Caring for Your Child with Cancer

Nemours. Alfred I. duPont Hospital for Children
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Caring for a child with cancer can be overwhelming. This handbook, developed by your health care providers at Nemours Center for Cancer and Blood Disorders, contains information about caring for your child at home. This is a reference with guidelines used by the Nemours Center for Cancer and Blood Disorders oncology team. Increasing your knowledge can help you in caring for your child. We hope this will improve the quality of life for your entire family. This handbook is designed to be used in addition to the Children’s Oncology Group Family Handbook.

**When to Call Your Health Care Team**

Your oncology team is available 24 hours a day, 7 days a week at (302) 651-5500.

For non-urgent matters please contact the oncology clinic Monday through Friday from 8:30 a.m. to 5:00 p.m. at (302) 651-5500.

Unless your child is having a medical emergency please call the oncology clinic or physician on call before arrival to the hospital. Many times visits to the emergency department can be avoided and your child can be admitted directly to the hospital after discussion with the oncologist.

**Guidelines for Children Receiving Chemotherapy**

Call your health care team right away at (302) 651-5500 if your child has:

- **fever by mouth** of 101°F one time or 100.4°F taken on two occasions at least one hour apart
- **fever under the arm** of 100.4°F one time or 100°F taken on two occasions at least one hour apart

Other signs of infection such as:

- pain, redness or swelling anywhere in the body
- sore throat
- earache
- stiff neck
- pain when urinating or having a bowel movement
- pain or redness at the central line/port-a-cath site
- chills
- an exposure to chickenpox
- bleeding
- nosebleed 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, or unable to eat or drink
- severe headache after waking
- break in the central line

Do not give Tylenol® or ibuprofen for your child’s fever unless your oncologist directs you to.
**Nausea and Vomiting**

Nausea and vomiting can be caused by many different factors. They can be symptoms of illness and common side effects of some cancer treatments. Some chemotherapy medications cause vomiting, some do not. Sometimes radiation treatment can cause nausea and vomiting.

Everyone is different in their reaction to chemotherapy, and there are many ways to help with nausea and vomiting. Your doctor will prescribe a medication called an antiemetic before treatments that may cause nausea or vomiting. If an antiemetic does not work for your child, talk with the doctor about other antiemetic choices.

- Sometimes antiemetics are needed on a regular basis as prescribed for 2-3 days after your child receives chemotherapy.
- Give antiemetics 30 minutes before meals and routine medications whenever possible.
- Allow your child choices in the food and drinks he/she eats.
- Offer small meals – six small meals are better than three large ones.
- Avoid cooking foods that have strong odors
- Avoid fatty, greasy and fried foods.
- Offer easy-to-digest foods such as toast, cereal, rice, potatoes, crackers pretzels, and soup.
- Offer clear liquids such as ginger ale, flat cola or sports drinks.
- Have a relaxing environment for eating
- Try to distract your child with TV, music, games and reading
- Rinse your child’s mouth after vomiting
- Carry a change of clothes for your child and a bucket, especially on car rides

**Call your oncologist when:**

- Your child vomits for more than 4 hours.
- Your child is unable to take routine medications due to vomiting.
- Your child looks ill.
- You notice blood in the vomit or the vomit is dark brown or black.
- Your child appears dehydrated. Being dehydrated means that you are losing more fluids than you are taking in.
- Common symptoms of dehydration are:
  - urinating less
  - a small amount of dark urine
  - not wetting a diaper for 6 hours for a small child
  - not urinating for 12 hours for an older child
  - weakness or dizziness
  - dry mouth
  - having the above symptoms and appearing very tired
Constipation

Constipation is a condition in which your child has not had a bowel movement (BM) in several days or has hard stools that are either small or much larger than normal. It might be difficult for your child to have a BM and may cause belly pain. Constipation can cause a bigger problem for kids receiving chemotherapy than for others.

Common causes of constipation are:
- Side effects of chemotherapy (vincristine)
- Side effects of pain medications (like morphine, codeine or dilaudid hydromorphone)
- Inactivity
- Side effects of some medications given for nausea and vomiting like Zofran® (ondansetron)

Tips to prevent and treat constipation:
- Give medications for constipation on a regular basis or as directed by your doctor.
- Never give your child an enema or suppository for constipation or put anything in the rectum to relieve constipation.
- Encourage your child to be as physically active as possible.
- Offer foods high in fiber – including fruits, vegetables, whole grains, bran, nuts, graham crackers, prunes, dates and raisins.
- Encourage your child to drink lots of liquids – fruit juices may be helpful.
- Offer sips of warm drinks.
- Wipe your child’s anal area after a BM with soft toilet paper or flushable wipes.
- Call the doctor if your child has not had a BM in three days.
- Call the doctor if your child has belly pain.
- Call the doctor if your child has pain when passing a stool.
- For children taking medication for constipation on a regular basis (especially those on vincristine or pain medications):
  - Even with daily BMs your child may become constipated and may need extra doses of medication. Look for hard stools or belly pain.
  - Cut back on the constipation medication only if your child has more than two loose stools per day.
- For children taking medications for constipation on an as-needed (PRN) basis, consider giving medication for constipation if your child:
  - Goes even one day without a BM
  - Has difficulty having a BM
  - If BMs are large or hard

Diarrhea

Diarrhea means that the stool is watery and more frequent than usual. Cramping and pain may also occur with diarrhea. Diarrhea in a child with cancer can have many causes. These include infection, side effects of cancer treatment and too much medication to prevent constipation. Cancer treatment can injure the cells that line the intestine.

- Diarrhea can cause irritation and skin breakdown to the area around the rectum – use a barrier cream such as Desitin® or Boudreaux’s Butt Paste® after each bowel movement.
- Wipe your child’s anal area after each stool with soft toilet paper or flushable wipes that are alcohol free.
- Encourage a light diet.
- Offer bananas, rice, applesauce and toast.
- Avoid fried, greasy and high-fat foods.
- Offer non-caffeinated fluids – avoid fruit juices.
- Do not give over-the-counter medications to prevent diarrhea unless directed by your oncologist.
- Please contact the medical team prior to a scheduled or unscheduled visit for instructions on whether or not a stool sample will be needed.

Call your oncologist when:
- Your child looks ill.
- Your child has more than one stool per hour.
- You notice blood in the stool or the stool is black.
- Your child has severe pain in their belly.
- Your child has pain in the anal area.
- Your child has pain when passing a stool.
- Your child appears dehydrated. Being dehydrated means that you are losing more fluids than you are taking in.
- Common symptoms of dehydration are:
  - Urinating less
  - Small amount of dark urine
  - Not wetting a diaper for 6 hours for a small child
  - Not urinating for 12 hours for an older child
  - Weakness or dizziness
  - Dry mouth
  - Having the above symptoms and appearing very tired
Mucositis

Radiation and chemotherapy work by killing cells that grow fast. These cells include those that line the digestive system from the mouth, to the stomach, all the way to the rectum. This is called the mucosa. When it is irritated it is called mucositis. Mucositis can cause pain and increase the risk for infection.

Some kinds of chemotherapy are more likely to cause mucositis than others. Symptoms will depend on what area of the digestive tract is irritated.

Some symptoms of mucositis are:

- mouth sores
- red or raw gums
- bleeding of the lips or mouth
- pain in the mouth, especially with eating or drinking
- not swallowing saliva or drooling
- stomachache or pain
- diarrhea
- pains in the rectal area

Treatment depends on the symptoms. Mucositis can range from mild mouth soreness that does not get worse to severe pain needing a hospital visit, IV fluids and narcotics.

Here are ideas that may help your child with mucositis:

- Avoid spicy foods.
- Offer soft foods such as pudding, mashed potatoes, and eggs.
- Encourage food and drinks at room temperature.
- Use a soft toothbrush or toothette sponges for mouth care after each meal and at bedtime.
- Rinse with warm water several times a day as tolerated.
- Do not use mouthwashes unless prescribed by your oncologist.
- Look in your child’s mouth if possible with a flashlight, check for redness, ulcers or white patches.
- Give pain medication on a regular basis.
- Encourage your child not to drink alcohol or smoke.

Neutropenia

Your white blood cells are one of the many defenses your body uses to keep you from getting infections from bacteria, viruses and yeast. Your body has other ways to prevent you from getting an infection including your skin, the lining of your nose, mouth and stomach and your bowels. Neutrophils are a type of white blood cell that are especially important in defending against infection. When the total number of white blood cells is low from chemotherapy, the number of neutrophils can be very low. This is called neutropenia (new-tro-pee-nee-ah).

These guidelines can help decrease the risk of your child getting a serious infection. Please remember these are guidelines and even if followed very carefully your child still remains at risk and can get an infection.

We are available at all times to answer your questions and respond to your child’s symptoms. The oncology clinic phone number is (302) 651-5500.

Why neutrophils are important

White blood cells are the cells in your body that fight infections or germs. Your bone marrow (the inside spongy part of your bones) makes these cells along with other types of blood cells. One kind of white blood cell is called a neutrophil. A young neutrophil is called a band. Neutrophils are important because they kill bacteria. Chemotherapy and radiation decrease the total number of neutrophils. When the neutrophil count in the blood is low there is a higher risk of serious infection with bacteria or fungi.

What is your absolute neutrophil count (ANC)?

You may hear your nurse or doctor discussing your “counts.” They get these numbers from a blood test, called a Complete Blood Count (CBC). They are referring to the number of different blood cells your child has including:

- white blood cells
- red blood cells
- platelets

We look at the ANC to see the number of cells that are ready to fight off infection. The ANC estimates the total number of neutrophils and bands available in the blood to fight off infections. Usually 7-14 days after receiving chemotherapy your child’s ANC will be low. An abnormal ANC is fewer than 1,500 (cells per mm³). The risk of getting a serious infection gets higher as the ANC gets lower, especially as it gets lower than 500. Also, the longer the ANC is very low, the higher the risk.
How do you calculate the ANC?

When calculating the Absolute Neutrophil Count (ANC), we multiply the total number of White Blood Cells by the percent of Neutrophils (sometimes also called polys or segs) and the bands.

\[(\text{Total # of WBC}) \times (\% \text{ of Neutrophils} + \% \text{ bands}) = \text{ANC}\]

1. Take the percent of neutrophils (may also be polys or segs) + percent bands = percent
2. Convert the percent of cells to a decimal by dividing by 100 (Example 52% = 52/100 = 0.52)
3. Multiply this number by the total White Blood Cells (WBC)

Example: WBC = 4,000, Neutrophils = 50%, Bands = 6%

1. 50 + 6 = 56
2. 56 divided by 100 = 0.56
3. 0.56 x 4,000 = 2,240 = ANC

Neutropenia and infection

It is very important to tell your child’s doctor right away if your child has any signs of an infection. If your child has a central venous line (CVL), Hickman, or Port, or a shunt this is especially important. An infection in a child with a CVL can lead to blood sepsis, a life-threatening condition.

Some signs of infection are:
- fever
- chills
- sweating
- cough
- sore throat
- mouth sores
- redness or swelling on skin
- diarrhea
- pain or trouble passing urine
- feeling “sick” or very tired

There are many things you can do to prevent an infection. Many of these are good tips you should follow all of the time. It is especially important to follow these rules when your child’s ANC is low. Ask your doctor or nurse for the counts and ANC every time you have a blood count done.

- Know the signs and symptoms of infection and report any signs to your child’s doctor or nurse.
- Have a working thermometer on hand to take your child’s temperature when needed.
- Call your oncologist IMMEDIATELY if your child has a fever.
  - BY MOUTH: Fever of 101°F one time OR a temperature of 100.4°F by mouth taken on two occasions at least one hour apart
  - UNDER THE ARM: Fever of 100.4°F one time OR a temperature of 100°F taken on two occasions at least one hour apart
- Do not give Tylenol® or ibuprofen (Advil®, Motrin®) for fever unless directed to do so by your oncologist

All patients receiving chemotherapy are at risk for infection. We have divided the risks into two groups. The risk group depends on both your child’s disease and the treatment your child will be given. Ask your physician or nurse what risk group is best for your child.
Moderate neutropenia
(for ANC less than 1,000)
- Most patients receiving chemotherapy fall into this group, including those with Acute Lymphoblastic Leukemia (ALL), Wilm’s tumor, bone tumors, brain tumors, lymphomas and rhabdomyosarcomas.

Severe neutropenia
(for ANC less than 100, expected for more than 10 days)
The following children fall into this group:
- patients with Acute Myelogenous Leukemia (AML)
- some patients with severe aplastic anemia
- patients undergoing a bone marrow transplant
- other patients at high risk according to their oncologist

Tips to prevent infection
Patients in both the moderate and the severe neutropenia group need to take measures to prevent infection. These are listed below. Patients in the severe neutropenia group will have to take some extra measures to prevent infection.

Measures to take all of the time regardless of ANC

Preventing Injury and Infection:
- Limit the number of people who are in contact with your child – do not let anyone who has a fever, flu, or any known infection near your child.
- Your child should not share drinking glasses with others.
- Your child should wear shoes at all times whether in the hospital, outdoors or at home to avoid injury and avoid getting germs on their skin.
- Call your child’s oncologist if your child is exposed to chickenpox, measles or mumps.
- Do not take your child with you when going to the doctor’s office or emergency room (ER) for yourself or for other family members.
- If you must take your child to the ER because of illness or injury, let the ER staff know your child is receiving chemotherapy and may have a low ANC. Ask to be moved to a private area. Have your child wear a mask.
- Your child should not clean up droppings from pets – no cleaning birdcages, fish tanks and litter boxes.
- Your child should not touch snakes, lizards, turtles or other reptiles.
- Your child should avoid playing or digging in the dirt, leaves, mulched areas or sandboxes.
- Your child should avoid caves and chicken coops.
- Your child should avoid damp basements and areas where mold can grow.
- Your child should avoid petting zoos.
- Your child should avoid changing diapers or should wash hands carefully afterward.
- Your child should avoid construction areas and sites.
- Your child should wear sunscreen with a sun protection factor (SPF) of 15 or higher and avoid getting sunburned.
- Your child should avoid hot tubs.
- Talk with your child’s doctor or nurse if your child is planning on traveling.
- Your child should not have dental work performed without first checking with his/her oncologist.
- Your child should not receive any immunizations unless the oncologist has approved them.
- Parents who do central line care should not have false nails and nail tips.

Personal hygiene
- Keep your child’s body clean by bathing every day.
- If your child has a central line keep it dry. Protect it from water. Do not allow your child to submerge the CVL or a port-a-cath that is accessed underwater.
- If your child has a CVL, check the site every day for redness or soreness.
- Teach your child to wash his/her hands with soap and water or hand sanitizer after using the bathroom, blowing their nose, coughing or sneezing.
- Teach your child to wash his/her hands before eating.
- Insist on washing with antibacterial soap and warm water often for all members of your household and always before touching your child.
- Your child should keep his/her mouth clean by brushing his/her teeth twice every day with a soft brush. Talk to your child’s doctor or nurse if you notice your child’s gums bleeding.
- Do not use alcohol-based mouthwashes unless prescribed by your oncologist.
- Your child should not receive any immunizations unless the oncologist has approved them.
- Avoid constipation and straining to have a bowel movement. You should be aware of how often your child is having bowel movements. Inform your child’s doctor or nurse if he/she is having bowel problems.
- Do not put anything in your child’s rectum including thermometers, suppositories and enemas.
- Girls should always wipe from the front to the back when cleaning after going to the bathroom.
If your child cuts or scrapes their skin, clean the area right away with soap and warm water. Apply a clean bandage to protect it.

If your child’s cut or scrape is red, swollen painful or tender, tell your child’s doctor.

Dietary precautions

- Everyone should wash his or her hands before handling food to be eaten by your child.
- Wash hands, utensils and area after handling raw meats and eggs.
- Wash dishes in hot water.
- Follow expiration dates on all food items.
- Throw out leftovers when left for two or more hours at room temperature or more than seven days in the refrigerator.
- Wash all raw fruits and vegetables, and peel if possible, before eating.
- Your child should not eat or drink:
  - raw milk or milk products: any milk product that has not been pasteurized, including cheese and yogurt made from unpasteurized milk
  - raw and undercooked meats, fish, chicken, eggs, sushi and tofu
  - any food that contains mold (for example bleu cheese, including that in salad dressings)
  - vegetable sprouts (alfalfa sprouts, beans sprouts and others)
  - fruit and vegetable juices and cider that have not been pasteurized
  - raw honey that has not been pasteurized
- Do not give probiotics such as concentrated bacterial supplements to your child unless approved by your child’s oncologist.

Neutropenia precautions

There are some extra steps you should take to try to prevent an infection while your child’s ANC is low.

When your child’s ANC is below 500

- Your child should avoid large crowds of people including:
  - shopping malls
  - theaters
  - churches
  - restaurants
  - crowded public transportation
- Do not keep fresh flowers or live plants in your child’s room.
- Do not have live Christmas trees in the house.
- Your child should avoid activities that could cause accident and injury – these include bicycling, roller-blading, skating, and skiing.

- School attendance is decided on an individual basis – ask your physician for guidelines.
- Girls should not use tampons, vaginal suppositories or douche.
- If your child shaves they should use an electric shaver instead of a razor – do not share shavers.
- Your child should avoid manicures, pedicures, false nails and nail tips.

Extra measures for children at risk for severe neutropenia

These are additional precautions for patients who fall into the severe neutropenia category (for those patients with an ANC less than 100, expected for more than 10 days).

Your child should not eat:

- ground pepper from a pepper mill
- hot dogs, deli meats, processed meats (unless they have been cooked again just before eating)
- cold smoked fish
- raw nuts and nuts roasted in their shells
- bagged salad greens
- public salad bars/buffets
- any fruit unless it can be peeled

Adapted from the ACS/NCCN guidelines, Version II, March 2006 and Nemours Practice Standards Committee Form  61449
Anemia

In our blood we have cells called red blood cells. These cells contain hemoglobin. Hemoglobin carries oxygen to all cells in the body, including the brain. The normal range for hemoglobin is 11.5 – 15.5 gm/dl. When the hemoglobin is low, we call this anemia. If your child has anemia he/she may have one or all of the following symptoms:

- tiredness
- pale skin, lips or gums
- feeling short of breath especially with stairs or distances
- headache
- heart beating fast
- dizziness
- being irritable

If your child’s hemoglobin is less than 7-8 or if your child has symptoms of anemia, your doctor may prescribe a blood transfusion.

Thrombocytopenia

Platelets are a kind of blood cell. They help form clots and stop bleeding. Cancer and its treatment can cause the platelet count to be low, which can cause bruising and bleeding. The normal platelet count is from 150,000 to 400,000. When the platelet count is below 20,000, or if your child has symptoms of bleeding, your doctor may prescribe a platelet transfusion.

Possible symptoms of low platelets include:

- bleeding from the lips or gums
- petechiae, these are small purple dots on the skin that do not change color when you press on them
- nosebleeds
- vomiting blood or material that looks like coffee grounds
- stool that is black or bloody
- red or pink urine
- severe headache
- pain

Care of a child with a low platelet count is aimed at preventing injury and bleeding. Here are some other helpful guidelines:

- Do not give your child ibuprofen (Motrin®, Advil®) or any over-the-counter medications that contain ibuprofen. Ibuprofen can prevent platelets from doing their job.
- Children should never be given aspirin or any over-the-counter medications that contain aspirin unless directed by a physician.
- If your child has a nose bleed, pinch the end of the nose and have your child tilt their head forward to keep the blood from going down his/her throat. Do not check it for 5 minutes. Call the oncologist or go to the emergency room if the bleeding does not stop within 5 minutes.
- If your child gets a cut that is bleeding cover it with a clean cloth. Apply pressure with your fingers or the palm of your hand. Do not check it for 5 minutes. Call the oncologist or go to the emergency room if the bleeding does not stop within 10 minutes.
- Avoid contact sports and activities that can result in injury such as riding bicycles, skating, skiing or horseback riding when platelets are below normal.
- Never put anything in your child’s rectum including enemas, suppositories or rectal thermometers.
- Prevent constipation – talk to your oncologist if your child is constipated.
- Use a soft toothbrush.
- Teens and young adults should use electric razors.
- Check with your oncologist before having any dental or surgical procedures done.

Guidelines for Swimming

Swimming is relaxing, fun and a good way to get exercise. Allowing your child to participate in as many activities as possible is important, even if they are receiving cancer treatment. We want to be sure that this is done with safety in mind. Having a central venous line (CVL) and low blood counts or a mixture of both puts your child at risk for infection. Germs that grow in a wet environment add to the risk. Cancer treatment lowers your child's defenses against infection especially when the Absolute Neutrophil Count (ANC) is low. Ask your child's nurse or doctor about the ANC.

General swimming guidelines for children getting treatment for cancer.

A child receiving chemotherapy is permitted to swim

- in chlorinated public and private pools
- in the ocean

A child receiving chemotherapy should not:

- swim in the bay, lakes, ponds or rivers
- use hot tubs

Some patients have an external CVL (one you can see). It comes out of the skin. This is sometimes called a Hickman. Some patients have a port-a-cath. This is under the skin. A special needle is inserted into the port when used for treatment or blood draws.
Children who have a port-a-cath have different guidelines for swimming than those with external CVLs.

**Children with a port-a-cath**

Children with a port-a-cath are permitted to swim if the port-a-cath is not accessed and the CVL insertion site is healed. Site healing takes at least two weeks from the time the line is put in.

**Children with an external CVL**

Children with external CVLs are not permitted to swim. Getting the CVL, CVL dressing or caps wet puts your child at great risk for infection. Children with external CVLs are permitted to go in water up to their waist in chlorinated pools if properly supervised. Keep an extra dressing change kit with you when involved in outdoor activities. Sunscreen or sweating may cause the dressing to loosen and need to be replaced.

Talk to your doctor or nurse about your child’s swimming plans, especially if you are unsure about the guidelines.

**Fatigue**

Fatigue is a feeling of tiredness. There are many causes for fatigue, and it is a common effect of cancer and treatment. There will be times when your child does not have energy. He/she may not feel like playing, talking or even opening his/her eyes. You may notice sadness, anger or other mood changes. In younger children you may notice that they are irritable. Fatigue can affect the quality of life for many children with cancer, and some children have more fatigue than others.

**Things that may help:**

- frequent rest periods
- quiet activities such as reading, video games or crafts
- relaxing by listening to music, watching a movie, or giving your child a massage
- being supportive of your child’s feelings
- drinking fluids and eating a healthy diet
- encouraging activity when your child has energy
Moisturizers and Care of the Skin

Chemotherapy and other medications can contribute to dry skin and eczema. Dry skin can be itchy, irritating and uncomfortable. Keeping your skin moist is one way your body protects itself from infection.

Here are some tips to help keep skin healthy.
- Bathing or showers should be warm not hot.
- A hot steamy shower may feel good while in the shower, but will remove the oil from the skin producing dry skin.
- In place of soap, nonsoap cleansers or washes can be used for bathing including:
  - Cetaphil® cleanser – does not make suds
  - Eucerin® cleanser or wash
  - Aveeno® cleanser or wash
- Avoid antibacterial or deodorant bar soaps such as Irish Spring®, Coast® or Axe® products. If an antibacterial soap is needed, Cetaphil antibacterial cleanser or Lever 2000® can be used.
- If your face is dry and sensitive, wash with water and fingers verses wash cloths. If your face is oily, wash with a gentle soap such as Dove®.
- Use creams instead of lotions for moisturizing.
- The best moisturizer is Vaseline®/petroleum jelly, though it is sticky and not tolerated by many. It can be applied at night.
- Moisturize the skin and face at least twice daily and after every bath.
- Adolescents and young adults should only use moisturizers that are noncomedogenic – does not cause pimples or acne by clogging pores.
- The optimal time to moisturize is after the bath when the skin is still moist.
- Some non-irritating, fragrance-free products for moisturizing include:
  - For children under the age of 10
    - Eucerin Cream
    - Cetaphil Cream
    - Nivea® cream
    - Vanicream®
    - CeraVe® Cream
    - Aquaphor® or Vaseline/petroleum jelly – ointment
  - For adolescents and young adults – noncomedogenic
    - Cetaphil cream or lotion
    - Neutrogena® moisturizer for combination skin
    - CeraVe cream or lotion

Immunizations

Immunizations are a way to guard against disease without getting ill. A killed or a weakened live version of the disease is given to the patient, and the body acts as if it was a real infection. It builds defenses that are able to fight off that illness if it later enters your body.
During cancer treatment your child should not receive immunizations. Children with cancer should not be near someone who was recently immunized with a live virus. It is rare to get an illness from someone who was recently immunized with a live virus.

Follow these safety measures:

**Oral Polio**
- A child getting cancer treatment should stay away from anyone who has received oral (by mouth) polio in the past 6 weeks.
- In the United States polio is given as an injection (shot) and is not a live virus. Oral polio is a live virus and is sometimes given in other countries.
- Your child should stay away from visitors from outside the United States who recently received oral polio.

**Varicella (Chickenpox)**
- Those living in your house can receive the varicella vaccine.
- If someone living in your house receives the varicella vaccine and your child getting cancer treatment develops lesions on his/her skin within a month, call your oncologist.

**Measles Mumps and Rubella (MMR)**
- Those living in your house can receive the MMR vaccines.

**Rotavirus**
- Rotavirus is an immunization that is often given to infants.
- A child getting cancer treatment is not at risk if they come in contact with children who have received this vaccine.
- A child getting cancer treatment should not change the diapers of children who were immunized with the rotavirus vaccine in the past 45 days.

Most children can receive immunizations a year after cancer treatment. Your oncologist will talk with you about the plan for your child.

Most children receiving treatment for cancer should get a seasonal flu shot each year. Household members should get immunized against the flu as well. Check with your oncologist for information about your child.

**Steroids**

Steroids are an important part of many cancer treatment plans. Prednisone and dexamethasone are two steroids commonly used. It is important not to miss any doses. Steroids have many side effects that range from mild to severe. Common side effects of steroids are:
- round face
- enlarged belly
- high blood pressure
- trouble sleeping
- decreased ability to fight infection
- muscle weakness that may cause leg and back pain
- pimples
- irritation to the lining of the stomach – medication will be given to prevent this
- stretch marks

Steroids may cause an increase in appetite and may cause the body to hold on to fluids, which can lead to weight gain. You can not prevent weight gain but can do some things to help.
- Have healthy fruits and vegetables on hand for snacking.
- Limit salty foods – no more than 1 - 2 servings per day.
- Limit sugary snacks and desserts such as cakes, pies, candy and cookies to 1 - 2 servings per day.
- Encourage your child to be active.
- Try to distract your child with TV, music, games and reading to keep attention away from eating.

Steroids cause changes in mood and behavior in some children. Parents have described this as a very difficult part of treatment.
- Your child may be happy one minute and crying, sad or angry the next.
- These mood changes are part of the steroid’s effect and your child’s personality will return to normal after the steroids are stopped.
- Try to remain calm with outbursts.
- Let teachers and others caring for your child know about steroids and side effects.
- Let your doctor know if the behavior is disrupting life at home or is affecting siblings.

**Call your oncologist when:**
- Your child is angry enough to cause harm to himself/herself or others.
- Your child is crying and you can not get him/her to stop.
- Your child, who has been able to walk stops walking.
- Your child drinks and urinates excessively.
- Your child has headaches.
Chemotherapy Safety

When a child receives chemotherapy, those medicines can be passed through the child’s blood, urine, bowel movements, vomit, and sometimes even sweat. During the 48 hours after your child receives chemotherapy, everyone who cares for your child should wear gloves when handling diapers, urinals, vomit basins or soiled sheets. Use caution not to get blood, urine or vomit on yourself. Always wash your hands after removing gloves.

Oral chemotherapy at home

Always wear gloves when handling oral chemotherapy. Pregnant women should never handle oral chemotherapy. If you are taught to mix a tablet or capsule of chemotherapy with liquid at home, we recommend that you wear a mask while doing this.

Do not prepare chemotherapy where food is prepared. Keep all medications and chemotherapy out of reach of small children and pets.

Safe Sex

The choice to be sexually active as a teenager is very personal. Here are some rules for safety. If your child getting cancer treatment is sexually active remind him/her of these rules often. These are guidelines. Discuss this with your child’s doctor. Ask for more specific information.

Anyone who is sexually active while being treated for cancer, needs protection from:

- Pregnancy or fathering a child
- Injury and infections

Pregnancy or Fathering a Child

The drugs and radiation therapy used to treat cancer and medical imaging can hurt an unborn baby. Stillbirths, miscarriages and birth defects are possible.

- Anyone being treated for cancer should not become pregnant or father a child
- Let your child’s doctor or nurse know if:
  - Your child is sexually active – your child will be given ways to prevent pregnancy
  - Your child is pregnant
- Talk with your child’s doctor about when it is safe for your child to plan a pregnancy after treatment is finished

Infection and Injury

- Anyone who is sexually active is at risk for sexually transmitted diseases (STDs) – use latex condoms every time to prevent STDs.
- Cancer treatment lowers the ability to fight infections. Use latex condoms to prevent infection.

- Anyone receiving cancer treatment should limit sexual encounters when:
  - They are not feeling well.
  - The platelet count is below 50,000. This means the risk for bleeding is high.
  - The ANC is below 500. This is one way of knowing that defenses against infection are low.

- Anyone receiving cancer treatment should not have anything inserted into their rectum at any time.
- Call your child’s doctor for signs of infection – this may be fever, pain, redness, discharge, sores and rashes.

Protecting Your Partner

Chemotherapy may be in body fluids for up to 72 hours from the time it is given. This includes chemotherapy that is given by injection, by mouth and by spinal tap. Avoid sexual activities (all types) for 72 hours after receiving chemotherapy to keep partners from being exposed.

Returning to School

Some children with cancer will be unable to go to school. Most children are able to return to school when they enter a less intensive phase of treatment or treatment is complete. Returning to school comes with feelings of excitement but also apprehension and nervousness. The oncology team wants to make this transition as easy as possible for your child, family, classmates and school. Communication between the health care team and the school is important. Our oncology staff will provide information to the teacher, school nurse or other staff members about comfort, preventing infection, central line safety, physical limitations and other issues as needed on an individual basis. Our staff is also available to meet with the school staff and/or classmates to give them a better understanding about your child’s illness. Please contact your social worker to arrange this.

Off-Therapy Guidelines

Please continue to call (302) 651-5500 for fever until 6 months from your child’s last dose of chemotherapy.

- By mouth of 101°F once or 100.4°F taken on two occasions at least an hour apart
- Under the arm of 100.4°F once or 100°F taken on two occasions at least an hour apart

After 6 months, contact your child’s pediatrician or primary care provider when your child has a fever or is not feeling well.

Your child can start getting immunizations one year
The promise of achieving higher standards in children’s health.