clinic Routine

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Visitor Guidelines

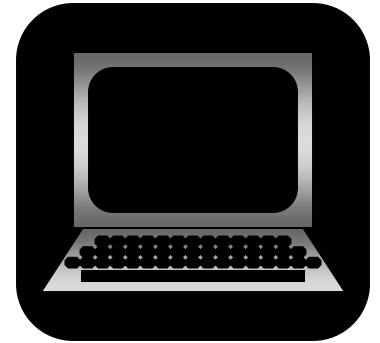
RESOURCES

Many resources are available at your hospital and clinic and in your community to help your child and family through this time. Types of resources available may include information, support, finance, housing, and transportation. The health care team needs you to let us know what types of resources would be most helpful to you. If you or your child needs something, let your health care team know.

Internet Sites

The Internet is a resource that you may find helpful. The Children's Oncology Group, your health care team, hospital, or clinic does not guarantee the accuracy of the content on these sites. If you have questions about what you read on any of the sites, please ask someone on the health care team to discuss the content with you.

The following web sites have information about cancer and cancer resources



| | |
|---|--|
| Children's Oncology Group | www.childrensoncologygroup.org |
| | www.curesearch.org |
| National Cancer Institute | www.cancer.gov |
| | www.cancer.gov/clinicaltrials |
| NCI Medical Dictionary | www.cancer.gov/dictionary |
| Association of Cancer Online Resources | www.acor.org/ped-onc |
| | www.acor.org/mailing.html |
| Bone Marrow Transplant Newsletter | www.bmtnews.org |
| Brain Tumor Foundation | www.braintumor.org |
| Childhood Brain Tumor Foundation | www.childhoodbraintumor.org |
| Candlelighters | www.candlelighters.org |
| Complementary Alternative Medicine | www.nccam.nih.gov |
| Leukemia and Lymphoma Society | www.leukemia.org |
| National Coalition for Cancer Survivors | www.canceradvocacy.org |

RESOURCES AT YOUR HOSPITAL AND IN YOUR COMMUNITY

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SUPPORT GROUPS AT YOUR HOSPITAL

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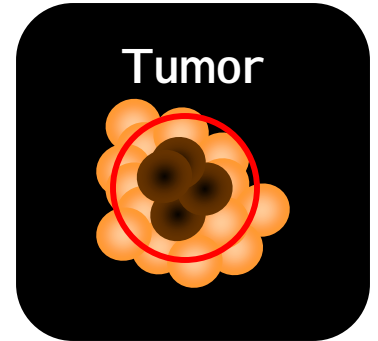
LAUNDRY RESOURCES

FOOD RESOURCES

WHAT IS CANCER?

Cancer is one name for a group of diseases. Each type of cancer has its own name, treatment, and chances of control or cure.

To understand cancer, you must first understand about cells. Cells are the basic building blocks that make up all the tissues and organs in the body. Cells divide to make new cells to replace damaged or old cells. Each cell has a nucleus (command center) that tells the cell when to divide and when to die. When cancer occurs, something goes wrong in the command center. The cancer cells grow out of control. Cancer cells divide when they shouldn't and stay alive longer than they should. Cancer cells can take the place of normal cells. A mass of cancer cells is called a tumor.



Types of Childhood Cancer

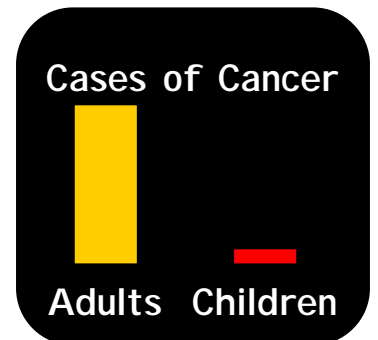
Cancer in children can be divided into three groups.

- Leukemias are cancers of the blood.
- Lymphomas are cancers of the lymph system.
- Solid tumors are cancers of the bone, organs, or other tissues in the body.

Your doctor and nurse will talk with you about your child's type of cancer.

How Childhood Cancer Differs from Adult Cancer

Cancers in children occur much less often and are different than in adults. Cancer in children usually grows in different types of body tissue. The most common sites of cancer in adults are skin, breast, prostate, lung, and colon. For children, cancers of the blood and bone marrow, lymph tissue, brain, nervous system, muscles, kidneys, and bone are most common. Cancer in children tends to respond better than cancer in adults to treatment.



Causes of Childhood Cancer

Many parents wonder what caused their child's cancer. They may fear that something they did or did not do caused the disease. As far as we know, nothing that you or your child did caused or could have prevented the cancer. We know that cancer is not contagious. You cannot catch cancer from another person.



Scientists are working to find the causes of cancer in children. For now, we do not know the exact cause of most childhood cancers. Only a few childhood cancers are hereditary (passed on from parent to child). Most parents think about what may have caused cancer in their child. Parents may feel responsible and blame themselves even though they could not have prevented the cancer. These feelings may be upsetting, but they are normal. If you have thoughts or concerns about what may have caused your child's cancer, talk to your doctor or nurse.

Questions for your doctor or nurse:

HOW IS CANCER DIAGNOSED?

Many procedures or tests can be done to see if cancer cells are present in the body. Depending on your child's symptoms and type of cancer, your child may have none, one, or all of these tests. For any test, you need to understand why the test is being done, what the test will feel like, what risks are associated with the test, and how to help your child be as comfortable as possible during the test.

Biopsy

In a biopsy, a small piece of tissue is taken out of the body and tested for cancer cells.

- An open biopsy is when the skin is opened during surgery to get a sample of tissue.
- A closed biopsy is when a needle is put into the tissue without cutting open the skin.

Some biopsies are done in the operating room under general anesthesia. Other biopsies are done using local anesthesia. The type of anesthesia used will depend on where the tumor is in the body.

Bone Marrow Aspirate

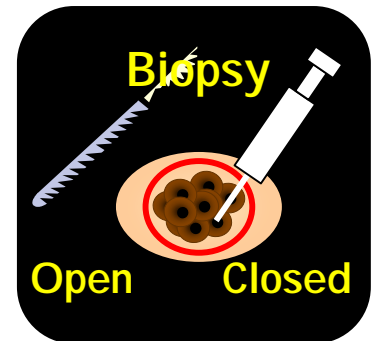
A bone marrow aspirate is a test that is done to see if cells in the bone marrow are healthy. Bone marrow is the liquid spongy part of the bone where the blood cells are made.

For this test, a needle is placed in a bone (usually the hipbone) and a small amount of bone marrow is pulled into a syringe. The marrow is sent to the laboratory to be tested for cancer cells.

Your child may feel some pain when the needle is placed in the bone and may feel pressure when a syringe removes the bone marrow cells. The most common risk related to this test is pain. There is a small chance that your child could bleed under the skin or get an infection where the needle is placed.

Bone Marrow Biopsy

While a bone marrow aspirate is done to look at the blood cells in the bone marrow, a bone marrow biopsy is done to study an actual piece of the bone. For this test a needle is placed in a bone (usually the hipbone) and a small piece of bone is removed. The bone is sent to the pathology laboratory for testing.



Your child may feel some pain when the needle is placed in the bone and may feel pressure or “tugging” when the needle removes a small piece of bone. The most common risk associated with this test is pain. There is a small chance that your child may bleed under the skin or get an infection where the needle is placed.

Lumbar Puncture

A lumbar puncture (also called a spinal tap) is a test that is done to see if there are cancer cells or an infection in the fluid around the brain and spinal cord. Your child will be asked to lie on his/her side with chin tucked to chest and knees pulled up to the chest. In some cases older children can sit up and curl the back by tucking the chin to the chest. When the back is in a curved position, a needle can be placed in between the bones of the spine (vertebrae). Fluid from the spinal canal can then be removed through the needle and dripped into a tube that is sent to the laboratory to be tested. For some types of cancer, chemotherapy may be given into the spinal canal through the same needle after the cells are removed for testing. Some children may have a headache or backache after the test. There is a small chance that your child could get an infection in the spinal fluid after the test or infection or bleed under the skin where the needle was placed.

Medicines to Help Decrease Pain During Procedures

For each of the tests listed above the most common risk is pain. There are ways to help decrease your child's pain. Different types of medicine can help to decrease pain during the tests. If you think your child has pain during a test, tell your doctor or nurse. Members of the health care team can help prepare your child for the test and help your child find positive ways to cope with the test.

Local Anesthesia (Numbing the Skin and Tissues)

Before a test is done, a numbing medicine (such as EMLA, ELAMAX) can be placed on the skin where the needle will be placed. The cream numbs the skin and tissue about ¼ of an inch under the skin. After the cream has numbed the surface of the skin, another numbing medicine can also be given using a small needle that is placed a little bit deeper into the tissue. The numbing medicine may burn a little bit, but after one to two minutes, the tissue will feel numb all the way down to the bone. Using this type of pain medicine alone may be useful for older children who can lie very still.



Sedation

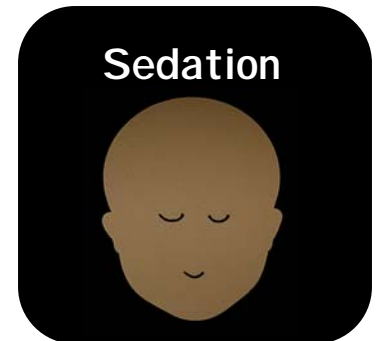
Sedation is the use of medicines that may make your child feel calm and sleepy, and possibly not remember having the test done. One medicine is a pain medicine (opioid) that works to decrease pain. Examples are fentanyl or morphine. Another medicine works to make your child relax and not remember the test. Examples are midazolam (versed) or valium. Using these two types of medicines together helps some children relax and not experience pain during the test.

These medicines may cause your child's breathing to slow down. Your child will be closely watched for changes in breathing and blood pressure. Your child may be on a heart monitor during the test and until your child is fully awake. Your child may not eat any solid foods or drink liquids for some time before these medicines are given.

Deep Sedation or General Anesthesia

Deep sedation or general anesthesia is the use of an anesthetic medicine, given into a vein or by a mask to make your child go completely to sleep. Your child will not feel pain, move, or remember the test during or after general anesthesia. Examples are ketamine and propofol.

There is a small risk that your child could have a slowing or stopping of the heartbeat or breathing. Your child will be watched closely on a heart monitor during the test and until your child is fully awake. A doctor or nurse, trained to give sedation or general anesthesia, will give the medicine and watch your child during and after the test. Your child will not be able to eat solid foods or drink liquids for a few hours before the test.



PROCEDURES AT YOUR HOSPITAL

CANCER STAGING FOR SOLID TUMORS

To determine the best treatment for your child, the health care team needs to know where the cancer is in your child's body. Staging is the way that doctors find out where the cancer is. To determine the stage of your child's tumor, the doctor will order a number of tests. Once the stage of the cancer is known, you and your child's doctor can talk about the best treatment plan.

The site where the cancer started is called the primary tumor. Cancer cells may spread to tissue around the primary tumor or break away and spread to other parts of the body (metastasis). Sites where the cancer has spread are called metastatic tumors.

Although the meaning of each stage may be different for different types of tumors, in general:

Stage I means that the cancer has not spread to other parts of the body.

Stage II usually means that the cancer has spread locally beyond the main tumor. The cancer may have spread to tissues or a lymph node close to the primary tumor.

Stage III usually means that the tumor is very large and difficult to take out.

Stages IV means that the cancer has spread beyond the primary tumor to distant parts of the body.



TESTS AND PROCEDURES FOR CANCER AND OTHER PROBLEMS

Bone Scan

A bone scan takes pictures of the bones to see if tumor or infection is present. A special dye (a radioactive marker) is given in the vein before the pictures are taken. This dye contains about the same amount of radiation as an x-ray. The dye goes to spots in the bones that are not normal. The scan may take up to an hour.

Your child will need to lie still during this test. Some children may need sedation (medicine that makes you sleepy) to be able to lie still for the whole scan. Some children feel closed in when the scanner passes over their body, but a bone scan itself does not hurt.

Other Nuclear Medicine Scans

There are other types of nuclear medicine scans that are like a bone scan: a PET scan, Gallium scan, and MIBG scan. The purpose of these scans is to look for cancer cells. A special dye is given in a vein before pictures are taken. Each of these scans uses a different type of dye. The dyes have a small amount of radiation. The dye goes to the areas of the body where cancer cells are. Your child will need to lie still during these scans.

Computerized axial tomography scan (CT scan)

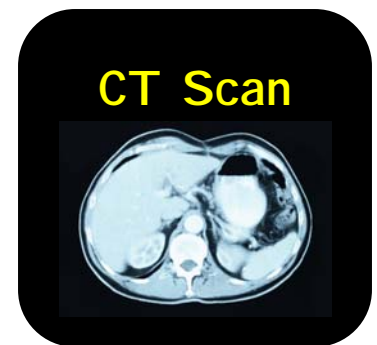
A CT scan uses a special x-ray to make a three dimensional picture of the inside of the body. The scan is done in the radiology department. Contrast dye may be given in a vein and/or by mouth.

Your child will need to lie still for up to 1 hour while the CT scan takes pictures around the body. Some children need sedation to be able to lie still for the whole scan. Having a CT scan does not hurt, but your child may become uncomfortable from lying still for a long time.

Magnetic resonance imaging (MRI)

An MRI uses a special machine (scanner) to look inside the body. The scanner uses magnetic waves to create a picture of the inside of the body. Your child will need to lie still on the table inside the MRI machine while the pictures are made.

Your child may not wear anything metal (jewelry, belt, etc.) because the machine attracts metal. Your child will hear a rhythmic knocking sound, like a drumbeat, when the machine is on.



X-Rays



You may not be able to stay in the same room with your child during this test; however, you and the staff can always hear and see your child. Having an MRI can last from 30 minutes up to 2 hours. Some children need sedation to lie still for the whole test. An MRI does not hurt, but some children do not like the knocking sound and may become uncomfortable from lying still for a long time.

X-ray

An x-ray is a picture taken of the inside of part of the body. For example, X-rays can show if a bone is broken or if an infection or fluid is in the lungs. X-rays do not hurt.

Ultrasound

An ultrasound works by bouncing sound waves off parts of the body. Clear jelly is placed over the part of the body that is being studied. A small round handle is then placed on the jelly and moved around to get a clear picture of the tissue or organ. An ultrasound does not hurt.

TESTS THAT DETERMINE HOW WELL THE ORGANS ARE WORKING

Complete Blood Count (CBC)

A CBC measures the different kinds of cells in the blood. The cells that are counted are the white blood cells, red blood cells, and platelets. A CBC is done to judge your child's response to treatment.

Audiogram

An audiogram measures hearing. Your child may be asked to wear headphones or have the hearing tested in a soundproof booth. Very young children may need to have their hearing tested while asleep. This type of hearing test is done by measuring brain waves when exposed to different sounds. An audiogram does not hurt.

Echocardiogram (ECHO)

An echocardiogram is a test of the strength and function of the heart. A clear jelly is placed on the child's chest. The person doing the test will use a small round handle on the chest to send sound waves, like in an ultrasound, to the heart. The sound waves create a picture of the heart. An ECHO does not hurt.



Electrocardiogram (EKG)

An electrocardiogram measures the rhythm of the heart. Small leads (plastic or paper circles with a metal center) are placed on different places on the chest and sometimes legs. A small amount of jelly is put on the skin under the leads. The leads are attached to a monitor that measures the heart rhythm. When the rhythm needs to be measured over several hours or a day, the test equipment is called a Holter monitor. The monitor is attached around the child's waist and hooked to the leads. Having an EKG or a Holter monitor does not hurt.



Glomerular Filtration Rate (GFR)

The glomerular filtration rate test looks at how well the kidneys are working. A special dye is given in a vein. After the dye is given, a sample of blood is taken at certain times to measure how much dye is still in the blood. The GFR helps to understand how well the kidneys are working by measuring how quickly the dye is removed from the blood. *

Creatinine Clearance

A creatinine clearance test is another way to measure how well the kidneys are working. Creatinine is a protein that is in blood and urine. You will collect your child's urine in a container for 24 hours. You will need to collect the urine every time your child goes to the bathroom. The amount of urine needs to be accurate. Your child's blood will be tested for the level of creatinine in the blood. The amount of urine and the amount of creatinine in the blood are used in a formula to measure kidney function. *

* If your child does not have a central line, a small needle will be placed in a vein (I.V.) to take several blood samples needed for the test. A numbing medicine may be put on the area to decrease pain or discomfort from the I.V.

Pulmonary Function Tests (PFTs)

Pulmonary function tests measure how well the lungs are working. The test measures how much air the lungs can hold and how well your child can push air out of the lungs. Your child will be asked to blow into a plastic mouthpiece connected to a machine. The machine measures the amount of air breathed in and the force of the air breathed out. Your child will probably be asked to repeat the test a few times to get an accurate reading.



Urinalysis

A urinalysis tests the urine. A small amount of urine is collected in a cup and sent to be tested. The number of white blood cells and red blood cells will be counted. The urine will also be tested for protein, bacteria and sugar.

CLINICAL TRIALS

Most children with cancer are treated on a clinical trial. A clinical trial is a research study done to improve treatment. The goal of clinical trials is to see if a treatment is safe and how well it works in treating cancer. In a clinical trial, children are followed closely over time to see which treatments offer the best chance for cure with the fewest side effects. New trials are planned based on results of past trials and what we know about the disease and cancer treatments.

Types of Clinical Trials

The different types of clinical trials are called phases. Each phase of a clinical trial answers a different question about the disease or treatment. Clinical trials can be designed to study how to prevent or treat cancer or how to improve a child's comfort or quality of life.

Clinical Trials

Phase I

Phase II

Phase III

Phase I

| | |
|--------------------|---|
| Purposes | Test a new treatment in humans that has been tested in the laboratory. Find the best way to give a new treatment. Find the safest dose of a new treatment or the highest dose with the least side effects. Learn how the body responds to a new treatment. |
| Methods | Patients are given a low dose of the treatment to see if side effects occur. The doses are increased in groups of patients until harmful side effects are seen. |
| Patients | Trial offered only to patients whose disease has not responded to other less experimental treatments. |
| Potential Benefits | Individual patients usually do not benefit from this type of study. A very small number of patients may respond to the new treatment. Future children benefit from what is learned in this type of trial. |
| Potential Risks | Side effects of new treatment may not be known. Patients may feel discomfort or pain from the new treatment. Patients may spend more time in the hospital or clinic to receive the new treatment or have tests done to evaluate the response. |

Phase II

| | |
|--------------------|---|
| Purposes | Learn if a new treatment works in patients with specific types of cancer. Learn how a new treatment affects the body. |
| Methods | Patients with different types of cancer receive a new treatment using a dose that was found to be safe in a Phase I trial. Patients are followed for side effects and response rates. |
| Patients | Trial offered only to patients whose disease has not responded to other less experimental treatments. |
| Potential Benefits | A small number of patients may have a response from the new treatment. |
| Potential Risks | Benefits of the treatment are not known. Patients may feel pain or discomfort from side effects. Patients may spend more time in the hospital or clinic to receive the new treatment or have tests done to evaluate the response. |

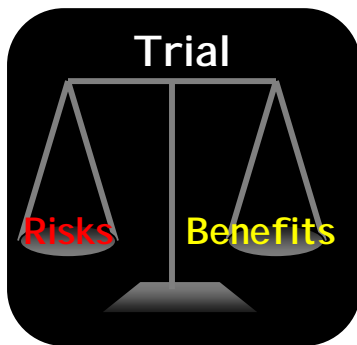
Phase III

| | |
|--------------------|---|
| Purpose | Learn if a new treatment that is known to be effective in treating a specific type of cancer is better in some way (better cure rates, longer control of disease, fewer or less serious side effects, or fewer days in the hospital) than standard treatment for the disease. |
| Method | Patients are assigned by a method called randomization to one of two or more treatment plans. |
| Patients | Patients with the same type of cancer who are eligible for standard treatment. |
| Potential Benefits | Trial offers the most up-to-date treatment with the best known response and cure rates. |
| Potential Risks | The new treatment being compared is thought to be at least as good as the standard treatment, but it is not known if the new treatment will be better than the standard treatment (that's the purpose of the Phase III study). |

Importance of Clinical Trials

The findings from clinical trials add to knowledge and progress in the treatment of cancer. Since childhood cancer is rare, by trying different treatments and looking at the results we can find out which treatments are the best much more quickly. In the 1960s, most children with cancer died. Since that time, the cure rates have increased dramatically. Today, overall more than 75% of children with cancer are cured. Organized clinical trials have helped to make the difference.

Benefits and Risks of Clinical Trials



You may ask yourself "How does my child benefit from being on a clinical trial"? When treated on a clinical trial, your child receives the most up-to-date treatment. Just as your child will benefit from what was learned by clinical trials in the past, other children in the future will be helped by what we learn from clinical trials today.

Some risks from clinical trials are that the treatment may have side effects. Your child may spend more time at the clinic or hospital to get the treatment or tests done. The treatment may not work for your child's disease.

Does my child have to be on a clinical trial?

To help you make a decision, you may want to get a second opinion. A doctor who is not a part of your current health care team will look at your child's history, laboratory findings, and exam. The doctor will give you his/her opinion about your child's treatment plan. Some insurance companies require a second opinion before starting treatment. Your doctor may refer you to another expert doctor. The National Cancer Institute has a toll-free number (1-800-4CANCER) and a web site (www.cancer.gov) to find cancer centers and doctors all over the country.

You may choose not to enter your child on a clinical trial. You may also choose to remove your child from a trial at any time. Your choice will not affect how the health care team feels about you or your child. Your child will still receive the best possible care.

If you decide not to enroll in a clinical trial, your child will receive what is known as *standard treatment*. Standard treatment is the best known therapy at the time.

Children's Oncology Group (COG)

The Children's Oncology Group is the largest pediatric clinical trials group. Over 240 hospitals participate in COG. For each new trial, a group of doctors, nurses, and other experts plan how the treatment will be given. Members of COG meet several times a year to learn from old trials, study the current trials and plan new trials.

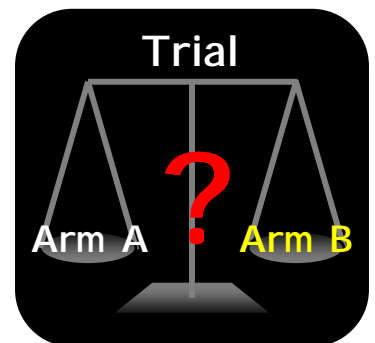
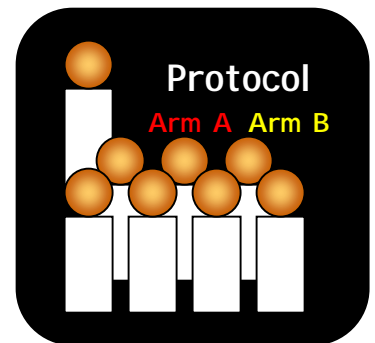
How are trials reviewed?

After a review by experts in COG, a trial is sent to the National Cancer Institute (NCI) for approval. Once approved by NCI, the trial is sent to your hospital's *institutional review board* (IRB). An IRB is a committee at a hospital or clinic that reviews a clinical trial to make sure that the rights of people who are in clinical trials are protected. Each trial is reviewed many times by many experts before any treatment center can start a trial.

Randomization

Your child may be in a clinical trial that compares two or more treatment arms (plans). The treatment arms come from other studies that have shown that both treatments are effective, but we do not know if one treatment may be better in some way. Usually one treatment plan is thought to be the "standard" or the current best known treatment. The other plan or plans have slight changes or additions that may improve cure rates, control disease longer, cause fewer or less serious side effects, or days spent in the hospital. To learn if one treatment is better, each child is assigned randomly to one of the treatment arms by a computer. Randomization is a process like flipping a coin that assures each child has a fair and equal chance of being assigned to any of the treatment arms.

In most studies we do not know which treatment is better until all the children on the study have completed treatment and have been followed for several years. However, if one of the treatment arms is found to be better than the others while the trial is in progress, the trial is stopped and all children are given the treatment with the best results. If for any reason the treatment plan is found to not be the best for your child, the plan will be changed. If a clinical trial is not currently open when your child is diagnosed, your child will receive the best standard treatment.



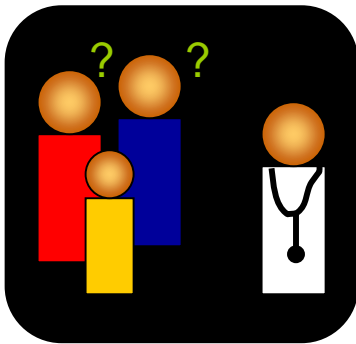
Roadmaps



Your doctor or nurse will review the treatment plan (protocol) for your child. In a protocol, a schedule for each treatment, test, and procedure is listed on a “road map” or guideline for your child’s plan of care. You can look at the roadmap to see when the next treatment is scheduled. You can also see what tests are planned to check your child’s progress. Your nurse may give you a calendar that has the roadmap information on it.

Keep in mind that each child is different and the treatment schedule may change. These changes will depend on how your child responds to treatment. A delay in treatment is common if your child gets a fever or has low blood counts.

Informed Consent



After your doctor reviews the treatment plan with you, you will be asked to give your permission for your child to start treatment. This is called giving *parental permission* or *informed consent*. You will be asked to sign a form that describes the plan. This form lists the risks and benefits of the treatment and what other treatments may be available. When you sign the form, you are saying that you understand what the doctor has explained to you and you agree to start the treatment.

If your child is old enough to understand, he or she will be asked to agree with the treatment plan as well. When a minor (a child less than 18 years old) agrees with the plan, the child is giving *assent*. Members of your health care team will help explain the treatment plan to your child in words that he/she can understand.

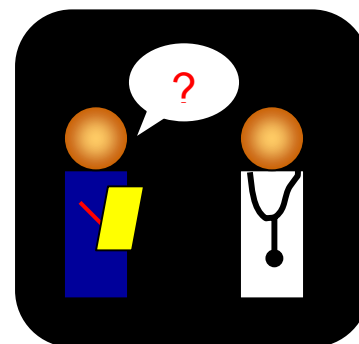
Informed consent is a process that does not stop after you sign the form or start treatment. Every day in the hospital or at each clinic visit, your doctor or nurse will talk with you about the plan of care. This is your chance to ask questions and decide whether or not you agree with the plan.

What questions should I ask?

Before meeting with your doctor, write down any questions you have. You may feel so overwhelmed that you can't think of any questions. Here are some examples of questions you may want to ask:

- What type of cancer does my child have?
- What is the stage of disease?
- What does this stage mean?
- What are the treatment choices?
- Which treatment do you recommend and why?
- How long will the treatment last?
- What are the chances that this treatment will be successful?
- How will we know if it is successful?
- What are the risks of this treatment (short-term and long-term)?
- What will I have to do as a part of this clinical trial that is different from standard treatment?
- How much will this treatment cost?
- How can I help prepare my child for this treatment?

Bring a pen and paper to your meeting so you can take notes. You may want to ask a friend or relative to come with you to take notes for you. You can also tape-record the meeting.



HOW IS CANCER TREATED?

Several different ways are used to treat cancer. As you read earlier, cancer cells grow out of control. Each type of cancer may be treated differently, depending on what researchers have found to be the most effective treatment in killing the particular type of cancer cell. In some cases, several types of cancer treatment are given. The main types of cancer treatment are described in the following section.

Chemotherapy

Chemotherapy is medicine that stops cells from growing or causes cell death. Each type of chemotherapy stops cell growth or kills cells in a different way. When chemotherapy destroys cancer cells, healthy cells may also be damaged. Chemotherapy can be given by mouth, or into a vein, muscle, or spinal fluid.

You will receive written information about the different kinds of chemotherapy medicine that your child will receive. Common side effects of most chemotherapy medicines include nausea, vomiting, low blood counts, mouth sores, and hair loss. Some side effects happen right away while some occur months to years later. The type and severity of long-term side effects depends on the type of chemotherapy that is given. For example, some chemotherapy medicines can cause learning problems while others can cause problems with fertility.

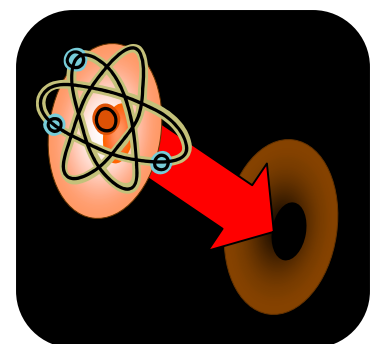


Radiation Therapy

Radiation is the use of high-energy x-rays to kill or hurt rapidly growing cells, such as cancer cells. Radiation can also damage healthy cells. Unlike chemotherapy, radiation does not cause cell damage throughout the body. Radiation only damages cells in the area of the body where the radiation is given.

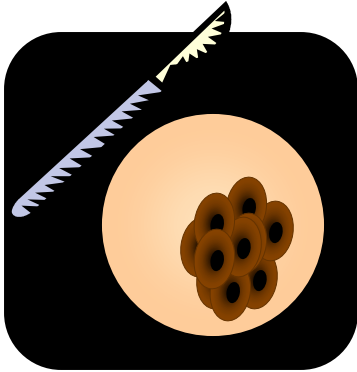
If your child needs to receive radiation, the radiation *field* (area) will be measured precisely and marked on your child's body. This process is called simulation.

You can clean your child's skin with mild soap and water. Do not wash off the markings until after the radiation treatments are finished. You should not use any deodorant, creams, or talcum powder on your child's skin while your child is receiving radiation, unless ordered by the doctor or nurse in the radiation department. Radiation makes the skin very sensitive.



Side effects of radiation depend on the dose received and the area of the body that is treated. Mouth sores are a common side effect of radiation to the head or neck. If the hip bones are radiated, blood counts may become low. Sometimes side effects of radiation are not seen for months or years. For example, radiation to the head and spine can lead to decreased growth, hormone production problems and/or learning disabilities. Radiation to the pelvis can cause problems with fertility.

Surgery



Different types of surgery are used to treat cancer. Taking out the tumor may be the only treatment needed, but usually chemotherapy or radiation is also used to kill any remaining cancer cells. Most surgeries take place in the operating room under general anesthesia.

Primary surgery

Primary surgery removes all or most of the tumor at the time of diagnosis. Sometimes, due to size or the area of the body, the tumor can not be safely removed right away. In this case, chemotherapy or radiation may be given before surgery to help shrink the tumor and make it easier to remove.

Second look surgery

Second look surgery is performed after treatment with chemotherapy, radiation, or primary surgery. Surgeons are able to see how well the treatments have worked in killing the cancer cells, and may be able to remove any remaining tumor.

Supportive care surgery

Supportive care surgery is done to help your child cope with cancer treatments. Your child may need to have a central venous line (catheter) placed in a vein in the chest. The line will allow treatments to be given and blood samples taken without your child being “stuck” with a needle. If your child is not able to take food by mouth, a gastrostomy tube (G-tube) may be surgically placed into your child’s stomach. The G-tube can be used to feed your child until your child can eat things by mouth.

Stem Cell Transplantation

The bone marrow is the factory where the blood cells are made. Bone marrow is found in the spongy part of bones, especially in the hips, ribs, breastbone, and legs. The youngest type of blood cell is called a stem or progenitor cell. As a stem cell gets older, it becomes a white blood cell, red blood cell, or platelet.

For some cancers, very high doses of chemotherapy and radiation are needed to get rid of all the cancer cells. These high doses of treatment may permanently destroy the normal stem cells in the bone marrow. The stem cells can be replaced with cells from a donor. This is called a stem cell transplant.

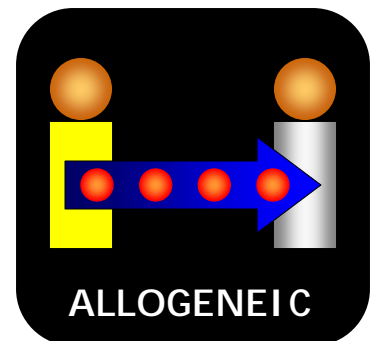
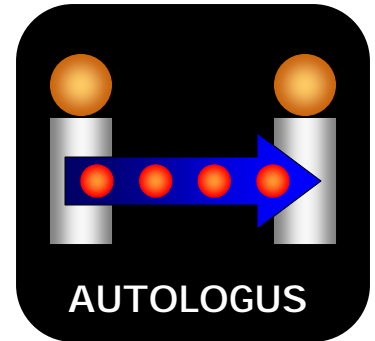
The stem cell donor may be the child with cancer, a relative, or someone not related to the child. If the child does not have cancer cells in his/her marrow, the child may be able to donate his/her own cells for a transplant. This type of transplant is called an autologous rescue transplant. If the child's bone marrow has cancer cells, most of the time healthy stem cells are donated by a relative or someone not related to the child. This type of treatment is called an allogeneic transplant.

If your child needs a stem cell transplant, a member of the stem cell transplant team will talk with you about the type of transplant that is best for your child. If your treatment center does not have a transplant program, you will be referred to a transplant center in your area.

Biotherapy

Biotherapy is sometimes called immunotherapy. Biotherapy uses the body's immune system to fight cancer cells. The immune system is a network of organs and cells that work to protect the body against disease. The immune system looks for cells that are not normal and tries to destroy them.

Biotherapy can help the immune cells to find cancer cells and destroy them. Biotherapy can also help to lessen the side effects of cancer treatments by helping the body to replace normal cells that have been damaged or destroyed. Biotherapy may also help prevent the spread of cancer cells in the body.



WHAT ARE THE SIDE EFFECTS OF CANCER TREATMENT?

Side effects occur when healthy cells are hurt. Different chemotherapy and radiation treatments cause different side effects. Side effects may happen right away, a week to ten days later, or even months to years later.

In general, the side effects from chemotherapy depend on the type and dose of chemotherapy that is given. Side effects of radiation depend on which part of the body is treated with the radiation therapy. For example, if the hips receive radiation, only the skin, bone marrow, and hipbone may be affected. Your doctor or nurse will talk with you about the side effects your child may experience.

In this section, some of the most common side effects of cancer treatment are described. Things that you and your child can do to prevent, watch for, and treat the common side effects are discussed.

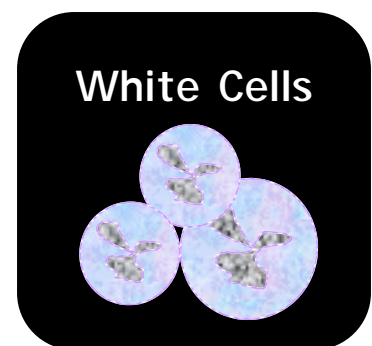
Low Blood Counts

The bone marrow is the spongy part of the bones of the body. The bone marrow is the “factory” where blood cells are made. When some types of chemotherapy are given or radiation is given to the bones, the factory slows down the making of blood cells.

Three types of cells are found in the marrow and the blood: white blood cells, red blood cells and platelets. Children who receive cancer treatment commonly have low counts of these blood cells. The blood counts usually drop one week to ten days after certain treatments are given and come back up in three to four weeks. The lowest level the blood counts reach is called the *nadir*. Your child’s blood count may be checked often around the expected time of the nadir.

Low White Blood Cell Count (Neutropenia)

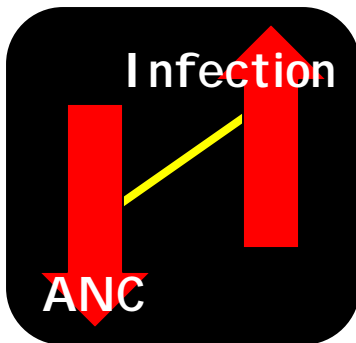
White blood cells fight infection. A normal white blood cell count is between 5,000 and 10,000 cells. The numbers on your blood count sheet may be written as 5.0 for a count of 5,000. When the white blood cell count drops below 1,000 cells (less than 1.0), the risk of infection increases. In some cases, your child may be given a medicine to help increase the number of white blood cells in the bone marrow.



Differential

Different types of white blood cells have different jobs. The *differential* is the breakdown of the different types of white blood cells in your child's blood count.

- Neutrophils help to fight bacterial infections.
- Lymphocytes make antibodies.
- Monocytes help to fight infection by killing and removing bacteria.
- Basophils and eosinophils respond during an allergic reaction.



You will hear the term *ANC* which stands for Absolute Neutrophil Count. The ANC is the total number of neutrophils in your child's white blood cell count. The lower the ANC drops, the higher the risk of infection. When the ANC drops below 500 the risk of infection is high.

You can use a formula to find out your child's ANC.

$$\text{ANC} = (\% \text{ segs} + \% \text{ bands}) \times \text{WBC}$$

Look at your child's differential. Add the percentage of *segs* and *bands* together. Segs, bands, polys or PMNs are neutrophils. Together they make up the neutrophil count. Multiply the neutrophil count by the white blood cell count (WBC).

Example:

$$\text{WBC} = 10,000 \qquad \% \text{ segs} = 20 \qquad \% \text{ bands} = 1$$

$$\text{ANC} = (\% \text{ segs} + \% \text{ bands}) \times \text{WBC}$$

$$\text{ANC} = (20\% + 1\%) \times 10,000$$

$$\text{ANC} = (0.21 \times 10,000)$$

$$\text{ANC} = 2,100$$

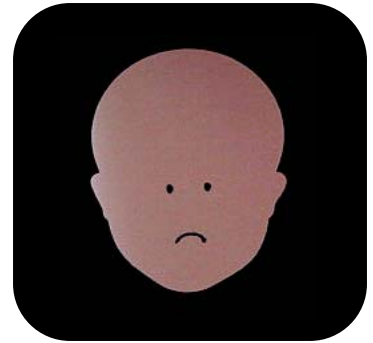
On most blood count reports you will see the ANC already calculated for you. You can also ask your doctor or nurse to tell you the ANC.

Signs of Infection

Call your doctor or nurse if you notice any signs of infection. If your child has a fever or pain (earache, sore throat, headache, pain with urination or having a stool), your child may have an infection. If your child has a central venous access device (central line or port), check for redness, swelling, pain, or pus at the site. If you see any of these signs, call your doctor right away.

Fever

A fever may be a sign of a serious infection. If your child has a fever, call your doctor right away. Children who receive cancer treatment are at high risk for getting a serious infection in the blood. If this happens and your child does not receive medical care right away, your child could get very sick and die. Any time your child has chills and does not look well, call your doctor right away. Do not wait for the clinic to open.



FEVER GUIDELINES AT YOUR HOSPITAL

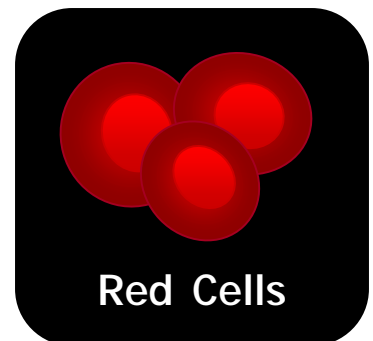
Taking your child's temperature

You do not need to take your child's temperature every day. Take the temperature if your child feels warm to touch or does not feel or look well. Take the temperature by mouth, in the ear using a special thermometer, or under the arm. **Do not take a rectal temperature** as this could cause bleeding or an infection. Make sure that you have a thermometer at home that works and that you know how to use it.

Low Red Blood Cell Count (Anemia)

Red blood cells carry oxygen throughout the body. Oxygen enters the lungs with each breath and binds (attaches) to hemoglobin in the red blood cells. Hemoglobin carries the oxygen to all the organs and tissues in the body. Two laboratory tests are done to measure the number and function of red blood cells: hemoglobin and hematocrit.

- Hemoglobin shows how much oxygen the red blood cells are able to carry. A normal hemoglobin is between 12 and 16.
- Hematocrit is the percentage of red blood cells in the blood.



Signs of a low red blood cell count

When the hemoglobin count is low, the body is not able to get as much oxygen to go throughout the body. A person with low hemoglobin may feel tired and short of breath. Other signs of low hemoglobin include having a headache, fast heart rate, pale skin or gums, or dizziness.

BLOOD TRANSFUSION GUIDELINES FOR YOUR HOSPITAL

For a hemoglobin less than _____, a blood transfusion may be given.

Blood transfusions

If your child needs a blood transfusion, the blood given will match your child's blood type. The blood will be given over several hours into a vein, through a central venous catheter, or an IV in the arm. Your child will be checked during the transfusion for signs of a reaction.

The most common concern about blood transfusions is related to the HIV/AIDS and hepatitis viruses. The risk of getting AIDS from a blood transfusion is very small, less than one chance in 676,000 donations. The American Red Cross or other blood bank centers provide the blood for transfusions. Each donor is tested for viruses, such as the HIV virus, hepatitis, and others. Blood that tests positive for any disease is thrown away. *Directed donation* (blood donated by a family member or friend) may also be available. Research studies have shown that directed donation does not increase the safety of the blood. However, giving blood is a way that friends and family can feel like they are helping. For more information about direct donation, ask your doctor or nurse.

Low Platelet Count (Thrombocytopenia)

Platelets stop bleeding in the body by forming clots. A normal platelet count is between 150,00 and 300,000 cells. When the platelet count is low, your child is at risk for bleeding.

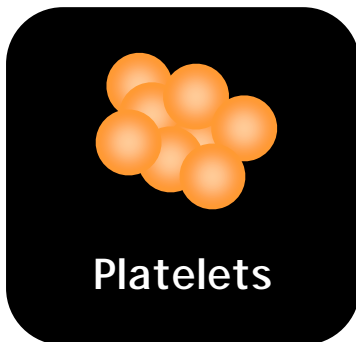
Signs of a low platelet count

If your child has a low platelet count you may see any of the following signs:

- Bruising or *petechiae* (small, red, pinpoint freckles on the skin).
- Bleeding from the nose, gums or central venous access device that doesn't stop with pressure for 5 - 10 minutes.
- Black stools or vomit may mean blood is in the stomach or bowel.

Nose bleed

If your child has bleeding from the nose, apply pressure to the soft part of the nose, just below the bridge. Pinch the area with your thumb and finger. Hold the pressure for 10 minutes. If the bleeding does not stop, call your doctor.



LOW PLATELET GUIDELINES FOR YOUR HOSPITAL

For a platelet count less than _____, a platelet transfusion may be given.

If your child has a low platelet count (less than _____), he or she should not play contact sports (football, rugby).

Use a soft toothbrush when brushing teeth to prevent bleeding of the gums.

How to prevent bleeding

Putting anything in the rectum can cause bleeding or an infection. Do not give your child an enema, a suppository (medicine put into the rectum), or check a rectal temperature. Do not give your child aspirin or ibuprofen (Motrin, Advil, and Pediaprofen) unless you are told to do so by your doctor. These medicines cause the platelets to not work well. Some over-the-counter medicines contain aspirin (salicylate) or ibuprofen. Read the labels and check with your doctor before giving your child any over-the-counter medicines.



Fatigue

Many children with cancer have fatigue during and off treatment. Children may describe fatigue as feeling tired, weak, or sad. Many things can cause fatigue:

- Cancer treatment (surgery, chemotherapy, or radiation)
- Low blood counts
- Poor nutrition
- Fever
- Pain
- Changes or decrease in sleep
- Worry
- Trying to do too much

Managing fatigue

Tell your doctor or nurse if your child has fatigue. You can do many things to help your child fight fatigue.

- If the red blood cell count is low, your child may need a blood transfusion.
- If your child's diet is poor, offer healthy foods every two to three hours, while awake. Try to make each snack as nutritious as possible. Talk to your nutritionist for ideas.
- Avoid caffeine.
- Find ways to decrease pain.



- Take frequent naps.
- Try to have a regular bedtime routine.
- Get 8 hours sleep each night.
- Try to have some physical activity every day.
- Talk with your doctor about working with a physical therapist to make an exercise program to increase your child's strength and endurance.
- Send your child to school for half the day instead of all day.

Nausea, Vomiting, and Diarrhea

Chemotherapy and radiation therapy can cause nausea, vomiting, and diarrhea. Any of these symptoms can place your child at risk for *dehydration* (loss of fluids in the body).

Nausea and vomiting

Chemotherapy and radiation therapy to the head, neck or stomach can cause nausea and vomiting. These treatments can irritate the stomach lining or trigger the nausea and vomiting center in the brain. Medicines to help decrease nausea and vomiting are usually given before chemotherapy or radiation. Some chemotherapy medicines cause more vomiting that lasts longer than others. The type and amount of anti-nausea medicine will be based on your child's treatment plan and reaction to the treatment.

Decreasing nausea and vomiting

Some ways to help decrease nausea and vomiting include:

- Eat small meals or snacks.
- Eat foods that are easy to digest (crackers, rice, jello).
- Take sips of cool clear liquids.
- Do not eat fried, spicy, or very rich foods.
- Eat food in a room that is free from cooking or other smells.
- Rinse your child's mouth after vomiting.

Diarrhea

If your child has *diarrhea* (frequent, liquid stools), tell your doctor or nurse the color, amount, and number of times in 24 hours your child had diarrhea. Some ways to help decrease diarrhea include:

- Eat a soft, bland diet (crackers, soup, rice).
- Eat small amounts of food more often, instead of large meals.
- Do not eat spicy, fried or fatty foods.
- Do not drink juices, milk or milk products (ice cream, cheese).
- Do not eat food high in fiber (fruits, vegetables, salad).
- Eat food with potassium (tomatoes, papaya, butternut squash).
- Limit high-sugar foods (juices, candies).



Dehydration

Fever, vomiting, and diarrhea can cause dehydration, especially if your child cannot drink to replace the fluid that is lost. If your child has dry skin or mouth, does not have tears when crying, or has small amounts of dark-colored urine, then your child may be dehydrated. If your child wears diapers, count the hours between wet diapers. Call your doctor if your child has any of the signs of dehydration (dry mouth, dry diapers, no tears).

Increasing fluid and food intake at home

If your child has vomiting, or diarrhea, have your child drink a small amount of fluid at least every 30 minutes. Give your child foods that are easy to digest like crackers, rice, toast, or soup. Offer your child cold foods that do not have strong odors. Your doctor may also prescribe medicines to decrease vomiting and diarrhea.

Constipation

Vincristine and other medicines, like pain medicines, can make your child constipated (have hard, less frequent stools). Encourage your child to drink water several times each day.

If your child is not able to drink a lot of fluid, try foods that are high in water (lettuce, fruits) to help decrease constipation. Give your child foods that are high in fiber (fruit, vegetables, salad, and whole grains). When starting a high-fiber diet, do it slowly (5-gram increase per day). A fiber supplement may also help. Your doctor may give you a medicine to make the stools softer. Do not use enemas or suppositories without talking with your doctor.

Weight Gain or Loss

Weight gain from steroids

Steroids (prednisone, decadron) may cause your child to gain weight. Steroids can cause an increase in appetite and a buildup of fluid (*retention*). Your child may gain weight in the face and stomach. Your child will be hungry and need to eat often. Give your child healthy snacks several times a day. Try to limit the amount of salty foods that your child eats. Salt causes fluid retention. Your child will lose weight after the steroids are stopped.





Weight loss

Many children lose weight during chemotherapy or radiation treatments. Your health care team will closely watch your child's weight. If your child cannot eat enough food to grow and stay healthy, your doctor will talk with you about giving nutrition through a tube or IV. Special formula can be given through a tube that goes through the nose into the stomach (*nasogastric* or NG tube). If your child has vomiting and cannot take food into the stomach, a special formula can be given through an IV. The formula is called *total parenteral nutrition* (TPN). See section on nutrition.

Suggestions to help your child maintain or gain weight include:

- Keep healthy foods that your child likes on hand.
- Give small snacks or meals every 2 hours during the day
- Try to add food that is high in calories, like ice cream in a milk shake or peanut butter on toast.
- Try not to offer a lot of fluids during meals, as this will make your child feel full quicker.
- Cook foods with strong flavors that may stimulate the appetite.
- Let your child help cook food.
- Activity before meals may increase appetite.
- Take advantage of the times that your child wants to eat. Always have food that your child can get easily.

Mouth Care

Cells in the mouth can be affected by chemotherapy and radiation therapy to the head and neck. Keeping the mouth and teeth as clean as possible is important. Your child will feel more comfortable and you can help prevent an infection from growing in the mouth.

Caring for your child's mouth

Have your child brush his/her teeth with a soft toothbrush after each meal and before bed. Rinse the mouth with water after brushing. Do not use mouthwashes that contain alcohol. Alcohol dries out the mouth. If a dry mouth is a problem, have your child suck on hard, sugar-free candy.

Caring for mouth sores

Some chemotherapy medicines and radiation therapy to the head and neck can cause mouth sores. The inside of the mouth and the tongue may be red. You may see white *plaques* (small raised areas) in the mouth and on the tongue. These plaques are from a fungal infection known as *thrush*.



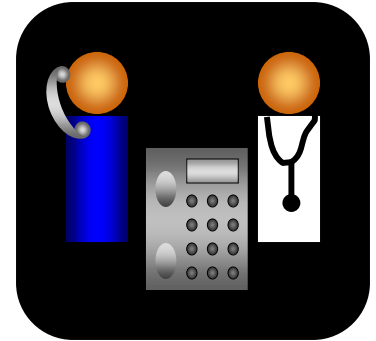
If mouth sores are a problem, give your child fluids. Have your child drink the fluids with a straw. Avoid hot, spicy, or acidic foods. Give your child foods that are cold or at room temperature. Try soft, tender, or pureed (beaten or blended) foods. Avoid dry or coarse foods. Cut foods into small pieces.

Rinse the mouth with water at least four times each day. Do not use mouthwash that contains alcohol.

Your doctor may give your child a medicine to treat a fungal infection in the mouth (thrush). If the mouth sores are painful, your doctor will give your child a pain medicine.

Call your doctor if your child cannot drink fluids, swallow spit (*saliva*) or if the medicine does not help take away the pain.

MOUTHCARE GUIDELINES FOR YOUR HOSPITAL



Pain

Pain in children with cancer can be from many causes. Cancer cells in the blood or solid tumors in the body can cause bone or tissue pain. Some side effects of cancer treatment, such as mouth or skin sores can be painful. Tests, like bone marrow aspirates and lumbar punctures, can be painful.

Telling the doctors and nurses if your child has pain is very important. The health care team will work to find out what is causing your child's pain. They will work with you to make a plan to decrease the pain as much as possible.

Children of different ages understand and respond to pain differently. Some information to help you understand pain in children and to know if your child is having pain is in the following section.



How children understand and respond to pain as they grow

| Age | Understanding and response to pain |
|--------------------|--|
| 0-3 months | Does not seem to understand pain. Memory for pain is likely, but not proven. May show pain by kicking or crying. |
| 3 - 6 months | Sadness and anger are a part of pain response. |
| 6 - 18 months | Memory for pain exists. Is fearful of painful situations. Uses words like <i>owie</i> , <i>ouchie</i> , or <i>boo-boo</i> to describe pain. |
| 18 - 24 months | Uses the word <i>hurt</i> to describe pain. Tries to avoid situations or objects that hurt them in the past. Will seek hugs, kisses, and medicine to deal with pain. |
| 2 - 3 years | Can describe pain and explain what caused the pain. |
| 3 - 5 years | Can describe the level of pain (no pain, a little pain, lots of pain). Will use distraction and play to relieve pain. |
| 5 - 7 years | Can more clearly describe levels of pain. Can use coping techniques to distract self from pain. Uses positive self statements. |
| 7 - 10 years | Can explain why a pain hurts. |
| 11 years and older | Can explain the value of pain. |

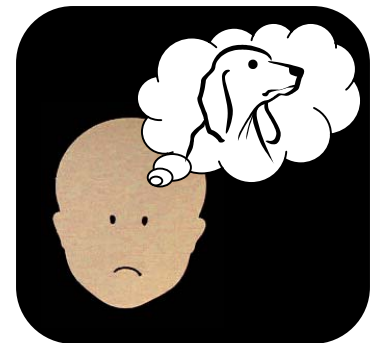
Use of pain medicines

Always talk with your doctor or nurse before giving your child pain medicine at home. If your child has pain, giving your child pain medicine is safe. Some parents worry that taking pain medicine, such as morphine, can lead to addiction. Less than 1% of people who take pain medicines become addicted. The type and amount of pain medicine and how it is given will depend on the type of pain, weight of your child, and whether or not your child can take medicine by mouth. The use of a pain scale may be helpful in rating how much pain your child is having. The goal of your health care team is to make your child as comfortable as possible.

Helping your child be more comfortable

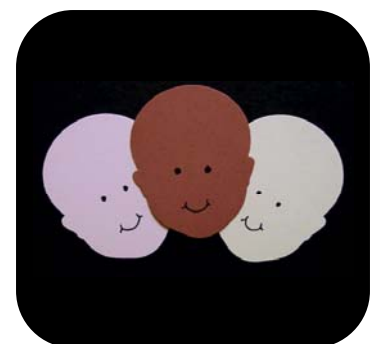
Parents usually know how to make their child more comfortable. As parents, you know your child the best. Tell the members of the health care team if you think your child has pain and what has helped to make the pain better in the past.

Some ways that you can help your child be more comfortable include distraction and visual imagery. *Distraction* is a way to help your child think or focus on something fun or relaxing. Watching a movie and listening to music are examples of distraction. Taking deep breaths helps the body to relax and may also serve as a distraction. *Visual imagery* is when a person pictures herself in a safe, relaxing, or fun place. Using any of these methods may help your child to feel more relaxed and less pain. A member of your health care team will talk with you about ways to help your child be more comfortable.



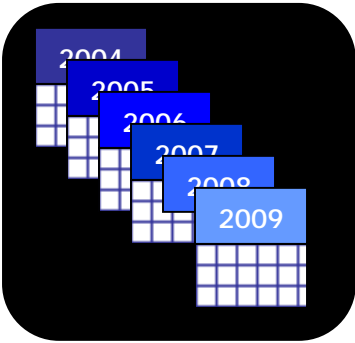
Hair Loss (Alopecia)

Some kinds of chemotherapy and radiation therapy to the head may cause hair loss or thinning of the hair. Hair loss may start 7 to 10 days after the treatment is given. In some cases all the hair falls out. Nothing can be done to prevent hair from falling out. Some children and parents prefer to cut the hair as short as possible when the hair starts to fall out. Others prefer to shave the head to keep the hair from falling out slowly. Many children wear hats or scarves and some buy a wig to wear until the hair grows back. Your social worker or child life specialist can help you order a wig or hair accessory.



Hair will usually grow back when the cancer treatments become milder or end. Your child's hair may be a slightly different color or texture (curlier, thicker, or thinner) than before the cancer treatment. In some cases, especially with high doses of radiation, the hair may not grow back where the radiation was given.

Late Effects of Cancer Treatment



Cancer treatment can cause side effects that happen years after treatment has ended. These effects include damage to the kidneys, liver, lung, heart, brain, reproductive organs, or a second cancer. The risk of late effects depends on the type and amount of treatment that your child receives. Your child needs follow-up care by a cancer specialist throughout adulthood. This care will include getting tests done on a regular basis to look for late effects. When you complete treatment, ask your doctor or nurse for a record of your cancer treatment. The records will help other health care providers know which long-term side effects to look for in the future.

TALKING WITH YOUR CHILD ABOUT CANCER AND TREATMENT

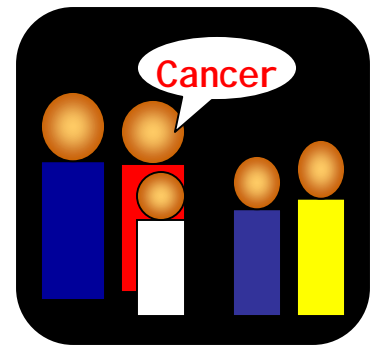
Often parents have a hard time telling their child about cancer. From years of experience, we know that not telling your child the truth can be harmful. Children quickly sense when something is wrong and can react by feeling lonely and separated from family and friends. Children often imagine that things are worse than they are.

Benefits of Telling Your Child About Cancer

You may be asking yourself, "Why should I tell my child about cancer"? Many parents want to protect their child by not telling them any information they think might scare their child. A child's world is scarier when they do not know what is happening to them and around them. The benefits of talking with your child about cancer and treatment are:

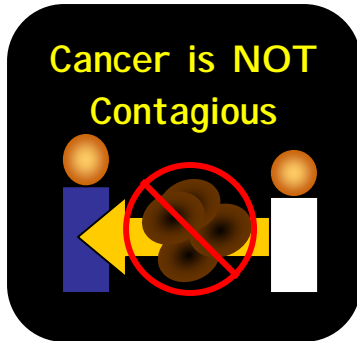
- Your child can build trust in both you and the health care team.
- Your child will know what to expect.
- Children fill in gaps of information with their imagination. Honest information helps correct any false ideas about cancer and cancer treatment.
- If your child understands the importance of doing some things (i.e. taking medicines, coming to the hospital, getting spinal taps, etc) they may be more cooperative during treatments.
- Knowing and understanding their illness allows children to have a sense of control during times when they feel out of control.
- You can help your child learn how to get through difficult situations.
- Your child will develop a skill that will be useful later in life.

Parents should consider their child's age when choosing the words that are used to talk about what cancer is and how it is treated. Your child life specialist can help you find ways to explain the diagnosis and treatment. You may use coloring books, teaching dolls, and other materials to help your child understand. Keep in mind that children learn from doing, seeing, and hearing things over and over. You may need to tell your child about cancer more than once. As children grow older they may need and want to know more about their cancer and treatment.



Cancer myths

Many myths about cancer exist that even adults believe. Talk to your child about what is true about childhood cancer.



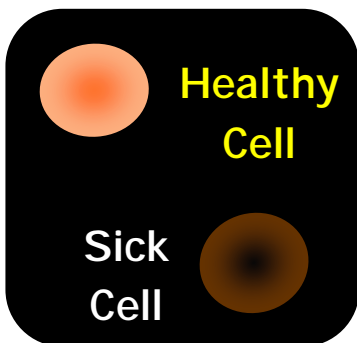
- **Cancer is no one's fault.**
Many children, brothers, sisters, and parents believe cancer is caused by something they did, said, or thought. What we think, say, and do cannot cause someone to get cancer. Cancer is not anyone's fault.
- **Cancer is NOT contagious.**
You CANNOT catch cancer from someone else.
- **Cancer causes hair to fall out.**
Many children believe that the cancer causes their hair to fall out. Actually, the chemotherapy or radiation treatment causes hair to fall out. Remember to tell your child that in most cases, the hair will grow back when the treatment is finished.
- **Cancer in children is the same as cancer in adults.**
Some children may have known an adult who was very sick with cancer or who may have died. Today, many children do very well with cancer treatments. Generally, children have much more energy and cope better than adults with cancer.

Tips on Talking with Your Child

Here are some tips to use when talking with your child about cancer. Remember that you will need to share more or less information depending on your child's age. Keep in mind that most children's hospitals have trained professionals, child life specialists, who can help you find ways to explain cancer to your child.

What is Cancer?

To help your child understand about cancer, first talk about how healthy bodies work. Cells are the building blocks of our bodies. Every part of the body is made of cells (hair, bones, blood, heart, skin, etc.). In healthy bodies cells work together to help us look the way we look and feel the way we feel.



After explaining how the healthy body works, talk with your child about cancer. Avoid using "bad cells" and "good cells" when talking about cancer so your child does not think they have "bad cells" because they are a "bad kid" or did something wrong. Instead use the words "sick cells" and "healthy cells."

Types of cancer

- **Leukemia**

Bone marrow is a factory where our blood is made deep inside our bones. It makes red blood cells (which carry oxygen and nutrients through the body), white blood cells (which fight germs and infections) and platelets (which help stop bleeding). Leukemia is a cancer of the blood. Leukemia cells are sick blood cells that do not work properly and crowd out healthy blood cells.

- **Lymphoma and Hodgkin's Disease**

The body has a defense system, the immune system. The immune system finds cells that are not healthy or cells that do not belong in the body and destroys them. The immune system stores fighter cells in lymphoid tissues in the body. Lymphoma and Hodgkin's disease are cancers of the immune system and lymphoid tissues. The sick cells do not work properly to protect the body and crowd out healthy cells of the immune system.

- **Solid tumors**

Explain the normal job of the area of the body where the cancer is located. (For example, talk about how leg bones support your body and help you walk and do the things you like to do). A solid tumor is a lump of sick cells stuck together. These sick cells crowd out the healthy cells and keep them from doing their job.

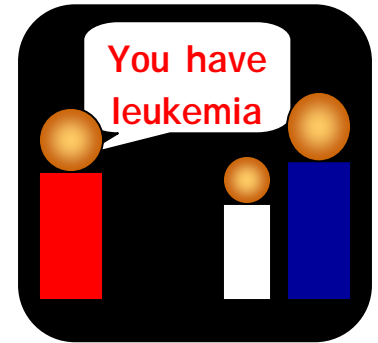
You may ask your child what he/she thinks causes cancer. You will have chance to correct any myths that your child may believe.

Types of treatment

After talking about what cancer is, talk with your child about cancer treatments. Be specific about the types of treatment your child will receive. Explain that other children with different types of cancer may receive different types of treatment or different amounts of the same treatment.

- **Chemotherapy**

Chemotherapy, often called *chemo*, is medicine that gets rid of fast growing cells. Cancer cells grow very fast. Chemotherapy is given to get rid of cancer cells. Our bodies also have healthy cells that grow fast. Chemotherapy hurts these cells too, but they usually get better. When chemotherapy attacks healthy cells, children may have side effects such as hair loss, upset stomach, mouth sores, fever, tiredness, or infection. Not all children have all of these side effects. The side effects that your child may have depend on the type of medicine that they get. Your treatment team will talk with you about what to expect based on your child's treatment plan.





- **Radiation**

Radiation uses strong energy rays that you cannot see or feel. Machines focus these rays on the area of the body where the cancer is located. Radiation destroys sick cells to stop them from growing and spreading. Radiation can also hurt healthy cells that are close to the tumor, but they usually get better. When radiation hurts healthy cells, children may have side effects such as hair loss, upset stomach, vomiting, mouth sores, tiredness, fever, and redness of the skin. Not all children have all of these side effects. The side effects that your child may have depend on the place where the radiation is given and the dose of radiation. Your treatment team will be able to discuss with you what to expect based on your child's treatment plan.

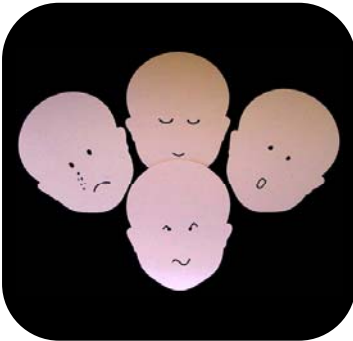


- **Surgery**

Surgery is when a special doctor takes out all or part of your tumor. During surgery you are given a special medicine (anesthesia) that allows you to be in a deep sleep so you cannot feel or see anything.

Feelings

After talking with your child about cancer and treatment, talk with your child about feelings. Assure your child that any feeling they have is normal. Many times children will feel angry, guilty, sad, lonely, scared, and sometimes even happy. Any feeling is all right.



Be honest with your child about your feelings. They can sense when something is bothering you. If you do not share your feelings or admit something is bothering you, your child may be scared. Sharing your feelings sends the message that it is okay to feel upset or angry.

HELPING YOUR CHILD COPE

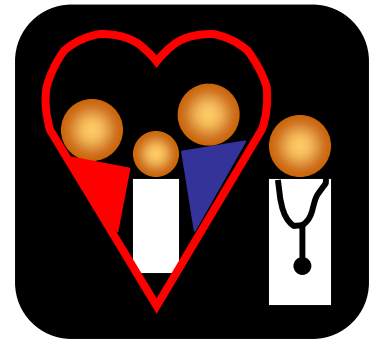
Cancer creates many changes and challenges for children and their families. As a parent or caregiver you may be asking:

- What does my child know about cancer?
- How will my child feel about the treatment?
- How can I support my child?

Children of different ages understand and react differently to cancer and its treatment. Your child's personality, normal coping style, support system, treatment plan, as well as age or developmental level will affect how your child copes with cancer. When children are faced with stress their normal behaviors may change. They often become more dependent on adults or may act younger than their age (baby talk, wetting pants after being potty trained, etc.). Your child may not know how to handle the many feelings that have been caused by the cancer diagnosis.

You are a very important part of your child's life for many different reasons. You know what your child has experienced in the past and how your child usually handles stress. You can help the health care team to understand your child. You and the health care team can work together to find new ways to help your child cope with cancer and treatment.

In the following section, common responses of children of different ages to stress and cancer are described. The section also contains specific suggestions for how to help children in each age group cope.



Infant (birth - 12 months)

Infants look to their parent(s)/caregivers to meet their needs. They rely on adults for food, comfort, play, and care. Infants learn about the world around them through their senses (i.e. can sense new smells, colors, tastes) and trust in people and things that are familiar. Infants have no concept of the meaning of cancer or its implications. They do respond to the new people and the environment around them.

Issues

How you can support your infant

Separation from familiar people

Be with your infant as much as possible.
Leave a shirt with your smell on it if you need to go.
Rock or hold your infant when in the hospital.
Keep a familiar blanket and toys in the crib.

Fear of strangers

Have familiar people care for your child.
Limit the number of people and voices in the room.

Development

Let your child explore toys with hands and mouths.
(Check for small pieces that may choke your infant.)
Use gentle touch and massage to comfort your infant.
Talk to and play games, like peek-a-boo, with your infant like you would at home.

Sense of safety

Keep your infant's crib safe.
Ask that any procedures be done in the treatment room.
Wake your infant before a painful procedure.
Continue or develop familiar feeding, bedtime, and bath time routines, like rocking, touch, singing.

Toddler (12 months - 3 years)

Toddlers are beginning to want to do more on their own. Your toddler's favorite words may be "me do" or "no." Growing toddlers need to be able to do some things by themselves to promote a sense of control. Toddlers show you how they feel in their actions because they do not have the words to describe their feelings. They have a hard time understanding how the body works. Toddlers tend to think that they make things happen. They can create their own false ideas about how they got sick and what happens to them (I hurt because I was bad).

Issues

How you can support your toddler

Fear of separation

Be with your toddler as much as possible.

When you leave, tell your toddler where you are going and when you will be back.

When you are gone, leave something of yours, like a picture or shirt, for your toddler to keep until you return.

Fear of strangers

Have familiar people care for your toddler.

Provide security objects like a blanket or stuffed animal.

Loss of control

Let your toddler make choices whenever you can.

Apple juice or orange juice?

Do not offer a choice when no choice exists.

Are you ready for your medicine?

Give your toddler a job to do. *Hold this band aid.*

Let your toddler play and be in control of the game or activity.

Loss of normal routine

Try to keep eating, sleeping, and bathing routines as normal as possible.

Let your toddler play with favorite toys.

Behavior changes

Give your toddler safe ways to express anger and other feelings. (Play-Doh, painting, building blocks)

Tell your toddler that it is all right to feel mad or sad.

Spend time with your child and offer reassurance.

Set limits with your toddler and discipline when needed.

Fear of treatment: Medicine, tests, vital signs

Assure your toddler that he/she did nothing wrong.

Keep security objects, like blankets, pacifiers, favorite toy, nearby.

Tell your toddler what will happen just before the treatment or procedure.

Use simple words, pictures, or books to tell them what will happen.

Preschooler (3 years - 5 years)

Preschoolers are also trying to do things on their own. They take pride in being able to do things for themselves; "I can do it." Preschoolers are learning more words to tell you what they think and feel. However, they often use their play to tell you these same things. They can see the hospital and treatment as punishment for something they did wrong. Also, they often get confused by adult words and make up reasons for the things that happen.

| Issues | How you can support your preschooler |
|--|--|
| Magical thinking (Made up reasons for what happens) | Tell your child what will happen a little before the treatment. |
| Use of terms that your child may not understand (A CAT Scan has to do with a cat.) | Use simple words, pictures, or books to tell your child about what will happen. |
| Fear of harm to their body and the unknown | Let your child play with doctor kits and safe medical supplies like a blood pressure cuff. |
| Loss of control | Allow your preschooler to make choice whenever you can. <i>Apple juice or orange juice?</i> Do not offer choices when choices do not exist. <i>Are you ready for your medicine?</i> Give your preschooler a job to do. <i>Hold the band aid.</i> |
| Loss of normal routines | Praise your child for doing things independently. <i>Dressing, brushing teeth, feeding</i> |
| Behavior changes | Give your preschooler time to adjust to new changes. Use play to help your child to show feelings. |

School Age (6 years - 12 years)

School age children take pride in being able to do most things by themselves. They enjoy school because it helps them to learn and master new things. Their friends are becoming more important. School age children are able to think in terms of cause and effect and have a better sense of time. They have more words to describe their bodies, thoughts, and feelings. School age children can also understand more of how their bodies work. However, they still may have a hard time with, and be confused by, medical words.

Issues

How you can support your school-aged child:

Loss of control

Allow your school-aged child to make choices whenever you can.

Do not offer choices when no choices exist.

Give your school-aged child a job to do.

Let your school-aged child practice things that are new and scary.

Let your school-aged child go to school or do school work and activities.

Provide games, play, and activities.

Being away from friends and school

Have your school-aged child write letters or call friends.

Let friends visit when your school-aged child feels well enough.

Fear of harm to body and unknown

Use simple words, pictures, or books to tell your school-aged child what will happen.

Tell your school-aged child what will happen a few days before the treatment, if possible.

Let your school-aged child play with safe medical supplies like a blood pressure cuff.

Teens (13 years - 18 years)

Teens are beginning to see themselves as individuals in the world. They are striving to be independent from the adults around them. As teens strive to think and act for themselves, their peers become even more important. Teens want to be like their friends and are concerned with how they are viewed by others. Illness and treatment cause teens to be different when they are trying so hard to be the same. Teens are able to see not only cause and effect, but also can see things from many points of view.

Issues

How you can support your teen

| | |
|------------------------|---|
| Loss of control | Allow your teen to make choices whenever you can. |
| Loss of independence | Let your teen be active in social and school activities. Involve your teen in the treatment plan by including them when talking to the team about the plan. Encourage your teen to do self care as much as possible. <i>Bathing, dressing, grooming, eating</i> |
| Body image | Give your teen chances to talk about physical and emotional changes. Tell your teen that having feelings about illness and treatment is all right. |
| Self-esteem | Point out things that your teen does well. Allow your teen to do things that makes him/her feel good about himself/herself. |
| Loss of privacy | Respect that teens may need to do some things by themselves when possible. <i>Bathroom, phone calls, email.</i> Offer your teen private time. |
| Separation from peers | Encourage time with peers. Allow friends to visit or call in the hospital or home. |
| Concern for the future | Answer questions openly and honestly. Help your teen plan for the future. Encourage your teen to keep doing normal things like school. |
| Behavior changes | Give your teen safe ways to express feelings, especially anger. <i>Physical activity, talking, writing.</i> Assure your teen that all feelings are normal. <i>Guilt, fear, sadness</i> |

CARING FOR YOUR CHILD AT HOME

Infection

Children who are being treated for cancer are at risk for infection. The most common types of infections that your child may get are bacterial, opportunistic or viral infections.

Bacterial infections

Bacteria can cause serious infections in children with low white blood cell counts. Bacteria lives on the skin and in the body. A healthy immune system and a normal white blood cell count prevent the bacteria from causing a serious infection. However, when the white blood cell count is low, the chance of getting an infection goes up. Children who have central lines also have a higher risk of getting a bacterial infection in the blood.

If your child gets a fever, it is important to call your doctor right away. Your child may need to come to the hospital or clinic to get antibiotics to treat the infection. Before antibiotics are started, blood cultures may be taken to see if bacteria are in your child's blood. Blood culture results may take up to 72 hours. Until the blood culture results are known, the doctor will order antibiotics that are most likely to kill the most common types of bacteria in children with cancer. If bacteria are present, the culture will help your doctor know whether to change to another antibiotic.

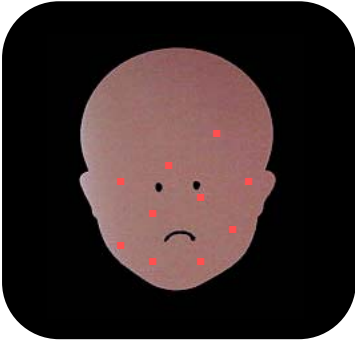
Opportunistic infections

Opportunistic infections happen only when the immune system is not working well. When that happens, germs that don't usually cause problems have an opportunity for infection. These infections include fungus (thrush or yeast) and a type of pneumonia called pneumocystis. Your doctor may give your child a medicine called Bactrim or Septra to help prevent pneumocystis. If your child cannot take this medicine by mouth, other medicines may be given.

Viral infections

Children who receive cancer treatment can get common viral illnesses such as colds and diarrhea. In most cases the body's defense system can handle these infections. Some viral illnesses such as chickenpox and shingles can be more serious in children with cancer. Both infections are caused by the varicella virus.





- **Chickenpox**

In healthy children chickenpox is a common, usually mild childhood illness. Chickenpox is caused by the varicella virus. It is spread through the air. The infection usually starts with 1 to 2 days of flu-like symptoms, such as fever and feeling tired. Then, an itchy rash appears. Small red spots with a clear, fluid-filled center appear on the face, head, or chest. The spots spread down over the arms and legs. New spots can develop for 3 to 5 days. After a few days the spots or "blisters" will dry up and form crusts.

For children who are receiving cancer treatment, chickenpox may be more serious because the immune system is not working well. If your child has been exposed to chickenpox or anyone in your family gets chickenpox, call your doctor right away. Exposure to chickenpox means that your child has been around a person who has chickenpox or breaks out with the spots within 1 - 2 days of playing with your child. Chickenpox is spread through the air. To be exposed, your child must breathe the same air as someone who has the illness. If other children in your family are exposed to chickenpox, they do not have to leave your home. Wait and see if they do get chickenpox.

Child has not had chickenpox

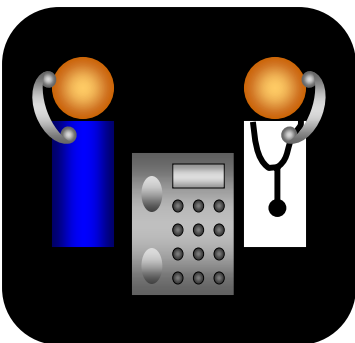
If your child has not had chickenpox or the vaccine and is exposed, your child will need to get a shot of Varicella Immune Globulin (VZIG). This shot has antibodies that help to prevent or decrease the severity of chickenpox. For the shot to work, your child must get the shot within 72 hours of the exposure.

Child has had chickenpox or chickenpox vaccine

If your child has had chickenpox in the past or has received the chickenpox vaccine, he/she may have antibodies to fight the virus, and does not need to get the VZIG shot. Ask your doctor if your child is at risk for getting chickenpox.

If your child gets chickenpox

If your child has symptoms of chickenpox, call your doctor right away. Do not bring your child or siblings to the clinic if they've been exposed to or have chickenpox. The doctor may order a medicine called acyclovir to be taken by mouth or IV to help control the infection. Your child may need to be admitted to the hospital for observation and treatment.



- **Shingles**

Shingles is another type of infection that is caused by the varicella virus. The virus stays in the body long after the infection goes away. If the immune system is not working well, the virus may become active again.

Shingles usually occur as a patch of red blisters along a line on the skin on the back, chest, or other part of the body. Shingles can be painful with a deep burning feeling. Your child may need to be admitted to the hospital for observation and treatment.

Prevention of Infection

Whether at school, home, or in your community, your child will be exposed to germs. We all have germs on our skin and in our mouth and gut that help us to break down food to be used by the body. Germs can also be found in the environment and in people with infections. Some suggestions for preventing infections in your child with cancer are described in the following section.

Handwashing

Encourage your child to wash his/her hands often to prevent the spread of germs from one person to another. Handwashing is the most important way to prevent infection. Encourage your child not to share cups, eating utensils, or toothbrushes.

Screen visitors and playmates for infections

Your child should play and visit with other children. Ask ahead if the playmate or visitor has been exposed to or has an infection. Find out if the person has a runny nose, cough, diarrhea, or rash. Anyone with these symptoms should not visit or play with your child. Do not allow your child to visit with someone who has been exposed to chickenpox. Chickenpox can be spread through the air for 1 to 2 days before the spots appear and until all the spots are crusted.

Cleanliness (Hygiene)

- **Dental care**

Keep your child's teeth, mouth, and gums clean. Brush the teeth after each meal and before bed with a soft toothbrush and toothpaste. Run warm water over the toothbrush to make it softer. Before going to a dentist, check with your doctor or nurse. Checking your child's blood counts before any dental work is important. Your doctor may want to prescribe antibiotics before dental work. If your child has a low white blood cell count or platelet count, the dental work may not be done or your child may need to receive an antibiotic before and after any dental work or cleaning.





- **Skin care**

Keep your child's skin clean by washing with mild soap and water. To prevent sunburn, your child should wear protective clothing such as a hat, long pants, and sleeves. Put sunscreen on exposed skin 30 minutes before going outdoors. Put sunscreen on again according to the package instructions or every two hours and after playing in the water. Remember that sun exposure happens all year, not just during the summer. Keep in mind that limiting the time spent in the sun is the best way to prevent skin damage.

Chemotherapy and radiation can affect the skin. Some treatments (methotrexate, busulfan, thiotepa, and bactrim) and radiation make the skin more sensitive to sunlight. Any skin that receives radiation will always be sensitive to sunlight. Sunburn can lead to blisters, which can get infected. Skin damage from the sun can lead to skin cancer as well.

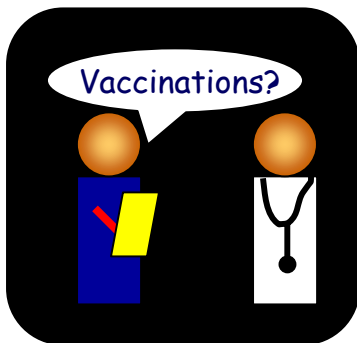
Caring for pets

Many children with cancer have pets. Your child should not clean animal cages (bird cage, turtle aquarium) or empty cat litter boxes. Stool and urine from animals can carry germs that can be spread to your child.

Vaccinations

Your child should not receive any live vaccines, such as oral polio or the mumps, measles, rubella vaccine (MMR) while on treatment. Live vaccines can cause illness in children who are at increased risk of infection. Talk to your cancer doctor (oncologist) before your child receives any vaccines.

To be safe, your other children should receive the inactive (dead) polio vaccine, which is given by shot.



Taking Medicines

Your child may need to take chemotherapy and other medicines by mouth. Always check to make sure your child is taking the right medicine in the right amount. Ask your doctor or pharmacist if different doses of the medicine have different colors or sizes. Some pills may not be crushed. Check with your doctor or pharmacist before crushing any pills. Here are some tips on helping your child to take medicine by mouth.

- Some medicines can be crushed and put in a small amount of food (applesauce, ice cream, juice, or flavored syrup). Make sure to use a small amount of food so your child can swallow all of it.
- Do not hide medicines in your child's favorite foods. Your child may not want to eat these foods in the future.
- Some medicines can be crushed and put in a gel cap for older children who can swallow a capsule.

In general, medicine should be taken 1 hour before meals or 2 hours after meals to help the medicine be better absorbed. Steroids (decadron or prednisone) should be taken with food. Steroids can irritate the stomach and cause bleeding if taken on an empty stomach. Ask your doctor or pharmacist for the best time to take each medicine. If your child vomits in less than 30 minutes after taking a medicine, call your doctor.

Herbal and Natural Products

You may choose to give your child herbal or natural products (vitamins, homeopathic remedies). While some of these products may be safe, some natural products may interfere with how well chemotherapy works. Cancer treatment often temporarily reduces a child's immune system. If supplements contain bacteria or fungi, infection may occur.

Listed below are some reasons why some natural products may not be safe for your child:

- Some of these products may interact with your child's treatment.

For example, if your child is taking methotrexate, vitamin C can cause the body to hold onto methotrexate longer, causing more side effects. St. John's Wort taken at the same time as etoposide (VP-16) may reduce the effectiveness of etoposide.



- Lack of studies to show that the product is safe (free of side effects) or effective.
- No dosing guidelines for young children.
- Each product may have different amounts of ingredients.
- Side effects may occur and interfere with treatment.

Talk with your child's doctor or nurse before using any vitamins, remedies, or other natural products.

Nutrition

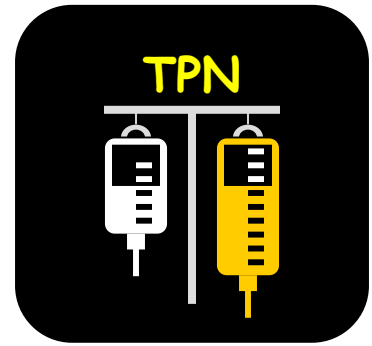
A healthy diet is an important part of helping your child's body to grow, heal, and work well. The body needs protein, carbohydrates, fats, vitamins, and minerals. As your child progresses through treatment, his/her appetite will change. Cancer treatment can cause changes in taste. For example, some food, usually proteins, may have a metal taste. These foods should be avoided until the metal taste goes away.

Steroids may cause your child to overeat and cause a temporary increase in weight. In some cases your health care team may want to limit further weight gain. You can talk with your doctor or nutritionist if you are worried about your child's weight gain. Together, you can make a plan to help your child get enough to eat but with less fat and calories.

You may notice changes in your child's choice of or desire for food (appetite). Your child may not like a past favorite food. New foods may taste good. Avoid forcing any food on your child. Your child may associate the food with a bad event, even after the cause is gone. The appetite usually returns to normal after a specific phase of treatment is over.

If your child cannot eat enough by mouth to keep the body working well, a special nutrient formula may be given through a tube. The tube may be placed in the nose and go into the stomach (NG tube or nose tube). A tube can also be surgically placed right into the stomach (G-tube or PEG). The formula will give your child fluid, calories, protein, vitamins, and minerals. You will be taught how to use the tube at home.

If your child cannot tolerate tube feedings or there is another medical reason to prevent the use of a tube, a different nutrient formula can be given through the IV. This special formula is called total parenteral nutrition (TPN or hyperal). TPN is made of two liquids. One is a yellow liquid that contains protein, carbohydrate, minerals, vitamins, and electrolytes. The other is a white liquid that contains fats. TPN can be given at home. However, formula that goes into the stomach is healthier for the body than TPN. In general, TPN will only be used if your child has nausea, vomiting, diarrhea, or another medical problem that prevents the use of feeding through a tube.

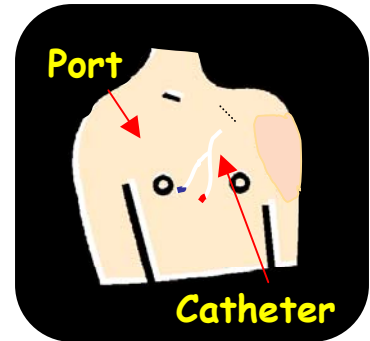


Caring for a Central Venous Line (CVL)

A central venous line (access device) is a soft tube that is inserted into a large vein that leads to the heart. The line can be used to give chemotherapy, blood products, nutrition, fluids, antibiotics, and other medicines. The line can also be used to take blood samples for lab work.

There are two types of central venous lines: external and internal.

- An external line is one in which the tube comes outside on the chest. Examples of external lines include a CVL, Broviac, or Hickman. Another type of external central line is called a PICC (peripherally inserted central line). This is a central line that is put in through a vein in the arm and then threaded up to a large vein that leads to the heart.
- An internal line is one that stays under the skin. Examples of internal lines include a Portacath, port, Medcomp, or Mediport.



With both types of lines, infection can be a problem. If you see any redness, swelling, pus, shaking chills after flushing, or your child complains of pain, call your doctor right away. Always wash your hands before touching the line or dressing.

If your child has an external line, never use scissors near the line or the dressing. If you see a break or leak in the line, clamp the line right away. Use a shoelace, rubber band, paper clip, or clamp to tie off the line between the break and your child. You must take your child to the hospital right away to have the line fixed.

If you are flushing the line and you feel *resistance* (fluid is hard to push in), do not force it. Check to make sure the line is not twisted or clamped and try again. If you still feel resistance, call your nurse or doctor.

**YOUR HOSPITAL'S INSTRUCTIONS ON CARING
FOR YOUR CHILD'S CENTRAL LINE**

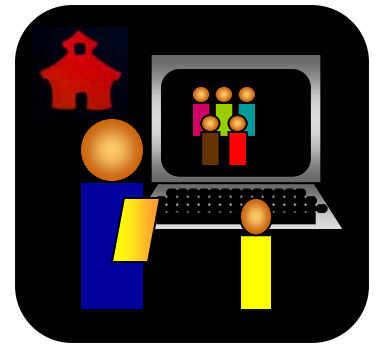
Going Back to School

Your child needs to continue to learn, grow, and interact with *peers* (friends). Going to school is an important part of your child returning to a normal routine. School also helps children to feel good about themselves and hopeful for the future. Your doctor will talk with you when your child is ready to go back to school. Your child's nurse or child life specialist may be able to go to your child's school to talk with the classmates and explain what cancer is and how it is treated.

Let your child's teacher know to call you if any child in the class gets a contagious illness like chickenpox.

Many children find it hard to go back to school, especially if they have changes in their body. Hair loss and weight loss, or weight gain are common concerns. Tell your doctor or nurse if your child is worried about going back to school. Your child life specialist, social worker, or nurse may be able to help. If your child is having problems doing school work, ask for extra help. Two laws in the United States allow for children with cancer to get a special education plan, which may include extra help. These laws are called the IDEA (Individuals with Disability Act) and Section 504 of the Rehabilitation Act. Talk with someone from your health care team to see how these laws may apply to your child.

If your child is not able to go to school, talk with your child's teacher. Your doctor can write a letter to the school to explain your child's diagnosis and treatment. Your child's teacher can send schoolwork home and find ways to keep your child in touch with the other children in the class. Your school must also provide homebound instruction, if needed. A tutor may come to your home to help your child with school work.



CARING FOR THE WHOLE FAMILY

Coping with Your Feelings

Since the time of your child's diagnosis, your lives have not been the same. The diagnosis of cancer brings changes to your life and the lives of the whole family. Every family is different. Each family has ways to cope with stressful experiences. Many families have told us about feeling fear, anger, depression, and guilt. All these feelings are common human emotions. You are not alone. Talking with family and friends, a member of the health care team, or another parent of a child who has cancer may be helpful. By sharing these feelings you may find it easier to cope with the changes you are experiencing.

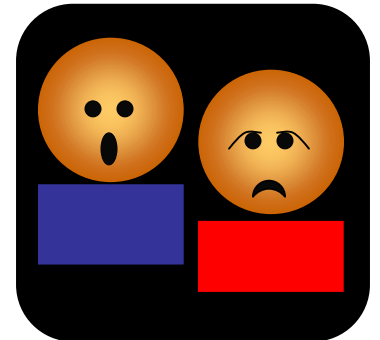


Fear

The time of diagnosis is often the most difficult. The fear of the unknown may be overwhelming. This experience may be your child's first hospitalization. Dealing with the stress of your child adapting to a new and sometimes frightening environment may be difficult. You may also have fears about treatment, your expenses, or how you will help your child to cope with cancer. Talking about these fears and getting them out in the open can be helpful. The health care team is here to listen to your concerns and help you.

Anger

At times you may feel very angry at what is happening. Some families are angry with God or a cruel fate for singling them out. Some are mad at the health care team for not finding an answer to what is happening with their child. You may even feel angry with your child for getting sick and turning your life upside down. Feeling angry is a normal reaction. Finding a safe outlet to let off steam may be helpful. For example, take a walk or talk with someone to let the tension out.

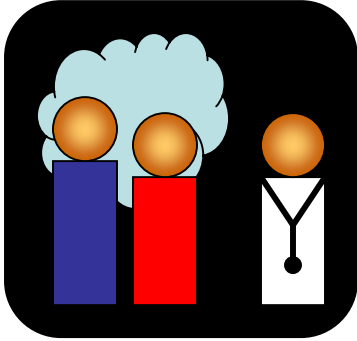


Guilt

Parents often feel guilty for not knowing that their child was sick. Many parents wonder if they did something to cause their child to get cancer. Siblings may also feel guilty that they are healthy. Young children often experience "magical thinking" and may feel that they caused the illness (*We had a fight and I wished he would die!*). Everyone in the family needs to be assured that they did not cause the cancer nor could they have done anything to prevent it.

Depression

People use depression to describe a range of emotions and behaviors. Feeling “blue” or sad is a normal reaction to the diagnosis of cancer and the treatment demands. The diagnosis may also require changes in family routine and bring feelings of social isolation. These changes and losses may produce grief reactions. You may notice symptoms of grief, such as crying spells, decreased appetite or compulsive eating, lack of interest, decreased energy, lack of concentration, poor problem solving, and physical symptoms such as tightness in the chest or headaches.



With the support of family, friends, and the health care team, most parents are able to work through these emotions and use coping skills that are needed to meet care demands. Individual or family counseling allows parents a way to discover their strengths within.

Sometimes parents find that their emotions are so overwhelming that they feel that they cannot cope with the demands being placed on them. When other life stressors, such as death, loss of a job, moving, marital problems, divorce, emotional problems, or substance abuse existed prior to the diagnosis, the situation may be more difficult. It may help to discuss your feelings with a trusted member of the health care team. Counseling and medications are available and may be needed.

Coping with Your Child's Illness

Some suggestions to help you cope with your child's illness include:

- Make a special effort to find a private time to talk with your spouse or a close friend. Try to talk about things other than your sick child.
- Try not to talk about your child in his/her presence unless he/she is included in the conversation.
- Find ways to reduce stress. You know what would work best for you. Some people exercise, while others enjoy reading or shopping.
- Try to take turns with your spouse or other support person when staying with your child in the hospital or coming for clinic visits. Both parents can be involved with the child's treatment. Sharing responsibilities also reduces the gap that may grow between parents when one is more involved in care than the other.
- Ask a member of the health care team for help and support.
- Talk to other parents of children with cancer.
- Attend a support group.



Impact of the Child's Cancer on a Marriage

A chronic illness can quickly turn a family's life upside down. Parents often become exhausted trying to cope with the needs of the child and the rest of the family. Many parents try to continue to work at their jobs and keep the home routine as normal as possible. Many couples feel a strain on their relationship. Parents often say that they do not have time for each other. They may feel angry and frustrated with what has happened to their child. Three things may help prevent the breakdown of a marriage: respecting coping styles, maintaining communication, and accepting changing roles.

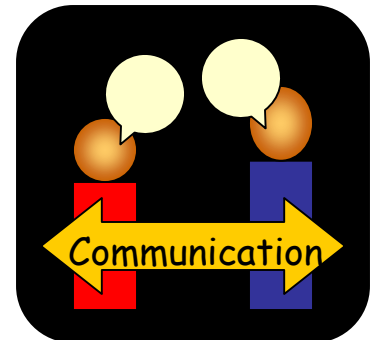


Respecting coping styles

Each person responds differently to stress. Some parents may withdraw, others may cry or get angry, while others may cope by gathering information. Parents need to learn and respect the different ways each has in coping with the child's illness. Try to understand where your partner is in accepting what is happening.

Maintaining communication

The key to any successful relationship is communication. The need to talk about feelings, fears, appreciation, and information is even greater during times of stress. Silence can make you feel separated from your partner. By sharing feelings and information you can stay connected and be better able to make decisions.



Accepting changing roles

The demands of illness and treatment can change the roles of family members. For example, the husband may have been the decision-maker in the family, but now the mother is making the decisions with the health care team because the husband is at work. Another example would be if the mother is used to taking care of the home, but doesn't have time because she is caring for the child in the hospital. An older sibling, other family member, or friend may have to help out more in the home. The change in roles can cause stress within a marriage or family. Some temporary role changes may be necessary to support the ill child. Some role changes may become permanent, if the changes help improve how parents or family members work together.

Parents Working Together

Adams and Deveau in their book, *Coping with Childhood Cancer*, list six ways that parents can work together when they have a child with cancer:

- Give partners sympathy and understanding instead of blame and criticism.
- Make the sick child a priority; both parents come together to learn about the diagnosis and treatment.
- Recognize that parents must continue to share in caring and loving for their other children.
- Share their own feelings of anger, sadness, sorrow, and hope with each other.
- Accept the help of family, friends, and neighbors.
- Be loyal to their partner in the face of criticism or blame from relatives or others.



Suggestions for divorced parents

While divorce is difficult for most families, problems may get worse when a child is diagnosed with cancer. In families where parenting issues are unresolved, children may use the diagnosis and treatment to "bring together" divorced parents. In some cases, the child may play one parent against the other in an attempt to gain some control. Work together and do not allow the stress of divorce to affect your child's care. Though the marriage has ended, the responsibility of parenting continues. Communication helps both parents get the best care for their child.

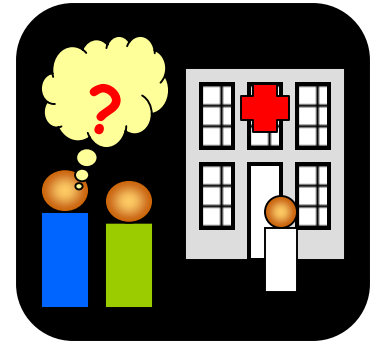
Some suggestions to help avoid problems include:

- Talk with a member of the health care team if your child is having behavioral problems.
- Place a copy of divorce decrees, custody, and visitation rights in your child's medical record.
- Meet together with the health care team to avoid confusion about the plan of care.
- Share notes, or a tape recording of information if one parent is not present for a meeting.
- Ask for two copies of all teaching materials so both parents can have the same information.

Impact of Cancer on Siblings

Brothers and sisters of a child with cancer may have many different feelings and responses. Often they have needs similar to their sick brother or sister. They may feel upset, scared, and unsure of what the future holds. Siblings may fear the word *cancer* and worry about death. Regardless of age, they will sense a change in their family life.

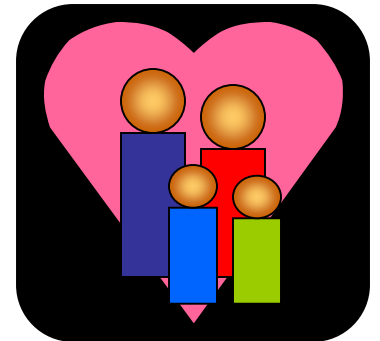
While siblings may feel sad and worried about their sick brother or sister, they may also feel some resentment or anger. Mom and Dad are spending all of their time with or talking about the sick child. Friends and family send gifts and money. Children, especially young ones, may feel jealous. Siblings may also feel sad and cry easily. Often siblings have problems of their own, such as depression, trouble sleeping, physical complaints, or problems in school.



How to help siblings

The following suggestions may be useful in helping your other children cope with their brother's or sister's illness:

- Try to spend time alone with your other children, doing things that are of interest to them.
- Let your other children know they are still loved and important to you.
- Talk with your other children about the diagnosis, treatment, and effect on their brother or sister. What you tell them will depend on their ages and ability to understand. Assure them that cancer is not contagious and they are not responsible for their brother or sister getting cancer.
- Take your other children with you to the hospital to help them feel involved in the care and treatments of your sick child. Taking them to the hospital or clinic may help to decrease their fears and help to keep a feeling of closeness with their brother or sister.
- Ask a loving friend or relative to stay in your home, rather than send your children elsewhere.
- Allow your children to help with chores at home to help them feel needed and help you too.
- Talk with your children's teachers. Teachers can be supportive to your children and let you know about any school-related problems.
- Ask for help from a member of the health care team: child life specialist, social worker, psychologist, or child psychiatrist.



Impact of Cancer on Grandparents

Grandparents have a variety of responses when they hear that their grandchild has cancer. Like you, they may feel shock and disbelief. Grandparents may feel guilty for living a long life. They may also feel they are responsible, thinking they in some way passed cancer through the family. Grandparents may also feel sadness, not just for their grandchild, but for their son or daughter as well.

Grandparents can be a great help to you and your family. If they are still in good health and can be with you, they can relieve you in the hospital or help you at home. A grandparent may also give your other children the attention, comfort, and love that they need.

Grandparents can also serve as contact persons. They can give information to other family members, so you don't have to spend as much time on the phone or emailing. Including grandparents in meetings with the health care team can help them to understand the plan of care for their grandchild.

Disciplining Your Child with Cancer

From the moment a child is diagnosed with cancer, the normal family routine is disrupted. The child becomes the center of attention of family members and friends. Often, the child receives many gifts. Although the child may feel sick, gifts and attention are still fun. Children can get use to being "special" and want the special treatment to continue.

Discipline problems are most common when the special attention stops and normal activities resume. The illness itself can also interfere with discipline. Children are likely to act more immature and more dependent when they feel sick. Pain and the side effects of treatment can make any child irritable. Many medicines, like steroids, can also cause irritability. These behavior changes can make it difficult to know what is reasonable to expect of your child.

Many parents feel helpless and guilty when they see their child suffer. You may feel the need to make up for the suffering by giving special privileges. These feelings are normal. However, becoming too lenient is a problem too. Children expect and need adults to give them structure. Rules and limits provide security. If a parent does not expect the child to behave or follow the same rules that were in place before the illness, the child may think the illness is worse than he/she has been told. The child may think that the condition is hopeless.



Keep in mind the following guidelines when deciding on how you can provide limits for your child:

- Set clear, consistent, and age-appropriate limits.
- Adjust your expectations to your child's current condition. If your child is not feeling well, "please" and "thank you" may not be reasonable with every request.
- Use praise and attention to reward good behavior.
- Use alternatives to spanking. Try using a "time out" approach or taking away privileges.