

ONCOLOGY *family* HANDBOOK



This document is not intended to be a substitute for, nor does it constitute, professional medical advice. Always seek the advice of a physician or other qualified health provider with any questions you may have regarding a medical condition. Do not delay seeking professional medical advice due to something you have read in this document.

Table of Contents

Below is a quick reference of information located within the Oncology Family Handbook.

Throughout your care, you will meet with oncology providers to discuss your child’s diagnosis, medications, and treatment plan. The oncology educator and social worker will meet with you to review the information within this handbook. Other members of our team include: child life specialists, nurses, certified nursing assistants, medical assistants, and nurse case managers.

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When to Call

After reading this section, you will be able to:

1. Locate the clinic and on-call provider's telephone number
2. Identify what signs and symptoms need immediate attention
3. Define fever and actions to take with fever
4. Demonstrate nose bleed treatment
5. Discuss infectious disease precautions

Contacting the Team

Call 911 if your child has a medical emergency and needs help immediately.

Contact the Hematology/Oncology Clinic or On-call Provider at

402-955-3950

Call the Oncology Clinic immediately for the following signs:

- Fever of 100.4°F (38.0°C) or higher
- Shaking or chills
- Exposure to chicken pox, shingles or measles
- Nosebleed that won't stop
- Multiple bruises
- Blood in the stools, urine or vomit
- Constant headache
- Severe pain anywhere in the body
- Pain during urination or bowel movements
- Red or swollen areas
- Uncontrollable vomiting
- Blurred or double vision
- Severe side effects after treatment, such as severe mouth sores, persistent diarrhea or constipation with stomach pain
- Difficulty waking up
- Trouble breathing

Call during 8:30 am – 4:30 pm for **routine** needs such as:

- Medication requests
- Lab results
- Cancelling or scheduling appointments
- Requests for letters or forms
- Routine pediatric care
- Before any vaccine or dental care

When calling during business hours, press:

1 to schedule an appointment

3 for non-urgent medical issue

4 for fever or an urgent medical issue

5 for all other calls

When calling on evenings or weekends:

Press **1** to leave message for non-urgent medical issues. **All calls will be returned the next business day.**

For fever or an urgent call, please stay on the line for the answering service.

Fever & Infection



If you suspect your child has a fever, take his/her temperature using a thermometer; do not guess. Temperatures may be taken in the mouth, in the ear or under the arm. **Do not take your child's temperature in the rectum** as this increases the risk of bleeding or infection from rectal tearing.

What to do if your child has a fever:

If your child has a **temperature of 100.4°F (38.0°C) or higher,
Call the Hematology/Oncology Clinic immediately (even after hours)
at 402-955-3950.**

Do not give your child acetaminophen (Tylenol) or ibuprofen (Advil/Motrin) until you have talked to the oncology provider or nurse. After calling, they will tell you if it is ok to give.

Never give acetylsalicylic acid (Aspirin) containing medicines.

You may be asked to bring your child to the nearest hospital to be evaluated.

Blood may be drawn from both the central line and another site (such as an arm) in order to determine if an infection is present. If the blood tests show that the Absolute Neutrophil Count (ANC) is less than 500 and your child has a fever, your child will be admitted to the hospital for IV antibiotics. If your child is at an Emergency Department other than Children's, your child may be transferred to Children's.

Emergency Department Your Child Will Use:

Contacting the Team

A few things to keep in mind when calling us...

For urgent issues that come up after clinic hours or on weekends or holidays, one of our Hematology/Oncology providers is always available to give medical advice.

Please note the provider may not be at the hospital or clinic, or have immediate access to your child's chart. Please be prepared to share your child's diagnosis, medications, most recent therapy, most recent blood counts (hemoglobin, platelets, and ANC), and the date and name of the last chemotherapy.

Bleeding

For prolonged bleeding from a cut or wound, apply direct pressure until the bleeding stops. A clean towel or cloth should be used.

If your child has a nosebleed, press the sides of the nose firmly together for 15 minutes without letting go. Have your child sit up or lean forward to prevent choking or swallowing blood. Do not let your child lie down or tilt their head back. Continue to hold pressure and call the Hematology/Oncology Clinic if the bleeding does not stop after 15 minutes.

Infectious Diseases

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

Preventing Infection

After reviewing this section, you will be able to:

1. Understand how hygiene helps prevent infection
2. State hand hygiene guidelines
3. Discuss CHG bathing practices
4. Discuss oral care recommendations
5. Recall when to wear a mask
6. Explain protective precautions

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Preventing Infection in the Child with Cancer

Keeping your child free from infections during cancer treatment is very important to us. As your child's absolute neutrophil count (ANC) drops, their chance of getting an infection increases. We want to help you keep your child infection free. The best way to do this is with: hand washing, bathing, oral care, and a clean environment.

HAND WASHING

- Hand washing is the best way to stop the spread of germs.
- Everyone who enters your child's room or your home should wash their hands with hand sanitizer or soap and water.
- Your child should wash their hands with soap and water before eating, after using the toilet, and any time they are visibly dirty.
- *Please read the Hand Hygiene teaching sheet for more information.*

BATHING

- Germs from the skin can get into your child's blood through the central line or an opening in the skin. Taking a bath or shower decreases the number of germs on your child's skin.
- Your child should take a bath or shower every day and then put on clean clothing.
 - In the hospital, your child will use CHG wipes or CHG liquid soap for their daily bath/shower. In addition, your child will also need to get into the bath or shower, and wash with soap and water, at least twice a week. *Please read the CHG Bathing teaching sheet for more information.*
 - At home, regular soap and lotion can be used.
- If your child has a central line, it needs to be covered with protective plastic before getting into the tub or shower. The central line dressing or caps should not get wet or submerge under water.

LINENS

- In the hospital, the bed sheets will be changed every day after bathing. The nurse or nursing assistant can help change the bed sheets if needed.
- All personal linens (when you are in the hospital and at home), such as favorite blankets or pillowcases, must be washed at least once per week and when dirty.

ORAL CARE

- It is important to keep your child's mouth clean, as some chemotherapy may cause mouth sores. If your child has mouth sores, germs can enter and cause an infection.
- Every day in the hospital and at each clinic appointment, the nurse and provider will look in your child's mouth to watch for sores. This is also something you can watch for too.
 - If your child has mouth sores, the provider may prescribe additional medications for pain control or treatment.
- It is also recommended to keep your child's mouth and lips moist.
 - Your child should use a petroleum free lip balm 2-3 times to prevent and treat dry or cracked lips.

BRUSHING TEETH & MOUTHWASH

- Your child should brush their teeth 2-3 times a day.
- Your child should rinse their mouth 2-4 times a day with alcohol-free mouthwash.
- *Please read the [Oncology Oral Care Bundle](#) teaching sheet for more information.*

MASKS

- Wearing a mask can help decrease exposure to germs.
- Disposable masks should be disposed of at least daily and if it gets wet or dirty.
- Cloth masks should be replaced at least daily and if it gets wet or dirty.
- A mask should be worn in all public areas at Children's.
- At home, masks should be worn in public areas when your child's ANC is less than 500.
- Masks are not required if your child is going to school. However it may be a good idea if there is a lot of illness going around.

AVOIDING CROWDS

- Your child should avoid crowds during their cancer treatment.
- Your child does not need to avoid public areas completely or be homebound, but pick activities and times of the day when fewer people will be there.
- Knowing your child's most recent ANC helps predict their chance of getting an infection.
- When your child's ANC is less than 500, their ability to fight off germs is very low.
- Your nurse or provider can help you decide which activities are safe for your child during therapy.

ROOM CLEANING

- Keep as few things in the room as possible. If the room is free of clutter, our environmental services staff can do their daily cleaning better.
- Uneaten food should promptly be discarded and never left in the room.
- If your child is in the hospital for more than a week, a thorough room cleaning, also known as a "deep clean", will be done every seven days. The staff will tell you the day and time that your child's room has been scheduled for a deep clean. This gives you time to remove any unnecessary items and have all surfaces cleared. If possible, your child will spend time in the playroom or in a treatment room while their room is being cleaned.

HOME ENVIRONMENT CLEANING

- Keeping the home environment clean is also important for your child. Remove any unnecessary items and keep surfaces cleared and clean.
- Uneaten food should be promptly discarded.
- Weekly cleaning of the bathrooms is recommended.
- Remember to keep cleaning chemicals out of reach of children.

KEEPING TRACK OF IT ALL!

- To help our patients and families to get this all done, we have checklists located on the whiteboard in your hospital room. Please feel free to checkmark each item as you help your child complete the task!

We realize that these practices may be different than your normal routine.

But by following these simple activities and working together, we can decrease the number of infections your child experiences. Please let us know if you have any questions.

Speaking up for your child and advocating for cleanliness is everyone's job!

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Hand Hygiene in the Hospital, Clinic, and at Home

What is hand hygiene?

Washing hands with soap and water or using alcohol based hand rub (hand sanitizer) that contains at least 60% alcohol.

Why is hand hygiene important?

Keeping hands clean is one of the most important ways to prevent the spread of germs.

Who should perform hand hygiene?

Everyone including visitors, caregivers, parents, patients, and health care workers should perform hand hygiene.

When should hand hygiene be performed?

- Before, during and after making food
- Before and after eating
- Before and after caring for someone who is sick
- After using the toilet, after changing diapers, or helping your child to the toilet
- After blowing your nose, coughing, or sneezing
- After handling trash
- Before and after caring for a cut or wound
- After touching an animal, pet food/treats, or handling animal waste
- Before and after removing gloves
- Before and after caring for a central line
- Before entering your child's hospital or clinic room, and before leaving (clean hands in, clean hands out)

When should I see my health care providers perform hand hygiene?

- Everyone who comes into your child's room or into your home should perform hand hygiene. If you see someone come in that does not perform hand hygiene, speak up and ask them to.
- You may also see them do it more often if they are performing tasks, such as giving an IV medication or drawing labs.
- Health care workers in the hospital or Specialty Pediatrics Center (SPC) will have an electronic badge showing a green hand that tells you they have performed hand hygiene.

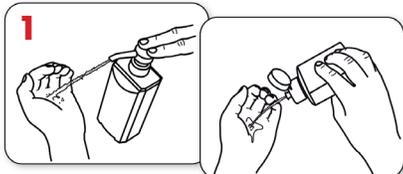
Nail care recommendations if you are caring for your child's central line:

- Keep nails short and clean
- Avoid wearing artificial nails because they can collect germs

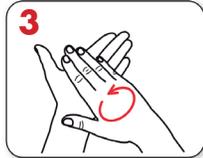


HAND HYGIENE

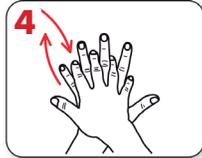
How to clean hands WITH ALCOHOL-BASED SANITIZER



1 Apply a quarter-sized amount of sanitizer to hands. Go to step 3.



3 Rub the palms of your hands together.



4 Rub on the top of each hand, including wrist.



5 Rub in between your fingers.



6 Clean under your fingernails on both hands.



Minimum 15 seconds

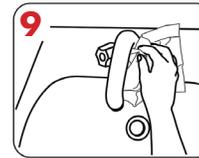
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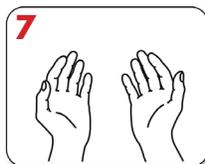
7 Rinse hands with water.



8 Dry hands with a clean towel.

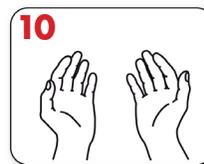


9 Use a towel to turn off faucet.



7 ... once dry, your hands are safe.

Please note: Sanitizer must dry completely before touching electrical equipment.



10 ... and your hands are safe.

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What is CHG?

Chlorhexidine gluconate (CHG) is an anti-germ cleanser that reduces the number of germs on the skin. CHG bathing is used before surgery, and for children who stay in the hospital and have a central line.

DO NOT use CHG if your child:

- Has a known allergy to CHG or any other ingredients in the product
- Has skin breakdown, a rash, a burn, open wounds, sores, or a severe skin disease (example: chronic graph versus host disease of the skin)
- Was born at less than 28 weeks gestation AND is less than 14 days old.
- Is receiving radiation therapy for cancer; do not use in the field of radiation and avoid for 2-4 weeks following last treatment
- Is receiving Isotretinoin (Accutane) therapy
- Has shaved within the last two days

Pre-Operative Bathing

Unless contraindicated, children must complete two CHG baths before surgery. The first CHG bath should be completed, after a regular soap and water bath, the day before surgery. The second CHG bath is completed at the hospital on the morning of surgery.

CHG Bathing in the Hospital

Unless contraindicated, CHG is used to help decrease the risk for central line associated bloodstream infections. If your child is less than two months of age, a CHG bath will be given on Mondays, Wednesdays, and Friday. All other children greater than two months of age will receive a CHG bath every day. Please note that if your child was born at less than 28 weeks gestation, they must be at least 14 days old before they can have a CHG bath.

General Guidelines for CHG Use:

- CHG cloths or soap are for external use only. Do NOT use CHG cloths or soap on your child's face, hair, genitals (vagina or tip of penis), or anus.
- Do NOT use cloths or soap on a rash, open wounds, sores, burns, incisions, or eczema.
- If your child has stoolled, please use regular soap and water to clean skin prior to using CHG.
- There may be some itching or redness after using the CHG cloths or soap. This should go away quickly. If the redness or itching does not resolve after 10 minutes, rinse off with cold water.
- CHG may stain linens brown.
- If your child is receiving a CHG bath for surgery, they should not shower, bathe, or apply lotions, deodorants, powders, or other skin products after bathing. The CHG works best on clean, dry skin.
- If your child is using CHG soap or wipes every day in the hospital, the skin may become dry with continued use. If your child's skin is dry, please ask the nurse before using any lotions or barrier creams, some products can deactivate CHG (Example: Johnson & Johnson® baby lotion is incompatible with CHG. Do NOT use.).

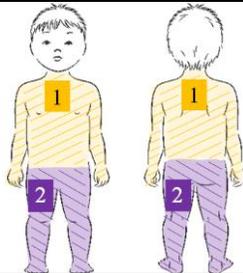
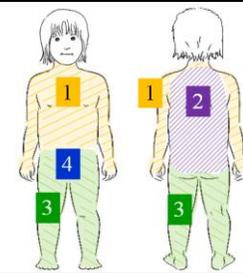
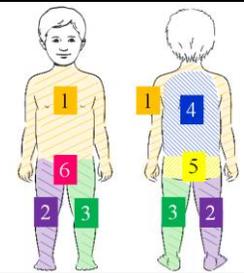
Instructions for using the liquid CHG soap:

1. Shower or bathe as usual, including shampooing the hair. Rinse completely.

- Turn off the shower or step out of the bathwater. Do not allow your child to sit in the bathwater while you clean with CHG liquid soap.
- Use a clean washcloth and apply enough CHG soap to clean the body from the neck down. You should clean for 3 minutes. DO NOT use CHG soap on face, hair, genital area (vagina or tip of penis), or anus.
- Turn on the shower and rinse thoroughly. Do not allow your child to sit back into the bathwater/tub after a CHG bath.
- Towel dry using a clean, freshly laundered towel.
- After the CHG bath, all bed linens should be changed and clean clothes put on.
- Do not apply lotions, deodorants, powders, or other skin products to your child's skin.

Instructions for using CHG cloths: The number of CHG cloths needed is based how much your child's weighs. *Do NOT flush CHG cloths down the toilet.* Please throw any used CHG cloths in the trash. If your child uses the CHG cloths every day in the hospital, a soap and water bath is needed twice a week to get rid of the CHG build-up.

- Shower or bathe as usual, including shampooing the hair. Rinse completely.
- Allow the skin to completely dry and cool before using the CHG cloths. Do not apply lotions, deodorants, powders, or other skin products to your child's skin.
- DO NOT WARM CLOTHS IN MICROWAVE. If you are at home and want to warm the cloths, place unopened package in warm water until desired temperature is achieved. If you are in the hospital, there is a special warmer for the cloths.
- When ready, open the package(s). Each package contains 2 cloths. Use the table below to guide you on how many cloths to use and the order in which to clean each part of the body.
- Wipe the CHG cloths using a circular or back and forth motion. DO NOT use CHG soap on face, hair, genital area (vagina or tip of penis), or anus.
- Allow the skin to completely air dry, including in between skin folds. Do not rinse or wipe off the CHG. It is normal to feel "sticky" for several minutes after cleaning. This will go away once it is dry.
- After the CHG bath, all bed linens should be changed and clean clothes put on.

	Less than 20 pounds: Use 2 cloths (1 packet)	20-65 pounds: Use 4 cloths (2 packets)	More than 65 pounds: Use 6 cloths (3 packets)
# of Cloths per weight			
Cloth 1	Chest, both arms, back, and neck	Chest, both arms, and neck	Chest, both arms, and neck
Cloth 2	Both legs, buttocks, and genitals (external use only)*	Back and buttocks	Right leg
Cloth 3	-----	Both legs	Left leg
Cloth 4	-----	Genitals (external use only)*	Back
Cloth 5	-----	-----	Buttocks
Cloth 6	-----	-----	Genitals (external use only)*
<p>*Do NOT use on: the face, hair, genitals (vagina or tip of penis), or anus. Do NOT use on: a rash, open wounds, sores, burns, incisions, or eczema.</p>			

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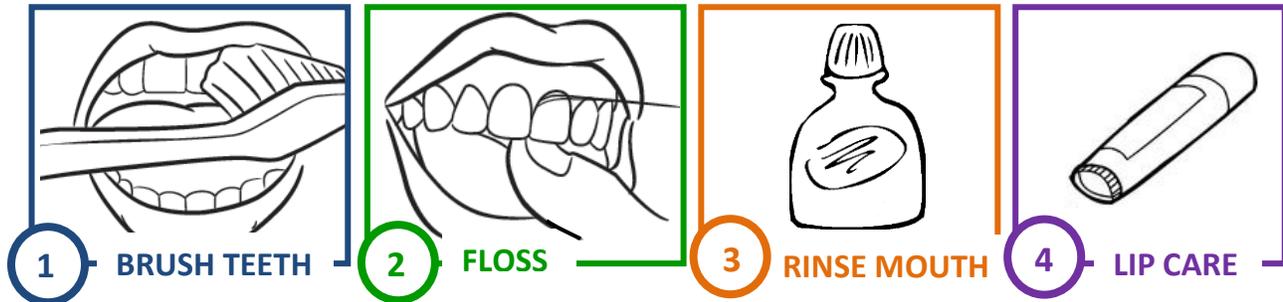
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Oncology Oral Care Bundle

It is important to keep the mouth as clean as possible to decrease germs and prevent infection. The following guidelines should be followed at home and in the hospital.



1. BRUSH TEETH

- Brush teeth and tongue 2-3 times a day (after meals and before bed).
- Use a soft nylon toothbrush. Do not use an electric toothbrush.
- Air dry toothbrush between uses. Do not cap toothbrush or store toothbrush by toilet.
- Replace the toothbrush:
 - after a hospitalization
 - every 3 months
 - after an infection
 - or, if bristles are worn
- Use fluoride toothpaste. Do not use toothpaste that contains whitening, brightening, tartar control or flavors that are irritating.
 - Ages 0-2, use a rice size amount of toothpaste.
 - Ages 2 and older, use a pea-size amount of toothpaste (child should be able to spit).

How to brush teeth:

- *Hold toothbrush at a 45 degree angle from the top of the tooth.*
- *Use a rotating motion as you brush.*
- *Brush teeth and tongue for 2 minutes.*
- *Children less than 7 years of age should have assistance with tooth brushing.*
- *Infants without teeth should have their gums and tongue cleaned 2-3 times per day using water and a washcloth or sponge.*

2. FLOSS BETWEEN TEETH

- Do not floss if platelets are below 50,000 or ANC is below 1,000.
- Use waxed floss.
- Do not use water flossers or toothpicks.

3. RINSE MOUTH

- Do not use if your child cannot spit out mouthwash. Mouthwash should not be swallowed.
- Rinse mouth 2-4 times per day with an alcohol-free mouthwash. Rinse for 15-30 seconds.
- Mouthwash does not replace tooth brushing. Your child should brush their teeth, and then use mouthwash.
- If your child can swish or gargle mouthwash, please encourage them to do so.
- If your child develops a mouth sore while in the hospital, alcohol free chlorhexidine gluconate mouthwash (Peridex) may be ordered.

4. LIP CARE

- Use a petroleum free lip balm 2-3 times per day or more often if lips are dry or cracked.

OTHER RECOMMENDATIONS:

- Diet:
 - Avoid spicy, hot, sour, or acidic foods. This can be irritating to the skin inside the mouth.
 - Avoid or limit sugary snacks and drinks.
 - Limit fruit juice to 4-6 oz. for children under six years old.
 - Avoid giving a bottle or sippy-cup with anything other than water during bedtime/nap.
- Dentist:
 - It is best to have a dental exam by a Dentist at the beginning of chemotherapy treatment, and every 6 months.
 - A dental exam may be needed more frequently for a child with mouth sores.
 - Notify your child's oncology provider at least two weeks before your child's scheduled dental appointment. Your child's dental appointment may need to be rescheduled if their blood counts are expected to be low.
 - If your child has braces, these may need to be removed before or soon after starting treatment.
- Kid Friendly Timer Applications:
 - Disney Magic Timer
 - Brush Up

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Protective Precautions Isolation

What is Protective Precautions/Isolation?

Your child is in Protective Precautions because he/she has a higher chance of catching an infection and may have trouble fighting off germs. Protective Precautions protects your child from other people who may have an infection.

How can I help protect my child?

- 1. Wash your hands or use hand sanitizer at the following times:**
 - Every time anyone enters or leaves the room.
 - After changing a diaper or helping a child to the bathroom.
 - Parents should wear chemotherapy gloves when changing diapers or helping a child to the bathroom for 48 hours after the last chemotherapy dose.
 - Children should also wash their hands after going to the bathroom and before eating or drinking.
- 2. Use safe practices when coughing or sneezing:**
 - Use hand sanitizer, masks and tissues, which are at the “Cover Your Cough” stations near all hospital entrances.
 - Cough or sneeze into a sleeve or tissue.
 - Throw tissues in the garbage can and wash hands or use hand sanitizer after blowing your nose, sneezing or touching your face.
 - **Visitors** who have a cough or cold should not visit until symptom free.
 - **Parents** who have a cough or cold should wear a mask in hallways and avoid public areas.
- 3. Protective clothing for hospital staff:**
 - Hospital staff may wear goggles, gowns and gloves, depending on the situation
 - Masks are required for any staff with a cold, cough or sore throat.

What else should I know about keeping my child and myself safe during this time?

- Fresh fruits and vegetables must be washed before being taken into the room.
- No live plants or flowers are allowed in the room because the water or soil may contain germs.
- Your child may need to wear a mask if outside the room, depending on your physician’s request.

*Help us to provide the best possible care for your child.
We want to know if you notice any hospital staff not practicing these guidelines.
Please call Infection Control at 955-3819 or 955-3816, if you have any questions. Thank you.*

Central Lines

After reviewing this section, you will be able to:

1. Identify the purpose for a central line
2. Understand Children's central line care standards and practices
3. Identify what central line signs and symptoms need immediate attention
4. Identify ways to help decrease risk of a central line infection
5. Understand components of the central line dressing and infusion caps

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Information and Care for a Central Venous Catheter

Your child has a Central Venous Catheter (CVC). This catheter is placed in a large vein and the end of the catheter sits near the heart. There are two types of Central Venous Catheters- tunneled and non-tunneled.

- A non-tunneled catheter can be placed in the neck, chest, or groin. These catheters are often put in for emergency or after surgery needs. They are taken out as soon as possible.
- A tunneled catheter can be placed in different parts of the body depending on how they will be used. Part of the catheter is tunneled under the skin. These catheters can be used a longer time.

CVCs are used for reliable intravenous (IV) access. A CVC allows medicine, hydration, or nutrition to be given through the vein. It may also be used to draw blood for lab tests.

Tunneled and non-tunneled CVC's are placed by a provider with anesthesia. CVC's can be removed while your child is awake. A non-tunneled CVC can be removed by a nurse or provider. Tunneled CVC's can only be removed by a provider.

Other names for Central Venous Catheter (CVC):

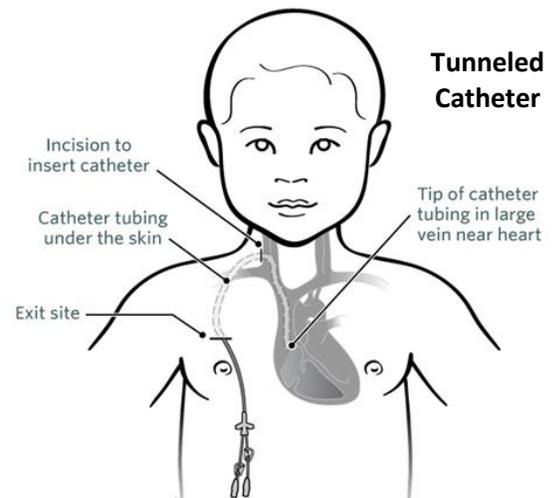
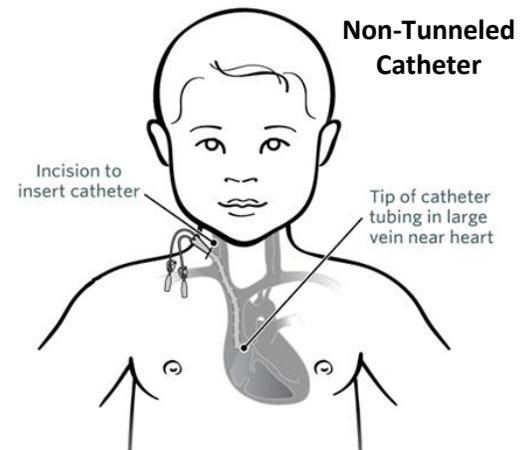
- Central Line
- Central Venous Line (CVL)
- Central Catheter

Potential risks and complications:

- Infection
- Blood clot
- Clotting of the central line
- Bleeding from the insertion site
- Develop a hole or crack within the central line
- Develop an abnormal heart rhythm (rare)
- A collapsed lung during insertion (rare)

Always follow these important rules:

- Keep your child's central line identification card with you at all times.
- Notify other health care providers that your child has a central line before having any medical testing, treatment, or procedures.
- Ask the provider managing your child's central line for activity recommendations. Children with a central line should not play contact sports.



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CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Central Venous Catheter care guidelines:

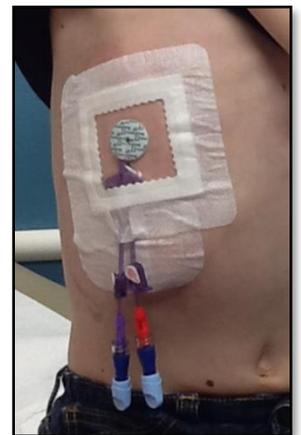
- Central line dressings are changed every 7 days or sooner if the central line dressing gets wet or dirty, or is no longer stuck down on all sides.
- Cap changes will be completed every 7 days or more frequently if your child receives: an anesthetic (medicine given for surgery) called propofol, lipids (IV fats), or blood products through their central line.
- All dressing, cap, and tubing changes are completed by a nurse. Do not flush the central line, change the central line dressing, or change the MicroClave cap unless you are instructed to do so.
- The dressing and caps should be kept clean and dry.
- The dressing should be covered with protective plastic before getting in the tub or shower.
- Do not submerge your child's central line dressing or caps underwater.
- Do not allow your child to swim or go in a hot tub while they have their central line.
- Do not add tape to the central line dressing if it is peeling up, or take off the central line dressing for any reason. This should only be done by a nurse in a sterile environment.

Dressing Change Procedure:

Below is a list of steps you will see the nurse perform during a dressing change.

1. Put on mask. Everyone in the room must wear a mask, including your child.
2. Wash hands. Everyone who helps will wash their hands.
3. Take off the old dressing.
4. Clean skin for at least 30 seconds to two minutes.
5. Let skin air dry for at least 1 minute and until completely dry.
6. Place antimicrobial disk.
7. Apply occlusive dressing over central line, covering the insertion site.

Please note: Not all companies or hospitals use an antimicrobial disk.



This is what the central line looks like after a dressing change.

Child Life Specialists are available to: explain the procedure to your child beforehand, provide distraction and support during the procedure, and for developmental play.

Heparin Use:

Central lines may be flushed with a medication called heparin to prevent clot formation within the central line tubing. Central lines are flushed with heparin once a day when IV fluids/medications are not given. Your provider will instruct you if heparin is needed based on your child's other IV medications or treatments they are receiving. If your child is going to discharge home with the central line, caregivers will be taught how to flush the line at home.

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Signs and Symptoms to Report with a Central Venous Catheter

Go to the **Emergency Department**, if your child develops:

- a fever of 100.4°F (38.0°C) or higher
- shortness of breath or trouble breathing
- chest pain
- a fast beating heart or 'skipping' beats
- dizziness, fainting, or passing out
- swelling in the neck, face, chest or arm on the same side of the body that the central line is placed
- pain is not relieved by pain medicine
- there is redness, swelling or drainage at the site of the central line
- bleeding from the central line site that does not stop
- your child hears "swooshing" noise when the central line is flushed
- Or, the central line is accidentally pulled on and comes part way out or all of the way out.
 - If the central line comes all the way out, hold firm pressure with a clean towel or paper towel over the site and bring the central line with you. **DO NOT THROW AWAY.**



RED

Emergency Department:

Name: _____

Address: _____

Call your **Home Health Company** right away, if:

- the central line dressing is not stuck down on all sides
- you notice a hole or tear in the central line dressing
- the disk is completely full of blood
- there is water or fluid under the central line dressing
- the MicroClave cap comes off of the central line
- the central line is hard to flush, or will not flush
- the central line leaks when you flush the line
- there is pain and/or discomfort when flushing the central line
- you cannot get a blood return from the central line (if applicable)



ORANGE

Home Health Company:

Name: _____

Phone number: _____

If a home health nurse is unable to come to your home within an hour, you may need to go to the Emergency Department.

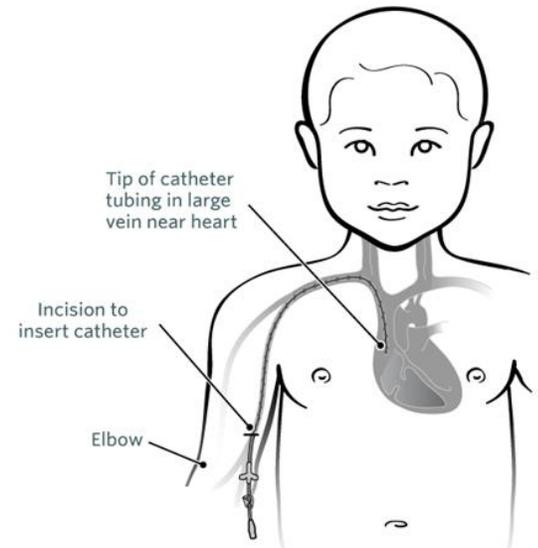
CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Information and Care for a Peripherally Inserted Central Catheter

Your child has a Peripherally Inserted Central Catheter (PICC). This catheter is placed into a vein in the arm or leg, and then threaded into a larger vein. The end of the catheter sits near the heart.

PICCs are used for reliable intravenous (IV) access. A PICC allows medicine, hydration, or nutrition to be given through the vein. It may also be used to draw blood for lab tests.

A PICC is inserted by a specially trained nurse or provider while your child is under anesthesia, sedation, or in some cases while they are awake (not common). A PICC can be easily removed by a nurse while your child is awake.



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Another name for Peripherally Inserted Central Catheter:

- Central Line

Potential risks and complications:

- Infection
- Blood clot
- Clotting of the central line
- Bleeding from the insertion site
- Develop a hole or crack within the central line
- Develop an abnormal heart rhythm (rare)
- Inflammation of the vein (phlebitis)

PICC care guidelines:

- PICC dressings are changed every 7 days or sooner if the PICC dressing gets wet or dirty, or is no longer stuck down on all sides.
- Cap changes will be completed every 7 days or more frequently if your child receives: an anesthetic (medicine given for surgery) called propofol, lipids (IV fats), or blood products through their PICC.
- All dressing, cap, and tubing changes are completed by a nurse. Do not flush the PICC, change the PICC dressing, or change the MicroClave cap unless you are instructed to do so.
- The dressing and caps should be kept clean and dry.
- The dressing should be covered with protective plastic before getting in the tub or shower.
- Do not submerge your child's PICC dressing or caps underwater.
- Do not allow your child to swim or go in a hot tub while they have their PICC.
- Do not add tape to the PICC dressing if it is peeling up, or take off the PICC dressing for any reason. This should only be done by a nurse in a sterile environment.

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Always follow these important rules:

- Keep your child's PICC identification card with you at all times.
- Notify other health care providers that your child has a PICC before having any medical testing, treatment, or procedures.
- Ask the provider managing your child's PICC for activity recommendations. Children with a PICC should not play contact sports.

Dressing Change Procedure: Below is a list of steps you will see your nurse perform during a dressing change.

1. Put on mask. Everyone in the room must wear a mask, including your child.
 2. Wash hands. Everyone who helps will wash their hands.
 3. Take off the old dressing.
 4. Clean skin for at least 30 seconds to two minutes.
 5. Let skin air dry for at least 1 minute and until completely dry.
 6. Place antimicrobial disk.
- Please note: Not all companies or hospitals use an antimicrobial disk.*
7. Apply occlusive dressing over PICC covering the insertion site.



This is what the PICC line looks like after a dressing change.

Child Life Specialists are available to: explain the procedure to your child beforehand, provide distraction and support during the procedure, and for developmental play.

Heparin Use:

PICCs may be flushed with a medication called heparin to prevent clot formation within the PICC tubing. PICCs are usually flushed with heparin twice a day when IV fluids/medications are not given. Your provider will instruct you if heparin is needed based on your child's other IV medications or treatments they are receiving. If your child is going to discharge home with the PICC, caregivers will be taught how to flush the line at home.

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Signs and Symptoms to Report with a Peripherally Inserted Central Catheter

Go to the **Emergency Department**, if your child develops:

- a fever of 100.4°F (38.0°C) or higher
- shortness of breath or trouble breathing
- chest pain
- a fast beating heart or 'skipping' beats
- dizziness, fainting, or passing out
- swelling in the neck, face, chest or arm on the same side of the body that the central line is placed
- pain is not relieved by pain medicine
- there is redness, swelling or drainage at the site of the PICC
- bleeding from the central line site that does not stop
- your child hears "swooshing" noise when the PICC is flushed
- Or, the PICC is accidentally pulled on and comes part way out or all of the way out.
 - If the PICC comes all the way out, hold firm pressure with a clean towel or paper towel over the site and bring the PICC with you. **DO NOT THROW AWAY.**



RED

Emergency Department:

Name: _____

Address: _____

Call your **Home Health Company** right away, if:

- the PICC dressing is not stuck down on all sides
- you notice a hole or tear in the PICC dressing
- the disk is completely full of blood
- there is water or fluid under the PICC dressing
- the MicroClave cap comes off of the PICC
- the PICC leaks when you flush the line
- the PICC is hard to flush, or will not flush
- there is pain and/or discomfort when flushing the PICC
- you cannot get a blood return from the PICC (if applicable)



ORANGE

Home Health Company:

Name: _____

Phone number: _____

If a home health nurse is unable to come to your home within an hour, you may need to go to the Emergency Department.

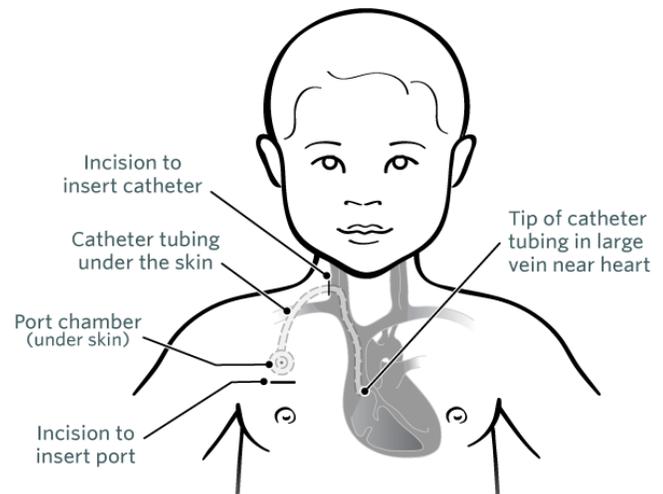
CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Information and Care for Implanted Port

Your child has an Implanted Port. An implanted port is placed under the skin in the upper or lower chest, arm, leg, or stomach. The port is connected to a thin tube (catheter), and the catheter is placed in a large vein. The end of the catheter sits near the heart.

Ports are used for reliable or long term intravenous (IV) access. A port allows medicine, hydration, or nutrition to be given through the vein. It may also be used to draw blood for lab tests.

Ports are inserted and removed by a surgeon under anesthesia.



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Other names for Implanted Ports:

- Port
- Infusaport
- Central Line
- Port-a-Cath
- Power Port

Potential risks and complications:

- Infection
- Blood clot
- Clotting of the central line
- Bleeding from the incision after surgery
- Develop a hole or crack within the central line
- Develop an abnormal heart rhythm (rare)
- A collapsed lung during surgery (rare)

Guidelines when the Port is accessed:

- The dressing and port needle will be changed every 7 days or sooner if the dressing gets wet or dirty, or is no longer stuck down on all sides. *See next page for more information about port access procedure.*
- Cap changes will be completed every 7 days or more frequently if your child receives: an anesthetic called propofol (medicine given for surgery), lipids (IV fats), or blood products through their port.
- All dressing, cap, and tubing changes are completed by a nurse. Do not flush the port, change the port dressing, or change the MicroClave cap unless you are instructed to do so.
- The dressing and caps should be kept clean and dry.
- The dressing should be covered with protective plastic before getting in the tub or shower.
- Do not submerge your child's dressing or caps underwater.
- Do not allow your child to swim or go in a hot tub when their port is accessed.
- Do not add tape to the port dressing if it is peeling up, or take off the port dressing for any reason. This should only be done by a nurse in a sterile environment.

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Always follow these important rules:

- Keep your child's port identification card with you at all times.
- Notify other health care providers that your child has a port before having any medical testing, treatment, or procedures.
- Ask the provider managing your child's port for activity recommendations. Children with a port should not play contact sports.

Port Access Procedure: Below is a list of steps you will see your nurse perform during a port access.

1. Put on mask. Everyone in the room must wear a mask, including your child.
2. Wash hands. Everyone who helps will wash their hands.
3. Take off the old dressing and remove port needle (only if the port is currently accessed).
4. Clean skin for at least 30 seconds to two minutes.
5. Let skin air dry for at least 1 minute and until completely dry.
6. Insert port needle through the skin into the port.
7. Place antimicrobial disk.

Please note: Not all companies or hospitals use an antimicrobial disk.

8. Apply occlusive dressing over insertion site and port needle.



This is what the port looks like from the outside of the body.

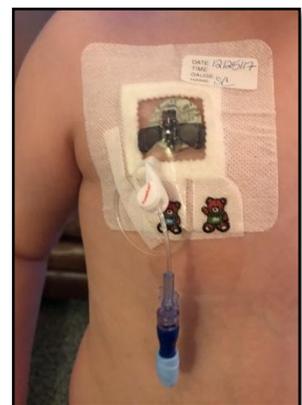
Child Life Specialists are available to: explain the procedure to your child beforehand, provide distraction and support during the procedure, and for developmental play.

Pain Agents:

Children's also has a variety of "pain agents" to decrease pain and numb the skin when accessing your child's port. Please ask your nurse for more information.

Heparin Use:

Ports are flushed with a medication called heparin to prevent clot formation within the port and tubing. Ports are flushed with heparin; at least once a month prior to de-accessing (taking the needle out), and if the port is accessed (needle placed into port) but IV fluids/medications are not given. Your provider will instruct you on how often heparin is needed based on your child's other IV medications or treatments they are receiving.



This is what it looks like when the port is "accessed".

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Signs and Symptoms to Report with an Implanted Port

Go to the **Emergency Department**, if your child develops:

- a fever of 100.4°F (38.0°C) or higher
- shortness of breath or trouble breathing
- chest pain
- a fast beating heart or 'skipping' beats
- dizziness, fainting, or passing out
- swelling in the neck, face, chest or arm on the same side of the body that the port is placed
- pain is not relieved by pain medicine
- there is redness, swelling, a rash, or drainage at or near the port site
- bleeding from the port site that does not stop
- your child hears "swooshing" noise when the port is flushed*
- Or, the port needle/tubing is accidentally pulled on and comes part way out or all of the way out.



RED

Emergency Department:

Name: _____

Address: _____

Call your **Home Health Company** right away, if your child's port is accessed and:

- the port dressing is not stuck down on all sides*
- you notice a hole or tear in the port dressing*
- the disk is completely full of blood*
- there is water or fluid under the port dressing*
- the MicroClave cap comes off of the port*
- the port is hard to flush, or will not flush*
- the port leaks when you flush the line*
- there is pain and/or discomfort when flushing the port*
- you cannot get a blood return from the port (if applicable) *



ORANGE

Home Health Company:

Name: _____

Phone number: _____

**If a home health nurse is unable to come to your home within an hour,
you may need to go to the Emergency Department.**

**Please note: This information does not apply to your child if their port is not accessed.*

CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

Preventing Central Line Infections

A central line can increase your child's risk for infection. A central line infection can occur when germs enter the bloodstream. To decrease the risk for infection, the below steps should be followed:

- **Wear a mask** every time the central line dressing or cap is changed.
 - Everyone in the room must wear a mask, including your child.
 - A mask decreases the chance of germs from your mouth or nose getting into your child's central line.
- **Wash hands** with soap and water or use hand sanitizer for a minimum of 15 seconds before touching the central line.
- **Wear clean gloves** when giving medications or drawing labs through a central line.
- **Clean the MicroClave** every time before giving medications or drawing labs. The MicroClave should be cleaned with an alcohol wipe for 15 seconds. Then allowed to air dry for at least 15 seconds, and until it looks completely dry before using.
- **Wear sterile gloves** when completing a central line dressing change or cap change.
- **Clean the skin with CHG** (an anti-germ cleanser) for at least 30 seconds to two minutes when performing a central line dressing change. The skin must air dry for at least 1 minute and until it looks dry before applying the central line dressing. This process gets rid of the germs on the skin.
 - *Please note: Central line dressing changes should only be completed by trained professionals. Also, if your child is allergic to CHG, another product will be used to clean the skin.*
- **Look at the central line dressing every day** to make sure it does not have a hole in it and is stuck down on all sides. Sometimes the dressing may peel up around the edges. This is ok as long as the dressing is stuck down at least one inch all the way around the insertion site.
- **Take a bath or shower every day.** In the hospital, you will use CHG liquid soap or wipes to bathe, unless told not to. At home, you will use your regular soap to bathe.
 - Cover the central line dressing with protective plastic before getting in the tub or shower.

What can you do to help protect your child?

- If someone does not do one of these steps, please ask them to STOP. Speak up and ask questions.
- Every time someone comes into your child's hospital, clinic room or home, ask them to wash their hands or use hand sanitizer.
- **Do NOT:**
 - let visitors touch your child's central line
 - let animals come close to your child's central line
 - submerge the central line dressing or caps under water
 - apply lotions or oils on the central line dressing or close to it
- **Tell your nurse right away if:**
 - the central line dressing is not stuck down on all sides
 - the central line dressing has water or fluid under it
 - the central line dressing has a hole or tear in it
 - the central line site has redness, swelling, a rash, or drainage
 - the central line tubing comes apart



CENTRAL LINE EDUCATION FOR PATIENTS & FAMILIES

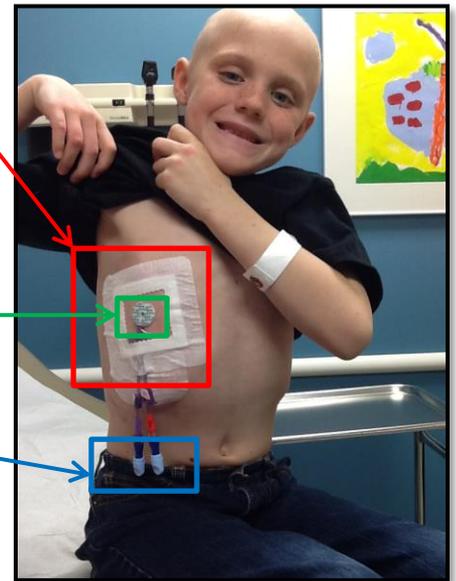
Reference Guide for Central Line Dressings & Infusion Caps

Central Line Dressing: There are many different parts of a central line dressing. Below is a picture of what your child's central line dressing may look like.

Central Line Dressing- the dressing protects the central line from germs. The dressing should remain clean, dry, and stuck down. Most central line dressings are clear so the nurse can easily see your child's central line and the area around it. Sometimes the dressing may peel up around the edges. This is ok as long as the dressing is stuck down at least one inch all the way around the insertion site.

Antimicrobial disk- the disk prevents germs under the central line dressing.

Light Blue DualCaps- the alcohol disinfecting caps covers the end of the MicroClave. *See below for more information.*



Infusion Caps: To help keep your child's caps and tubing clean, here a few picture of caps you may see used at Children's. *Please note: Not all companies or hospitals use disinfecting caps.*

	<p>MicroClave</p> <ul style="list-style-type: none"> • A MicroClave is attached to the end of a central line and should only be removed by a nurse. • The MicroClave must be cleaned every time before use. The MicroClave should be cleaned with an alcohol wipe for 15 seconds. Then allowed it to air dry for at least 15 seconds, and until it looks completely dry before using.
	<p>Light Blue DualCap</p> <ul style="list-style-type: none"> • The Light Blue DualCap is a sterile, one-time use, disinfecting alcohol cap. • This cap covers the MicroClave • If the Light Blue DualCap comes off, it should be replaced with a new cap as soon as possible.
	<p>Dark Blue DualCap</p> <ul style="list-style-type: none"> • The Dark Blue DualCap is a sterile, one-time use, disinfecting alcohol cap. • The Dark Blue DualCap covers the end of IV tubing.

Medications

After reviewing this section, you will be able to:

1. Understand prescribed medications and side effects
2. Discuss precautions to take with non-prescription medications and chemotherapy
3. Recall purpose, frequency, and precautions needed while taking Bactrim
4. Recall who and when to call with medication refills
5. Discuss immunization recommendations while on therapy
6. Demonstrate subcutaneous injection (if applicable)

Medications

It's helpful to bring your current medication calendar and all of your child's medication bottles to your child's appointments. This will allow us to answer any questions you may have about the medicine your child is taking.

Taking Medications



Check with your child's oncology nurse or provider before giving your child any non-prescription medicine. They may make chemotherapy less effective or interact with other medications your child is receiving. This includes acetaminophen (Tylenol), ibuprofen (Advil/Motrin), aspirin, vitamins, and herbal supplements.

Carefully check the label of any medications for these ingredients:

- Aspirin
- Acetylsalicylic acid
- ASA content
- Acetaminophen
- APAP
- Ibuprofen
- Naproxen

If you are unsure whether a medication contains any of these ingredients, ask a pharmacist.

Tylenol & Ibuprofen

Tylenol (acetaminophen), Advil/Motrin (ibuprofen), or Naprosyn (naproxen sodium) can mask symptoms of fever or infection. **Do not give Tylenol (acetaminophen), Advil/Motrin (ibuprofen), or Naprosyn (naproxen sodium) until you have talked to the oncology provider or nurse. After calling, they will tell you if it is ok to give.** Before giving these medications, always check your child's temperature.

Aspirin & Aspirin Substitutes

Avoid giving your child aspirin, which can prolong bleeding and is not recommended for children.

Medications

Vitamins & Supplements

If you are considering vitamins, supplements or other herbal therapies for your child, please discuss this decision with your oncologist. Some supplements (such as vitamins, herbal therapies, and natural remedies) can interfere with chemotherapy or other medications. If there is a supplement you would like to give your child, please bring it to your next clinic appointment. Our providers and pharmacists can review the ingredients to help determine their safety.

Oral Chemotherapy

If you are giving your child chemotherapy by mouth, you should wear gloves when handling the medication. After giving the chemotherapy to your child, remove gloves and discard in trash. Then wash hands with soap and water. Caregivers who are pregnant or breast feeding should not handle chemotherapy.

Do not open capsules or crush/split tablets without teaching from the oncology pharmacist. When crushing or splitting tablets a mask and gloves must be worn. The mask is used to prevent fine powder from the capsule or tablet from being inhaled through the lungs. After giving the chemotherapy to your child, thoroughly clean the surface where you prepared the medication. Then remove gloves and mask and discard in trash, and wash hands with soap and water.

Why Is My Child Taking Bactrim?

Bactrim is a medication used to prevent a lung infection called pneumocystis pneumonia. You may also hear this type of pneumonia referred to as Pneumocystis Carinii Pneumonia (PCP) or Pneumocystis Jirovecii Pneumonia (PJP). Your child is now at risk for this lung infection because of their decreased immune system.

Bactrim should be taken two times a day for two days in a row each week. We recommend that all patients take their Bactrim on Saturdays and Sundays, at morning and at night each of those days. If your child is not able to tolerate Bactrim, a different medication will be prescribed. These medications are usually continued throughout the entire course of treatment, and until the immune system recovers after treatment is complete.

Bactrim also can cause your child's skin to be more sensitivity to sunlight. Please make sure your child wears sunscreen and protective clothing (long sleeves and a hat).

Medications

Reordering Medications

When medication is prescribed for your child, you may be given more than what is needed for that particular course. This is because you will need many of the same medications at another time.

When your child's supply of medications starts to run low, additional medications may be ordered by calling your pharmacy. Some medications may not be in stock and will need to be special-ordered. For that reason, it is best to order refills when you still have **at least a one-week supply** of the medication(s) remaining.

Immunizations

We recommend your child receive the flu vaccine while receiving treatment. Treatment suppresses your child's immune system, which can make other vaccines ineffective.

Live vaccines such as varicella (chicken pox) and MMR (measles mumps and rubella) can be especially dangerous for patients with a suppressed immune system and should not be given during therapy.

Siblings of a child with cancer who need vaccinations can usually receive their vaccinations as scheduled. Please check with your child's oncologist.



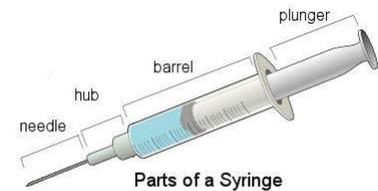
We encourage anyone who will have close contact with your child to have the annual flu vaccine.

A Guide to Subcutaneous Injections (shots)

Definition: A subcutaneous injection (shot) is a shot into the tissues just below the outer layer of the skin. The amount of medications for subcutaneous shots is small, no more than 1 mL (milliliter).

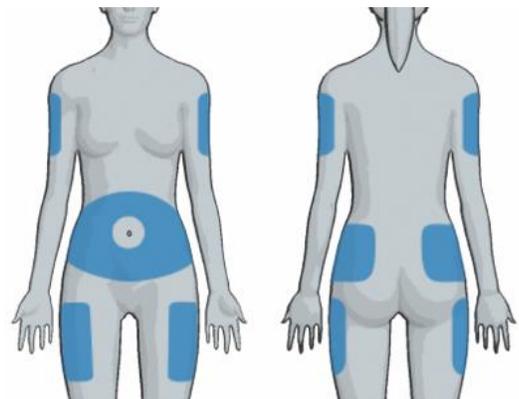
Getting medication ready:

- Gather supplies:
 - New syringe
 - Vial of medicine
 - Alcohol wipes
 - Hard plastic container to throw away needles and syringe
- Wash hands with soap and water.
- Use a new alcohol wipe to clean the top of the medication vial for 10 seconds. Allow alcohol to dry.
- Draw up the prescribed dose of medication into the syringe, as instructed.



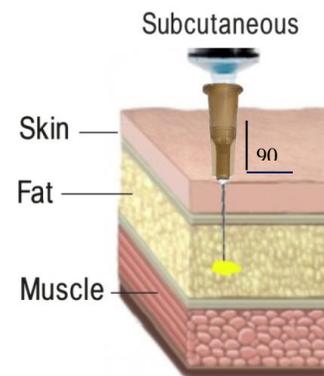
Preparing the site for a shot:

- Choose a spot on the body for the shot (see picture).
The preferred spots are:
 - Abdomen
 - Top or outsides of the thighs
 - Top of the buttocks
 - Backs of upper arms
- Avoid areas that are:
 - Bruised
 - Have signs of an infection, like redness or swelling
- Rotate preferred spots on the body with each shot.
- Cleanse spot with a new alcohol wipe for 10 seconds.
- Allow alcohol to dry (about 10 seconds).



Giving the shot:

- With your thumb and first finger, grasp the skin on both sides of the spot that you just cleaned (similar to a pinching position).
- Hold the syringe like a pencil at a 90-degree angle.
- Using a quick, smooth motion, insert the entire needle into the skin.
- Slowly press down on the syringe plunger; release your grasp on the skin.
- Remove the needle smoothly, pulling out at the same angle as it was inserted.
- Cover the injection site with a finger for a couple seconds. Avoid using a tissue or cotton ball for this.
- Do not place the plastic cover back on the needle.
- Placed the used syringe in a hard plastic container.



Caring for Your Child

After reviewing this section, you will be able to:

1. Recall chemotherapy precautions for body fluids
2. Discuss nail and skin care guidelines
3. Identify food recommendations
4. Discuss hair loss
5. Discuss treatment effects on fertility
6. State guidelines for when child can return to school
7. Identify resources specific to adolescents (if applicable)
8. Understand purpose for therapies (OT, PT, ST)
9. Locate information on educational support services and school re-entry program.
10. Summarize adolescent specific care (if applicable)

Caring for Your Child

Chemotherapy in Body Fluids

Chemotherapy medication remains in your child's body fluids (blood, urine, stool, vomit and semen) during chemotherapy and for 48 hours after chemotherapy is completed. **Caregivers should always wear gloves before coming into contact with your child's body fluids during chemotherapy and for at least 48 hours after the chemotherapy has been given.**

If your child accidentally soils clothing or bedding with any body fluids within 48 hours of receiving chemotherapy, wash the soiled laundry twice in hot water with detergent separately from other laundry.

When you are at home, flush the toilet twice with the lid down after your child uses the restroom during the 48 hours after receiving chemotherapy. If your child wears diapers, double-bag the soiled diapers and gloves and dispose of them immediately.

Nail Care

Your child's fingernails and toe nails should be kept trimmed by using nail clippers, an emery board or cuticle scissors. Discourage nail biting and thumb sucking as they both can be a source of infection. Never let your child tear nails or hang nails.

Sun Protection

Chemotherapy will make your child's skin extremely sensitive to sun. To avoid sunburn, we recommend that your child wears sunscreen (SPF 50 or higher) and reapplies at least every two hours, a hat to cover their head, and you limit the amount of time your child spends in direct sunlight.

Food Recommendations

You usually will not need to make any major changes in your child's diet during therapy. It is recommended to avoid unnecessary exposure to bacteria in foods while your child's immune system is decreased. This includes avoiding raw or undercooked meat, unpasteurized dairy products, raw honey and uncooked Brewer's yeast. In addition, wash all fruits and vegetables thoroughly (at least twice) and avoid any expired food or any food with visible mold.

Most milk and yogurt, as well as some cheeses, are pasteurized and are safe to eat.

Caring for Your Child

Hair Loss

Chemotherapy and/or radiation to the head may cause hair loss, or your child's hair to thin. This may include your child's eyelashes, eyebrows, under arm hair, pubic hair, etc. In some cases, children and parents may decide to cut the hair short before it falls out or shave their head bald. Many children wear hats, wigs, or scarves to cover their head. The social worker or child life specialist can help you order a wig for your child if you are interested.

Fertility

Radiation and certain types of chemotherapy that are used to treat cancer may cause problems with your child's ability to get pregnant or make someone pregnant, also known as fertility. You can talk with your health care team about how likely it is for their treatment to affect fertility. They may be able to offer some options for fertility preservation or ways to make it more likely for your child to have a baby in the future.

Returning to School

Going to school is an important part of helping your child feel "normal." We can help to ease the transition for children returning to school. Timing for when your child can return to school will be based on their diagnosis and type of treatment. In general, your child should have an ANC greater 500 to return to school. There may be times throughout therapy in which we anticipate your child's counts to be dropping. During those times we may decide it would be best to keep your child home from school. This can be discussed with your provider.

Adolescent Care

Taking Responsibility

We have given your parents/caregivers a binder and book with detailed information about your treatment. Your parents/caregivers need to know what is going on to be able to help you. However, the information we have given them is also really important for you. We encourage you to read this information. It is your body – and it is your responsibility to take good care of it.



Privacy

Your privacy is important to us. If you are an adult (19 years of age or older and live in Nebraska, or 18 and live in Iowa) your medical information does not have to be shared with parents/caregivers (with the exception of abuse or risk of self-harm). If you are not yet an adult, your parents will have some access to your medical information. However information about most sexual or mental health issues will stay confidential. If you have questions about your privacy, please ask.

Exercise

As long as your health care team says it is okay, exercise is a great idea. Just make sure that you don't push yourself too hard and take breaks when you need them.

Vitamins & Supplements

It is important to tell your health care team if you are taking or thinking about taking any herbal or nutritional supplements. They can help you figure out if what you are taking is safe.

Friends

Friends are an important part of your life. We encourage you to stay connected to your friends throughout your cancer treatment. However, if your friends are sick (cough, runny nose, upset stomach), we recommend that they don't visit, as germs could spread.

It is your decision on how much you want to tell your friends about your cancer and treatment. Some choose to post information on social media, while others keep things private. Your Child Life Specialist can help you choose the best way to share your story.

Adolescent Care

Alcohol & Drugs

It is important that you stay as healthy as possible during this time and avoid using drugs or alcohol, including tobacco products. Drugs and alcohol can interact with your cancer treatment and cause damage to organs in your body. Please be honest with your oncology provider about your current or planned use of alcohol, drugs, or tobacco products.



Tattoos & Body Piercings

It is not a good idea to get tattoos or body piercings during treatment because there is a risk of infection and bleeding. If you already have a piercing, your oncology provider may recommend that you take it out during treatment. This is really important for tongue piercings because of the bacteria found in your mouth.

Sexual Activity

As an adolescent/ young adult, sexuality is a normal part of your life. If you are sexually active it is important that you talk with your oncology provider about any questions, concerns and your sexual behaviors.

Chemotherapy puts you more at risk for bleeding and sexually transmitted infections (just like other infections). It is recommended to avoid sexual intercourse (including oral sex) for at least 48 hours after chemotherapy, because chemotherapy remains in your bodily fluids for 48 hours and could be harmful to your partner.

If you are sexually active during treatment, condoms and birth control should be used to decrease the chance of infection or pregnancy. If either partner is on chemotherapy when pregnancy occurs, the baby can have serious birth defects.

Adolescent Care

Web Resources for Teens and Young Adults:

National Collegiate Cancer Foundation provides need-based financial support to young adult survivors who are pursuing higher education throughout their treatment and beyond.

Website: www.collegiatecancer.org

Group Loop is a safe place for teens affected by cancer to connect, find support, education and hope while dealing with a cancer diagnosis.

Website: www.cancersupportcommunity.org/group-loop

TeensHealth is a safe, private place for teens that need honest, accurate information and advice about health, emotions, and life. They also have information about cancer.

Website: www.kidshealth.org/en/teens

13Thirty Cancer Connect provides resources for adolescents and young adults related to coping and self-esteem. Website: www.13thirty.org

The Ulman Cancer Fund provides a community of support for young adults, and their loved ones, impacted by cancer. Website: www.ulmanfund.org

First Descents offers young adult (ages 18-39) cancer fighters and survivors free life-changing outdoor adventures. Website: www.firstdescents.org

Rehabilitation Therapies

What is Occupational Therapy?

Occupational therapy (OT) is a part of the rehabilitation team. OT's focus is to help your child gain or regain independence in all of their daily activities, which include; self-care skills, functional mobility, and play.

What is Physical Therapy?

Physical therapy (PT) is a part of the rehabilitation team. PT's focus is to help evaluate current or anticipated changes in your child's strength, balance, and mobility. PT can help your child with; getting out of bed, moving from sitting to standing, walking, climbing stairs, and tasks that require balance and coordination.

How can occupational therapy and physical therapy help your child?

As your child goes through treatment you may notice a decrease in strength, endurance, balance, or coordination which can negatively impact their participation in daily activities and play.

To decrease or prevent this from occurring, our therapy team would like to get involved at the beginning and follow your child throughout their course of treatment. Our goal is to improve your child's strength and mobility skills so they can return to their desired activities between and after treatments.

What does therapy look like at Children's Hospital?

Play is an important part of your child's life. During our treatments we will use games and activities to focus on improving their overall function. Depending how your child is feeling or their current medical status, we may work in the room, in the hallway, or even in our therapy gym. Family involvement is always encouraged.

What can I do to help my child?

When a child is in the hospital it is difficult to stay active. To encourage an active lifestyle during your hospital stay, we recommend your child:

- Sit up in the chair or on the parent bed for all meals
- Get out of bed for as much of the day as possible
- Maintain a regular sleep/wake schedule
- Maintain your child's home routine (getting dressed, brushing teeth, etc.)
- Get out of the room each day- walk in the hallways with a mask, reserve the playroom for an hour, or go to hospital events (if your child's medical status allows)

Rehabilitation Therapies

When should I ask for an occupational therapy or physical therapy referral?

OT and PT are often consulted at the time your child is diagnosed with cancer. However if your child isn't receiving OT/PT services and they are experiencing any of the following difficulties, please ask your provider for a therapy consult:

- Decreased strength and endurance
- Unable to perform self-care skills (dressing, getting to the restroom, brushing teeth)
- Weakness on one side of the body
- Abnormal sensations in arms, hands, legs, or feet (such as; numbness or tingling)
- Decreased willingness to move around in bed, stand, or walk
- Decreased balance or increased tripping/falling
- Back pain
- Decreased willingness to spend time out of bed
- Decreased ability to move a specific area of the body
- Any changes resulting in abnormal movements

Rehabilitation Therapies

What is a Speech Therapy?

Speech therapy (ST) is a part of the rehabilitation team. ST's focus is to prevent and treat speech, language, communication, and swallowing disorders.

How can speech therapy help your child?

Language development begins in early childhood. Cancer treatments (chemotherapy, surgery, radiation, and other procedures) may cause delays in the language center of the brain. This could lead to speech, language, and cognition impairments.

Children who are hospitalized for long periods of time may also experience decreased speech, language, and practical skills due to limited opportunities. Early intervention is important. ST can be provided at the beginning of your child's cancer therapy and throughout. Outpatient ST may be necessary after discharge from the hospital if your child is not meeting developmental milestones. Our goal is to help your child develop to their full potential.

What does speech therapy look like at Children's?

Play is an important part of your child's life. It is how children develop and learn. ST will select games and activities that focus on your child's individualized goals. Depending on how your child is feeling we may work in the room, in the hallway, or even in our therapy gym. Family involvement is always encouraged.

When should I ask for a speech therapy referral?

ST is often consulted at the time your child is diagnosed with cancer. However if your child isn't receiving ST services and they are experiencing any of the following difficulties, please ask your provider for a speech therapy consult:

- Decrease in babbling, words, or overall speech
- Decrease in desire to play or appropriate play skills
- Decrease in auditory tracking, listening, or following directions
- Speech is difficult to understand
- Difficult time expressing wants and needs
- Word finding difficulties
- Higher level language deficits (figurative language, inferences, summarizing, drawing conclusions)
- Impaired memory, forgetfulness, or overall mental slowness
- Decreased executive functioning skills (focus, attention, juggling multiple tasks)

Educational Support Services

Educational Support Services for Your Child

In keeping with Children's philosophy of treatment of the whole child, we recognize that stimulation of the mind and healing of the body go hand-in-hand. The goal of our education program is to help patients who miss a significant amount of school, remain academically involved.

If your child will be missing school due to a lengthy stay, keeping up with school work can become a pressing concern. Our Children's Educational Support Services team is comprised of Peggy Smith and Margaret McCawley, both certified teachers, who are eager to support you! We are here to advocate for you and your child during their treatment; we can act as a liaison between you and your child's school team in order to provide your child with the best support possible.

During a patient's stay, it will be our job to stay in close contact with their teachers in order to get any information needed that might assist them in completing their assignments. As educational liaisons, we can send and receive assignments as needed through fax and e-mail. We can assist older students to make sure they are able to communicate directly with their classroom teachers, complete online assignments, print out documents and access additional support resources. We can also help your child stay connected with their teacher and classmates by supporting streaming services through platforms such as Skype and FaceTime. There are numerous platforms that can be utilized to help your child stay connected with their education, and we look forward to helping each patient find the right fit for them.

Prior to being discharged, we will communicate with the school team about expectations and accommodations to help create a smoother transition back into the school setting. If needed, we can facilitate setting up homebound instruction through your school district.

Ultimately, we are here to be a support to you by answering questions or offering assistance and encouragement. Please feel free to contact either of us regarding any school related questions or concerns. It is a privilege and an honor to be an advocate for your child and their education.



Peggy Smith B.S., M.S.
Elementary & Middle School
Phone #: (402) 955-3836
Email: marsmith@childrensomaha.org



Margaret McCawley
Middle & High School
Phone #: (402) 955-3894
Email: mmccawley@childrensomaha.org

School Re-entry Program

School Re-entry Program

Children's Hospital & Medical Center Child Life Services offer a school re-entry program for patients in our care. The school re-entry program offers an opportunity for your child's classmates and teachers to learn basic and important information regarding their diagnosis, treatment plan and side effects. It provides an opportunity for health care professionals to clarify misconceptions, alleviate confusion, and disqualify myths that the children and school staff may have.

The school visit is coordinated and conducted by a Certified Child Life Specialist. Each re-entry presentation is designed for the age and developmental level of the class.

The program is available for school classes within a 50 mile radius of the Omaha area. The program is for children grades Kindergarten through 12th grade. There is no charge to the family for this service. It is preferred that each child have only one school visit during their treatment. For families who live greater than 50+ miles, child life specialists can provide presentation resources to the school nurse or counselors.

If you would like more information or would like to discuss a school re-entry for your child or your classroom please contact Christy Hogan or Melissa Epley.



Christy Hogan

Certified Child Life Specialist

Phone #: (402) 955-8845

Email: chogan@childrensomaha.org



Melissa Epley

Certified Child Life Specialist

Phone #: (402) 955-5328

Email: mepley@childrensomaha.org

Helpful Resources

In this section you will read about:

1. Children's Connect
2. Home Healthcare
3. Rainbow House
4. Children's Oncology Group Clinical Trials
5. What You Need to Know About Research Studies
6. Rights of Research Subjects
7. Patient and Family Resources

Helpful Resources

Children's Connect

Children's Connect is our free, personalized and secure online tool that allows you can access your child's medical information, and message your child's outpatient health care team, via your home computer, cell phone or tablet.



With Children's Connect, you can:

- Review medications, immunizations, allergies, medical history and visit summaries
- Receive test results online following clinic visits or discharge from the hospital
- Review education topics and discharge instructions
- Pay your medical bills online and much more

The process to sign up is simple! You can sign up at your next clinic appointment or online. To sign up online, visit our website at ChildrensOmaha.org and click on the Children's Connect icon. The process involves filling out our consent form and submitting it. Patients age 19 and older may fill out the consent form on their own behalf. Once we receive the consent form, we will send a Children's Connect activation code to your email. This code enables you to create your own user ID and password – and the process is complete!

For any additional questions related to Children's Connect, please contact the Children's Connect help line at 402-955-7237.

Home Health

Home Health Services

Some children may need to use home health services during their cancer treatment. If services are needed, our Home Health Liaison will provide you with a comprehensive list of companies to choose from. Below is a brief list of some of the services that can be offered in the home.

Home Infusion: A nurse may need to visit your home to help give intravenous (IV) nutrition, IV hydration, IV antibiotics, and/or other specialty medications if prescribed by your doctor.

Home Health Nursing: A nurse may need to visit your home to monitor your child's condition, collect blood samples, care for your child's central line (example: central line dressing change or cap change), and/or help with enteral feeds.

Home Medical Supplies: Some children may need specialized supplies, such as; urinary, ostomy, respiratory or enteral supplies.

Rehabilitation Equipment: Some children may need rehabilitation equipment for short term or long term use, such as; manual or power wheelchairs, gait trainers, bath chairs, standers, and lifts. These items may be rented or purchased based on your child's needs and what the company offers.

Private Duty Services: If needed, a private duty nurse may come into your home to care for your child. The number of hours or visits per week depends on your child's needs and medical condition.

Below is a brief list of some home health companies in the Omaha area. For a complete list, please ask our Home Health Liaison.

<p>Children's Home Healthcare</p> <p>Address: 3000 S. 84th Street, Omaha, NE 68124 Phone #: 800-747-7334 or 402-955-7777</p>	<p>Infuscience</p> <p>Address: 8710 F Street, Suite 118, Omaha, NE 68127 Phone #: 1-800-252-5094</p>
<p>Coram (CVS Specialty Infusion Services)</p> <p>Address: 11111 Mill Valley Road, Omaha, NE 68154 Phone #: 1-800-666-1435 or 402-330-5482</p>	<p>Option Care (Walgreens)</p> <p>Address: 10924 John Galt Blvd, Omaha, NE, 68137 Phone #: 402-331-0980</p>

Helpful Resources

The Carolyn Scott Rainbow House

The Rainbow House is located at 7825 Farnam Drive, within walking distance of the hospital. A shuttle bus is available to transport families to and from Children's. As required by law, all children should be secured in an appropriate car seat during transportation.



Please call 402-955-7815 for shuttle times and information, or to reserve a room.

To be a guest at the Rainbow House, your child must be admitted to or have an appointment at Children's and you must live outside a 60-mile radius of Omaha.

Only immediate family may seek accommodations at the Rainbow House, and anyone under the age of 18 must be accompanied by a parent or legal guardian. One room is assigned per patient for parents or legal guardians and siblings.

All monetary donations are greatly appreciated. There is a suggested monetary donation per night but no one is turned away due to their inability to pay. You may make your donation using cash, check or credit card.

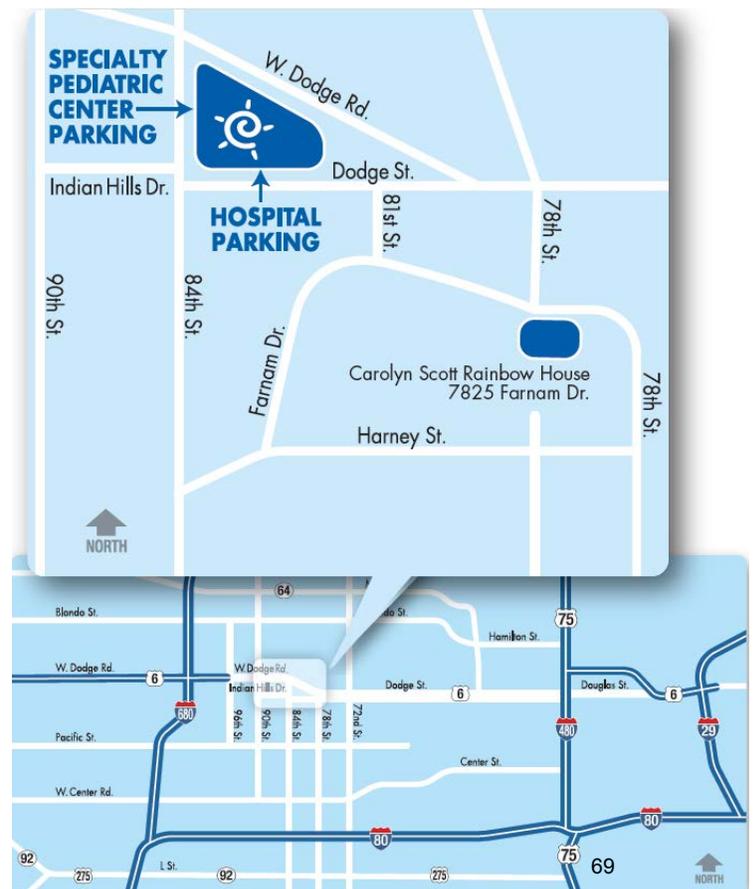
Reservations & Check-In

- Please call 402-955-7815 to reserve a room.
- Check-in is preferred by 9 pm.

Accommodations

- Each room is equipped with a queen size bed (a limited number have two queen beds), a pull-out sofa and private bath.
- Cable television and Wi-Fi access is available.
- All families share a large kitchen and dining room. A personal pantry and refrigerator is provided for each family.
- Media, game, meditation, exercise, computer and play rooms are available.
- Free laundry facilities; guests are to provide their own laundry detergent and dryer sheets.

Families who have a child in the hospital, but are not staying overnight, also are welcome to use the Rainbow House to take a break from the hospital, wash clothes or to join guests for a meal provided by volunteer groups.



Participation in Children's Oncology Group Clinical Trials

Children's Hospital & Medical Center is a member of the Children's Oncology Group (COG). COG is an international research group and the largest pediatric clinical trials group in the world. COG has treated more children and adolescent with cancer than any other organization and over 200 hospitals participate in COG.

All children who are being treated for cancer at a COG center will be invited to participate in the Project Every Child (PEC) study. PEC is a registry study with the initiative to find better ways to diagnose, treat and prevent cancers in children, adolescents and young adults. We can best learn by combining information from as many children with cancer as possible. The PEC study will collect information about your child's cancer. After your child's diagnosis, his or her physician, nurse, or research staff may visit with you about participating in the PEC study. Details about the PEC study will be presented to you in an informed consent form. We encourage you to take time to think about this study and discuss any questions you have with your physician. If you choose, you may sign the consent form to enroll your child on the study. The study is completely voluntary and will not affect your child's care or treatment in any way.

There are many types of clinical trials, which are separate from the PEC registry study mentioned above. Your child's physician may approach you about clinical trials that are available to your child. Some clinical trials involve collecting blood or other specimens from your child. Some trials involve your child's cancer treatment. These are completely voluntary and your physician will discuss your options with you thoroughly. If your child is eligible for a clinical trial and you are interested in learning about participation in the trial, you will be given an informed consent form. Your child's physician will discuss this form with you in detail and answer any questions you have about the clinical trial. This informed consent form will describe the clinical trial in detail. Please ask as many questions as you want. If your child is 7 or older, he or she may be asked to listen to and be involved in the clinical trial discussion.

For more information about clinical trials which involve your child's treatment, please see the [Children's Oncology Group Family Handbook](#) that is also given to you at diagnosis. This handbook may also provide guidance for you in your decision to participate and help you know what kinds of questions to ask.

Institutional Review Board (IRB)

What Do I Need To Know Before Being In A Research Study?

You have been invited to be in a **research study**. Research studies are also called “clinical trials” or “protocols.” **Research** is an organized plan designed to get new knowledge about a disease or the normal function of the body. The people who are in the research are called **research subjects**. The **investigator** is the person who is running the research study. You will get information from the investigator and the research team, and then you will be asked to give your **consent** to be in the research.

This sheet will help you think of questions to ask the investigator or his/her staff. You should know all these answers before you decide about being in the research.

What is the **purpose** of the research? Why is the investigator doing the research?

What are the **risks** of the research? What bad things could happen?

What are the possible **benefits** of the research? How might this help me?

How is this research different than the care or treatment I would get if I wasn't in the research? Are there other treatments I could get?

Does **everyone** in this research study get the same treatment?

Will being in the research **cost** me anything extra?

Do I have to be in this research study? Will the doctor still take care of me if I say **no**?

Can I **stop** being in the research once I've started? How?

Who will look at my **records**?

How do I reach the investigator if I have more **questions**?

Who do I call if I have questions about being a **research subject**?

Make sure all your questions are answered before you decide whether or not to be in this research.

Institutional Review Board (IRB)

THE RIGHTS OF RESEARCH SUBJECTS

AS A RESEARCH SUBJECT AT CHILDREN'S HOSPITAL AND MEDICAL CENTER YOU HAVE THE RIGHT ...

... to be told everything you need to know about the research before you are asked to decide whether or not to take part in the research study. The research will be explained to you in a way that assures you understand enough to decide whether or not to take part.

... to freely decide whether or not to take part in the research.

... to decide not to be in the research, or to stop participating in the research at any time. This will not affect your medical care or your relationship with the investigator or Children's Hospital and Medical Center. Your doctor will still take care of you.

... to ask questions about the research at any time. The investigator will answer your questions honestly and completely.

... to know that your safety and welfare will always come first. The investigator will display the highest possible degree of skill and care throughout this research. Any risks or discomforts will be minimized as much as possible.

... to privacy and confidentiality. The investigator will treat information about you carefully, and will respect your privacy.

... to keep all the legal rights you have now. You are not giving up any of your legal rights by taking part in this research study.

... to be treated with dignity and respect at all times

The Institutional Review Board is responsible for assuring that your rights and welfare are protected. If you have any questions about your rights, contact the UNMC Institutional Review Board at (402) 559-6463.

Resources & Support

This is a partial list of available resources and support for children with cancer and their families. The **social worker** may also be helpful in identifying support and resources that are more specific to your needs.

13Thirty Cancer Connect

Provides resources for adolescents and young adults related to coping and self-esteem.

Address: 1000 Elmwood Ave., Rochester, NY 14620

Phone #: 585-563-6221

Email: staff@13thirty.org

Website: www.13thirty.org

Alex's Lemonade Stand Foundation- Travel for Care Program

Offers assistance to families who need to travel for childhood cancer treatment. Transportation, lodging, and meal accommodations are available to eligible families who meet criteria.

Website: www.alexslimonade.org/travel-fund

American Cancer Society

Provides information on research, education, and prevention of cancer.

Address: 250 Williams Street NW, Atlanta, GA, 30303

Phone #: 1-800-227-2345

Website: www.cancer.org

American Cancer Society - Omaha Office

Address: 9850 Nicholas Suite 200, Omaha, NE 68114

Phone #: 402-393-5800

American Childhood Cancer Organization

Provides information and support for children and adolescents with cancer and their families.

Address: 6868 Distribution Drive Beltsville, MD 20705

Phone #: 855-858-2226, Local #: 301-962-3520

Fax #: 301-962-3521

Website: www.acco.org

Resources & Support

Angels Among Us *

Provides financial assistance to families with children 19 and under who are battling cancer.

Address: 3858 Jones Street Suite A, Omaha, NE 68105

Phone #: 402-934-0999

Website: www.myangelsamongus.org

BMT InfoNet

Provides information and resources to support transplant patients and families.

Address: 1548 Old Skokie Road, Suite 1, Highland Park, IL 60035

Phone #: 888-597-7674 or 847-433-3313

Fax #: 847-433-4599

Email: help@bmtinfonet.org

Website: www.bmtinfonet.org

The Bone Marrow & Cancer Foundation

Offers financial assistance and free support services to bone marrow/stem cell transplant patients and their families.

Address: 515 Madison Ave Suite 1130, New York, NY 10022

Phone #: 800-365-1336 or 212-838-3029

Fax #: 212-223-0081

Email: thebmf@bonemarrow.org

Website: www.bonemarrow.org

Camp CoHoLo *

Offers a free summer camp for children ages 6-17 who are impacted by cancer or blood disorders. Camp information will be mailed to your home.

Address: PO Box 24466, Omaha, NE 68124

Email: director@campcoholo.com (Berta Ackerson)

Website: www.campcoholo.com

Resources & Support

Camp Quality USA Heartland *

Provides support to families dealing with a diagnosis of pediatric cancer, including a free, medically supervised, 5 day summer camp and yearly activities for children ages 5-17 with cancer and their siblings. Camp Quality Heartland pairs each camper one-on-one with an adult companion throughout the entire 5 days of camp.

Address: PO Box 24322, Omaha, NE 68124

Phone #: 402-450-1674 (Laura Peitzmeier, Camp Director)

402-730-5474 (Tony Foreman, Camp Director)

Email: heartland@campqualityusa.org

Website: www.campqualityusa.org/htl

CancerCare

Provides free professional support services including counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer. Financial assistance is limited to homecare, childcare, transportation, medication and copays.

Address: 275 Seventh Avenue, New York, NY 10001

Phone #: 800-813-HOPE (4673)

Email: info@cancercare.org

Website: www.cancercare.org

Candlelighters *

Several times a year, Candlelighters offers social events for families to meet and to share enjoyable moments together as families. Children with cancer, their parents and siblings will have an opportunity to talk with one another, to play or to enjoy an outing together in an atmosphere in which exposure to opportunistic infection will be minimized. The groups are facilitated by pediatric oncology social workers and child life specialists. Past Candlelighter events have included movies, picnics, parties or visits to local venues.

To receive e-mail notification about upcoming group activities, please provide your e-mail address to your Hematology Oncology Social worker along with names and birthdates of your children.

Resources & Support

Caringbridge

Create a free personal website where you can share health updates, photos and videos with your friends and family.

Website: www.caringbridge.org

Chemo Angels

You are matched with an "angel" who may provide prayers, uplifting messages, or small inexpensive gifts.

Website: www.chemoangels.com

Childhood Leukemia Foundation

Offers various programs to patients with cancer. Programs including: receiving Wish Baskets, obtaining an iPad through the Keeping Kids Connected, and hats and wigs through Hugs-U-Wear. A social work referral is needed for these programs.

Address: 807 Mantoloking Road, Brick, New Jersey 08723

Phone #: 888-253-7109 or 732-920-8860

Website: www.clf4kids.org

Children's Brain Tumor Foundation

Provides research, support, education, and advocacy to families and survivors of brain and spinal cord tumors.

Address: 1460 Broadway, New York, New York 10036

Phone #: 866-228-4673

Email: info@cbtf.org

Website: www.cbtf.org

Children's Cancer Association

This program uses music, friendship, play, and resources to create moments of joy for families facing cancer and other serious illnesses.

Address: 1200 NW Naito Parkway Suite 140, Portland, OR 97209

Phone #: 503-244-3141

E-mail: office@joyrx.org

Website: www.joyrx.org

Resources & Support

Children's Organ Transplant Association

Provides fundraising assistance and family support to children and young adults who need a life-saving transplant.

Address: 2501 West Cota Drive, Bloomington, IN 47403

Phone #: 800-366-8885

Email: cota@cota.org

Website: www.cota.org

Comfycozy's for Chemo (Amanda Hope Rainbow Angels)*

Provides a Comfycozy t-shirt, hoodie, onesie, or dress to children with cancer. The adaptive apparel line has zippers, buttons, snaps, pockets, and openings to allow nurses to access the child's port or get to their central line while allowing them to remain covered. Go to the website below to apply for a Comfycozy for chemo.

Address: 340 E. Coronado Rd. Suite 100, Phoenix, AZ

Phone #: 602-775-5090

Email: hello@amandahope.org

Website: www.amandahope.org/comfycozy

Corporate Angel Network

Helps provide free travel to cancer treatments across the country using empty seats on private and corporate jets. Eligibility is open to all cancer patients, bone marrow donors, and bone marrow recipients. Eligibility is not based on financial need, and patients may travel as often as necessary.

Address: Westchester County Airport One Loop Road, White Plains, NY 10604

Phone #: 914-328-1313

Fax #: 914-328-3938

Email: info@corpangelnetwork.org

Website: www.corpangelnetwork.org

Resources & Support

CureSearch *

Provides resources for patients, their families and support systems, including educational videos, webinars, and podcasts regarding diagnosis, treatment, and survivorship.

Each year (usually at the beginning of June) there is a CureSearch Walk in Omaha. The walk is a family friendly event that honors all those affected by childhood cancer while raising funds for cancer research and treatment.

Address: PO Box 45781 Baltimore, MD 21297

Phone #: 800-458-6223

Fax #: 301-718-0047

E-mail: info@curesearch.org

Website: www.curesearch.org

First Descents

Offers young adult (ages 18-39) cancer fighters and survivors free life-changing outdoor adventures.

Address: 3001 Brighton Blvd, Suite 623, Denver, CO 80216

Phone #: 303-945-2490

Fax #: 303-474-3005

Email: info@firstdescents.org

Website: www.firstdescents.org

Friends4Michael

Provides financial assistance for patients with brain tumors and their families.

Address: 2510 N. Castle Rock Dr. Tucson, AZ 85749

Phone #: 845-401-8689

Email: mkwinn@friends4michael.org

Website: www.friends4michael.org

Grandparents Booklet (Redkite)

The Grandparent Booklet is an online guide for grandparents of children with cancer. The Grandparent Booklet can be found at the website listed below. This booklet was developed by Redkite. Redkite is an Australian based organization that financial and education resources and support.

Website: <http://redkite.realviewdigital.com/?iid=87391#folio=1>

Resources & Support

Group Loop

Provides a safe place for teens affected by cancer to connect, find support, education and hope while dealing with a cancer diagnosis.

Address: 734 15th Street NW, Suite 300 Washington, DC 20005

Phone #: 202-659-9709

Email: help@cancersupportcommunity.org

Website: www.cancersupportcommunity.org/group-loop

Heartland Cancer Foundation

Provides financial assistance for transportation and medications for residents of Nebraska: Boone, Butler, Cass, Fillmore, Gage, Jefferson, Johnson, Lancaster, Nemaha, Otoe, Polk, Pawnee, Richardson, Saline, Saunders, Seward, Thayer and York counties. As well as residents of Kansas: Brown, Marshall, Nemaha, Republic and Washington counties. You must meet financial eligibility criteria.

Address: PO Box 5203, Lincoln, NE 68505

Phone #: 402-261-9974

Website: www.heartlandcancerfoundation.org

Imaginary Friend Society*

Offers kid-friendly videos covering a wide range of cancer-related topics – everything from defining cancer itself to chemotherapy and MRIs. These films are sponsored by the Pediatric Brain Tumor Foundation.

Website: www.imaginaryfriendsociety.com/films

Leukemia and Lymphoma Society of America

Provides information, education and support for patients, survivors, families and healthcare professionals about leukemia, lymphoma, multiple myeloma and Hodgkin's disease.

Address: 3 International Drive, Suite 200, Rye Brook, NY 10573

Phone #: 800-955-4572

Website: www.lls.org

LLS Resources:

Information Resource Center: www.lls.org/article/patient-referral-form

Caregiver Workbook: www.lls.org/resource-center/download-or-order-free-publications?language=English&category=Caregivers&sortBy=alpha&el-view=card-view

Resources & Support

Leukemia and Lymphoma Society of America- Iowa Chapter

Address: Century 1 Building 2700 Westown Pkwy #260, West Des Moines, IA 50266

Phone #: 515-270-6169

Website: www.lls.org/iowa

Leukemia and Lymphoma Society of America- Nebraska Chapter

Address: 11840 Nicholas Street Suite 215, Omaha, NE 68154

Phone #: 402-344-2242

Website: www.lls.org/nebraska

Love Your Melon*

The Request a Hat program gives friends and family the opportunity to surprise a child or family member battling cancer with a Love Your Melon Hat.

Website: www.loveyourmelon.com/pages/requestahat

Magic Yarn Project

Request a soft, comfy, and warm Magic yarn wig. Magic yarn wigs are inspired by beloved Disney characters, and invite children back to the world of play and daydreaming.

Address: PO BOX 83, Palmer, AK 99645

Email: info@themagicyarnproject.com

Website: www.themagicyarnproject.com

Make-A-Wish Foundation of Nebraska *

Grants wishes to children between the ages of 2½ and 18 who have a life threatening medical condition, including a hematology, oncology, or transplant diagnosis.

Address: 11836 Arbor, Omaha, NE 68144

Phone #: 402-333-8999 or 800-760-9474

Website: www.nebraska.wish.org

Make-A-Wish Foundation of Iowa *

Address: 3009 100th Street, Urbandale, IA 50322

Phone #: 515-334-2636 or 800-797-9474

Website: www.iowa.wish.org

Resources & Support

Metro Area Youth Foundation *

Provides financial support to children diagnosed and receiving cancer treatment at Children's Hospital or Nebraska Medicine. Contact the social worker for more information.

Mission4Maureen

Provides support and financial assistance for patients with brain cancer and their families.

Address: 1568 S. Green Rd. #21602, South Euclid, OH 44121

Phone #: 440-840-6497

Email: info@mission4maureen.org

Website: www.mission4maureen.org

National Bone Marrow Transplant Link

Provides information and psychosocial support to bone marrow/stem cell transplant patients and their caregivers.

Address: 2900 Union Lake Rd., Suite 213, Commerce, MI 48382

Phone #: 1-800-LINK-BMT or 800-546-5268

Email: info@nbmtlink.org

Website: www.nbmtlink.org

National Cancer Institute (NCI)

Provides information on cancer diagnoses, treatments, and clinical trials.

Address: BG 9609 MSC 9760, 9609 Medical Center Drive, Bethesda, MD 20892-9760

Phone #: 1-800-4-CANCER or 800-422-6237

Website: www.cancer.gov

National Collegiate Cancer Foundation

Provides need-based financial support to young adult survivors who are pursuing higher education throughout their treatment and beyond.

Address: 8334 North Brooke Lane Bethesda, MD 20814

Phone #: 240-515-6262

Email: info@collegiatecancer.org

Website: www.collegiatecancer.org

Resources & Support

National Marrow Donor Program (Be The Match)

Provides one-on-one support to patients and their families throughout the transplant journey.

Address: 500 N 5th Street, Minneapolis, MN 55401-1206

Phone #: 1-888-999-6743

Email: patientinfo@nmdp.org

Website: www.bethematch.org

Nebraska Coalition to End Childhood Cancer*

Provides childhood cancer awareness and support for the patients, families, and medical professionals in Nebraska.

Address: 515 South 55th Street, Omaha, NE 68106

Website: www.nebc3.com

Pediatric Brain Tumor Foundation

Provides free educational information about brain tumors and college scholarships.

Address: 302 Ridgefield Court, Asheville, NC 28806

Phone #: 800-253-6530

Fax #: 828-665-6894

Email: familysupport@curethekids.org

Website: www.curethekids.org

Pediatric Cancer Action Network *

Provides financial support to pediatric cancer families and advocates for a cure through awareness, education and action.

Address: PO BOX 22992, Lincoln, NE 68542

Phone #: 402-310-7331

Email: karri.pcan@gmail.com

Website: www.pcanaction.org

Pinky Swear Foundation *

Provides financial and emotional support to kids with cancer and their families.

Address: 7835 Telegraph Road, Bloomington, MN 55438

Phone #: 952-974-9600

Fax #: 952-400-8838

Email: info@pinkyswear.org

Website: www.pinkyswear.org

Resources & Support

Scare Away Cancer *

Provides a financial gift to patients and their family for assistance with medical expenses, daily living, and travel expenses. Applicants must reside in Lincoln, Omaha, or Council Bluffs area. There is no income limit.

Address: 14124 Industrial Road, Omaha, NE, 68144

Phone #: 402-339-2221

Website: www.scareawaycancer.org

Songs of Love Foundation

Will create a free personalized original song for children and teens currently facing medical, physical, or emotional challenges.

Address: PO BOX 750809, Forest Hills, NY 11375

Phone #: 1-800-960-SONG or 800-960-7664

Website: www.sonsoflove.org

SuperSibs! at Alex's Lemonade Stand Foundation

Provides information, support, activities, and resources to siblings during their family's battle against childhood cancer.

Address: 111 Presidential Blvd, Suite 203, Bala Cynwyd, PA 19004

Phone #: 1-866-333-1213 or 610-649-3034

Fax #: 610-649-3038

Website: www.alexslimonade.org/campaign/supersibs

Team Jack Foundation

Provides information, support, and resources for pediatric brain cancer.

Address: PO Box 607, Atkinson, NE 68713

Email: Info@TeamJackFoundation.org

Website: www.teamjackfoundation.org

TeensHealth

Provides a safe, private place for teens that need honest, accurate information and advice about health, emotions, and life. They also have information about cancer.

Website: www.kidshealth.org/en/teens/center/cancer-center

Resources & Support

The National Children's Cancer Society

Provides emotional, financial and educational support to children with cancer, their families and survivors.

Address: 500 North Broadway, Suite 1850, St Louis MO 63102

Phone #: 314-241-1600

Fax #: 314-241-1996

Website: www.thenccs.org

The Purple Drug Guide

A free app to research your child's prescribed medications.

Website: www.purpledrugguide.com

The Ulman Cancer Fund for Young Adults

Provides a community of support for young adults, and their loved ones, impacted by cancer.

Address: 1215 East Fort Avenue, Suite 104, Baltimore, MD 21235

Phone #: 410-964-0202 or 1-888-393-FUND (3863)

Fax #: 888-964-0402

Email: info@ulmanfund.org

Website: www.ulmanfund.org

Wigs for Kids *

Provides wigs to children who have lost their hair due to treatment or disease.

Address: 24231 Center Ridge Rd, Westlake, OH 44145

Website: www.wigsforkids.org

Tips for New Patients and Families

The following tips have been written to give you answers to some of your non-medical questions about the hospital, Hematology/Oncology clinic, Infusion Center, and CARES.

THE HEMATOLOGY ONCOLOGY CLINIC **402-955-3950**

Arrival & Registration

The Hematology Oncology (H/O) Clinic is located on the 3rd floor of the Specialty Pediatric Center (SPC). The closest parking for the lab, the H/O clinic, or the Infusion Center is the SPC parking garage. Enter the garage from West Dodge Road, just east of 84th Street. There is free valet parking available 8:30am-5pm.

If your child has labs to be drawn before your appointment you should arrive 1 hour prior to your scheduled appointment time. If your child does not need labs, please arrive 15 minutes before your scheduled appointment time to allow enough time for check-in. This will help keep everyone on schedule for the day. If you think you will be late for your appointment or need to change it, please call the clinic 24 hours in advance, if possible.

Registration is located at the Access Center on the 3rd floor of the SPC. Once registered, you will be given a pager, which will light up and buzz when the staff is ready for your child.

Your child should wear a mask when waiting in the waiting room and walking through the hallways. Wearing a mask can help decrease exposure to germs. Masks are located by the elevators and registration desk.

What to Expect with Lab Draws

If your child has a port, please place EMLA (numbing cream) on your child's port site before arriving to the clinic. EMLA is a prescription medication. Prior to your appointment, ask your doctor for the prescription and directions for use.

The clinic has several child life specialists who can help teach, support and encourage play and positive coping for your child. Child life and the medical team work together with you to provide the best experience possible.

After labs are drawn, it will take time for the results to be finalized. If your child is being seen by a provider, you will stay until your scheduled appointment time. If your child is only in clinic for a lab draw, you may or may not have to stay until the results are finalized depending on your child's needs. Please ask your nurse if you have questions.

Tips for New Patients and Families

Activities & Play

Try to relax while you wait. You may bring something to read or some of your child's favorite activities or toys. Parents and patients may also bring tablets/laptops, etc. from home to access Children's free Wi-Fi.

Our child life specialists have some activity items available for children while they wait, such as: card games, coloring, electronics, and DVD movies.

Kids Camp is a play area for patients and siblings located on the 1st Floor of the SPC. Hours of operation are: Monday- Thursday 8:30am- 5pm and Fridays 8:30am- 4pm. Kids Camp is closed from noon-1pm daily. The program can take care of siblings so that you can give full attention to your child who is here for a medical appointment. If your child is potty trained they may be left alone at Kids Camp. Children who are not potty trained may stay to play if accompanied by an adult caregiver. You will be asked to complete a wellness form. Meals and snacks are not served in this area. Children may also wait with parents in the lobby outside of the clinic.

Food & Drink

Food is not available in the clinic. However there are vending machines on the 1st floor of the SPC and an eating area as well. It is a good idea to bring snacks or money for food.

Communication

You may get a pager to take with you while you are waiting to be seen. The pager reaches all parts of Children's Hospital & Medical Center. Please do not hesitate to ask the staff if you do not understand why you may be waiting, if there is something you need or if there is something you don't understand about your visit.

Understanding Treatment

You are a vital part of your child's care and medical team. It is important that you become very familiar with your child's specific cancer diagnosis and treatment. Your oncologist, nurse practitioner, educator and nursing staff will help you learn about your child's diagnosis. If you need more information, please ask for time with them. It is appropriate to ask questions or clarify something if it isn't consistent with what you have been told before.

It may be helpful to carry a copy of your child's treatment protocol ("Roadmap"). You may also want to have a copy of your child's recent blood counts. These are available upon request, just ask a nurse. Your child's lab results will also be available in Children's Connect, following a clinic visit or discharge from the hospital. If you need copies of your child's medical records, please discuss with staff or contact Health Information Management (Medical Records) at 402-955-3800.

Tips for New Patients and Families

Coping

Our staff wants your child and family to have the most positive experience possible. Child life specialists are health care professionals who work with children and families to help with challenges and fears of hospitalization and diagnosis. A child life specialist is available to talk with your child about fears, concerns and can assist in preparing and supporting your child with medical procedures and new experiences.

Children's also has a resident facility dog for the HO Clinic and Infusion Center, her name is Sansa. Sansa can provide unique, specialized therapy to patients through the Child Life program.

Diagnostic and treatment procedures involving your child can be stressful. Social workers are available in all areas of Children's Hospital & Medical Center. Services include emotional support, assessment and referral as well as information about financial resources. Please ask to speak with a social worker regarding issues which impact getting your child to medical appointments or non-medical concerns which are worrisome.

You know your child best, please talk with staff about how best to interact and communicate with your child.

Tips for New Patients and Families

THE INFUSION CENTER 402-955-5400

The Infusion Center is located on the 3rd floor of the SPC. They are open Monday-Saturday. Evening scheduling is also available during the weekdays. The Infusion Center provides medication infusion and injection treatments to patients who are referred from the specialty clinics. The Infusion Center is staffed by a nurse practitioner, specially trained nurses, a certified nursing assistant, child life specialists, and social workers.

Arrival, Registrations & Rules

The closest parking for the Infusion Center is the SPC parking garage. Enter the garage from West Dodge Road, just east of 84th Street. There is free valet parking available 8:30am-5pm.

Patients should register at the Access Center on the 3rd floor of the SPC prior to their appointment. If your child was seen in the Hematology/Oncology clinic, you will need to re-register at the Access Center for the Infusion Center.

Children must be accompanied by someone who is 19 years of age or older. This person must stay with the child throughout the entire appointment. A legal guardian must be available by phone at all times to give consent.

Children who have a cold, flu, fever, cough, rash or other potentially infectious symptoms will be isolated throughout the entire appointment. All who accompany the child to the appointment will be isolated with the child as well.

Due to limited space in the Infusion Center, it is a policy that no more than 2 adults accompany the child. Siblings who must come to the appointment are requested to utilize Kids Camp.

Activities & Play

Parents and patients may bring tablets/laptops, etc. from home to access Children's free Wi-Fi.

The Infusion Center has the following items for patients to enjoy: toys, board games, arts and crafts, DVD movies, and some electronic games.

Tips for New Patients and Families

Food & Drink

Snacks are available in the Infusion Center, along with menus for the patients to order food if needed. Parents may also bring in outside food or food from the cafeteria. The Infusion Center also has a microwave, refrigerator and coffee for family use.

Nebraska Medicaid provides a meal, in the Children's cafeteria, for a child and one parent who are away from home for 10 or more hours; or who leave home by 6am and live at least one hour from Children's and have Nebraska Medicaid. Please request to talk with a social worker if this applies to you.

Resources

The social worker is available to provide emotional support or to help families identify resources and assist in making referrals.

Child life specialists have resources available to support patients and siblings on topics such as: diagnosis teaching, hair loss, sibling needs, and school support.

Tips for New Patients and Families

CARES 402-955-4777

Children's Ambulatory Recovery Express Services (CARES) is located on the 1st floor of the hospital behind the Access Center. This department prepares and recovers children who are having outpatient surgeries and procedures including: port placement, central line placement, biopsies, lumbar punctures, and bone marrow aspirations.

Arrival & Registration

The Hematology Oncology clinic nurses will give you instructions about preparing for your child's procedure. Your child will not be able to eat prior to going to CARES.

The closest parking for CARES is the hospital parking garage. Enter from Dodge Street. There is free valet parking available as you pull up to the front door from 5:15am-5pm.

Patients should check in at the hospital Access Center, located in the lobby, two hours prior to the procedure time.

What to Expect

Please place EMLA (numbing cream) on your child's port or IV site before arriving to CARES. EMLA is a prescription medication. Prior to your appointment, ask your doctor for the prescription and directions for use if needed. A nurse will complete an assessment and draw labs. The child life specialist will work with your nurse and you to create a positive port access/IV routine. Child life specialists can be present during access to encourage play and comfort.

You will also have a visit from the anesthesiologist and the doctor or nurse practitioner performing the procedure.

There will be wait time during this process. You may bring something to read or some of your child's favorite activities or comfort item like a stuffed animal, toy or blanket. Parents and patients may also bring tablets/laptop, etc. from home to access Children's free Wi-Fi.

Tips for New Patients and Families

Following the procedure, your child will go to the **P**ost **A**nesthesia **C**are **U**nit (PACU) for at least 30 minutes and then will return to CARES. Many times a parent may come into the PACU to be with your child while they are waking up from sedation. Talk to the CARES staff for more information.

If your child is being admitted to the hospital or going to the Infusion Center for chemotherapy, you and your child will be escorted to your hospital room or the Infusion Center after your child recovers.

Improving Your Child's Experience

Your child life specialist in CARES will assist in preparing you and your child for what to expect prior to the procedure. They also can provide age appropriate activities to help you distract your child, support and pain management during IV and port starts and lab draws.

Food & Drink

Menus are available in CARES for your child to order a meal, if they are allowed to eat after their procedure.

Nebraska Medicaid provides a meal, in the Children's cafeteria, for a child and one parent who are away from home for 10 or more hours; or who leave home by 6am and live at least one hour from Children's and have Nebraska Medicaid. Please request to talk with a social worker if this applies to you.

Tips for New Patients and Families

THE HOSPITAL 402-955-5400

The H/O Providers Schedule:

During your inpatient stay, your orders and care will be provided by the Hematology/Oncology doctor who is on call. This may not be your primary oncologist as the inpatient doctor will change from week to week. The inpatient doctor is also responsible for answering the after hour calls during the week. To maintain consistency, the oncology team meets every Monday morning to review all of the patients.

The inpatient nurse practitioner (NP) writes orders, makes rounds with the on-call doctor and addresses issues that arise. The NP provides communication and continuity from week to week. The NP assists the doctor and helps manage many aspects of your child's symptoms and treatment.

Other members of the health care team include resident and fellow physicians. These are doctors who are receiving extra training from our oncologist, and will assist the doctor on call in caring for your child.

There are also medical students, nursing students, and students in other health care fields. These students add to your child's care by checking on your child through the day and helping communicate your child's needs to the rest of the health care team.

Please feel free to ask each team member about his/her role.

Expect Changes

Try to remain positive in front of your child - your child's attitude will reflect your own. If you have decisions to make, uncertainty to express or conflicts with family members, find a private place to talk away from your child. Your child needs an atmosphere that is restful and stress free in order to feel better. At least once a day, remember to take time for yourself.

Often, plans change when a child is in the hospital. This may mean a change in the plan for a surgery, chemo treatment or even going home. There may be times when you expect your child to be discharged on a specific day. These changes may happen if your child's medical condition has not reached the targeted goal. For your child's sake, please do your best to be positive about changes in the plan. Staff are sensitive to knowing that these changes can be disappointing and stressful on you and your family and will do everything possible to work with you.

Tips for New Patients and Families

What to Bring

You may wish to bring some things from home to make your stay in the hospital more comfortable. Some parents bring:

- Sleeping bag to put on top of parent's sleep area
- Parents or child's blanket / pillow
- Sound machine or white noise maker
- Child's school work
- Reading light
- Your child's favorite DVD's, electronic games and music
- Laptop - Children's has free Wi-Fi.
- Ear buds/ headphones
- Each room has a small refrigerator so you may bring food and drink items.

Activities & Play

If your child does not have IV chemotherapy actively infusing through their central line, fever free and not in isolation, and has a physician's order to leave the floor, they may take a walk to the lobby, gift shop, or the cafeteria. The best time to do this is after 6pm when there are fewer people in these areas. Your child must wear a mask when out of the room.

If your child is fever free and not in isolation, you may ask to reserve a daily playroom time. Playing and socializing helps children feel normal. For immune suppressed children, the playroom will be closed to the general population to prevent exposure to germs. However, playroom times may be shared with other H/O or immune suppressed patients. This is an opportunity for your child to meet and interact in a positive way with other children.

Ask about special activities that may be going on during your admission. Periodically we schedule a magician, sports players, have arts and crafts, or a carnival in the hospital lobby. Your child will need a physician's order to leave the floor to attend certain activities.

We encourage you to take a break from the hospital room. Volunteers are scheduled throughout the day and may be available to relieve you. Please coordinate your request with your nurse or child life specialist. Getting out of the room to go to the cafeteria, taking a walk outside, or making phone calls can provide balance in your daily activities.

There are game systems available for children 6 years and older that can be taken to the room for something new to do. For younger children, there are wagons to ride around the halls if your child's condition allows.

Tips for New Patients and Families

There is an activity room on the 6th floor. You are encouraged to select toys to take to your child in the room. Ask your child life specialists for any special request your child may have.

Hospital BINGO is offered most Thursday afternoons from 2-3pm. If your child has an order allowing them to leave the floor, they can attend the live broadcast and play BINGO in the Glow Auditorium. If your child is not allowed to leave the floor he/she can play BINGO from the TV in their room.

Pet Therapy dogs visit each Thursday morning for patients who wish to see them. These trained dogs and their volunteer owners may be able to visit your hospital room if your child is free of fever and not in isolation. Children's also has a resident facility dog named Sven. Sven can provide unique, specialized therapy to patients through the Child Life program.

Maintaining a Routine

Maintaining a routine can help your child adjust to his/her hospital stay. A good hygiene routine is especially important. Your child should bathe every day, brush their teeth twice a day, and comb their hair. Getting cleaned up and dressed will normalize the daily routine. Please let your nurse or child care partner know if you prefer to bathe in the morning or at night. It is also OK for your child to wear their own clothes if that makes them feel more comfortable.

Because of the IV fluids your child receives during chemo, accidents happen often; especially at night. If necessary, Pull-ups are available to minimize changes of clothing and bedding.

Visitors

All visitors will be screened by the receptionist. Visitors are allowed to visit if they are free of colds, flu, fever, cough, rash or any other symptoms.

Children often enjoy when their friends and family come to visit and play. However you may want to limit visitors to those who are most important in your child life (i.e.- close family members and a few friends/classmates). For the rest of the class, family, or friends you could ask them to make videos or recordings for your child to listen to, or encourage them to send notes, cards and/or gifts in the mail during hospital stays.

Skype or FaceTime is also a great option for family / friends who cannot make it up to visit. Skype can also be used to link into your child's classroom.

Tips for New Patients and Families

Siblings

It's important to support siblings as much as you can during your child's treatment. They worry, their routine has changed and they have less time with parents. The following are some tips to help siblings:

- Involve siblings in the conversations about care. Let them help.
- Have them make a visit to the clinic or hospital.
- Sign them up for SuperSibs.
- Come to Candlelighters events.
- Spend some time with them and ask if they want to talk about anything.
- Take photos of each of your children. Let them keep each other's photos while they are apart.
- Give the sibling something of yours or their brother's or sister's to take care of until you all get home.
- Read some of the resources available in supporting siblings or cancer patients available in books or online.
- Your child life specialist can talk with siblings or find resources to help you have open conversations about what is happening to their brother or sister and how it affects them.

Resources

The social worker for inpatient Hematology Oncology patients will meet with you for support and to gather information about you.

Labs and Procedures

After reviewing this section, you will be able to:

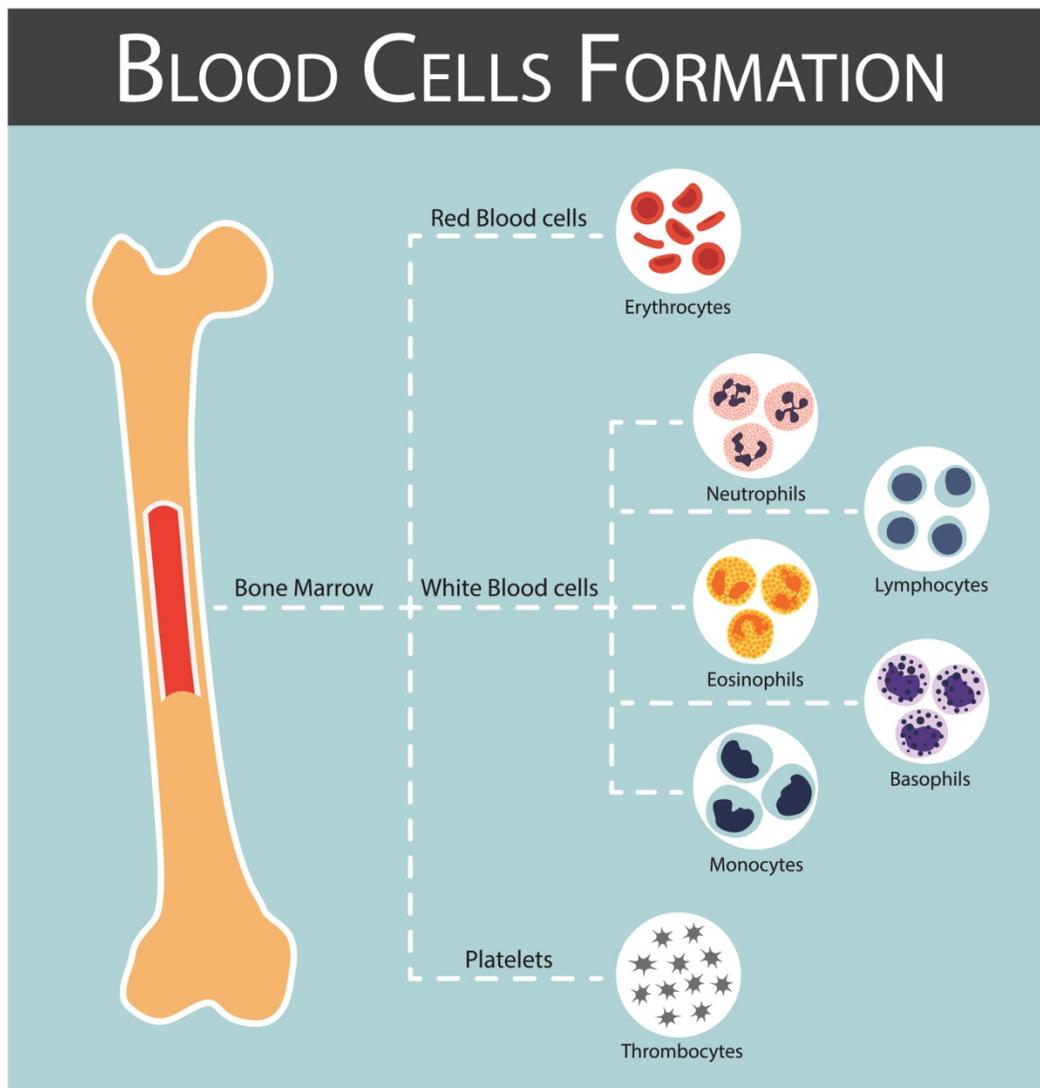
1. Recall effects of chemotherapy/radiation on blood counts
2. Describe the role of hemoglobin, platelets, and neutrophils
3. Understand threshold for transfusions
4. Identify Absolute Neutrophil count on lab report
5. Review sedation related to procedures
6. Identify how a Child Life Specialist can provide support

Labs

Bone Marrow

The bone marrow is a spongy tissue in the middle of bones. The bone marrow is the factory where all the blood cells are made. This includes red blood cells, white blood cells, and platelets.

Chemotherapy or radiation therapy may suppress the bone marrow and cause the production of blood cells to decrease. This may also cause low blood counts (red blood cells, white blood cells, and platelets).



Labs

Hemoglobin

Hemoglobin is what carries oxygen in the blood to the rest of the body.

When hemoglobin is low, your child may be pale, tired, have less energy, or complain of a headache. If the hemoglobin is less than 7 or your child is symptomatic, we will give your child a blood transfusion to increase this number and make them feel better.

Platelets

Platelets help the blood clot.

When platelets are low, your child is at risk for bleeding or bruising. If the platelets are less than 10,000 in the hospital (less than 20,000 at home/clinic) or if your child is actively bleeding, we will give your child a platelet transfusion to increase this number and prevent or stop bleeding.

There may also be other situations when we would need to keep your child's platelets greater than 30,000 or 50,000. This may be before surgery, before giving a subcutaneous or intramuscular injection, or if your child's condition permits. The provider will discuss this with you if needed.

Absolute Neutrophil Count

A neutrophil is a type of white blood cell that helps fight infections caused by bacteria. To determine how well your child is able to fight off infection, you will hear the providers or nurses refer to a term called ANC or **A**bsolute **N**eutrophil **C**ount. ANC is the total number of neutrophils in the body.

ANC is reported as "Neutrophil #" on the lab report. Neutrophil # may also be reported as "Segmented Neutrophil #" and/or "Band #". If there is both Segmented Neutrophil # and Band # reported, you should add these two numbers together to get the ANC.

When the ANC is less than 500, your child is at risk for infection. If exposed to germs or infection, they are not able to easily fight them. This is why it is important to watch for fever (sign of infection) and maintain a clean environment and personal hygiene.

BLOOD TRANSFUSION

The provider has ordered a blood or blood product transfusion for your child. The transfusion will help increase the amount of these cells in your child's body.

The blood will come from the "authorized blood product supplier". Before your child receives it, many screening processes are done. These screening processes match the blood for the transfusion to your child's blood type. The screening processes also test the blood transfusion for many diseases.

Every effort is made to ensure that the blood your child is receiving is correct and safe. However, blood transfusion reactions can occur. The nursing staff will monitor your child closely during the transfusion.

Signs of a blood transfusion reaction are listed below. **If your child has any of these signs during the transfusion, please let your child's nurse know right away. If your child is receiving the blood transfusion as an outpatient, and any of the signs are seen after you are at home, please call your child's provider right away:**

- Fever or chills
- Flushing of the face
- Hives, rash or itching
- Difficulty breathing or shortness of breath
- Pain or oozing of blood from the IV needle site
- Decrease in urination
- Low back pain
- Nausea and/or vomiting
- Weakness or fainting
- Chest pain
- Blood in the urine

If you have any other questions or concerns regarding the blood transfusion, please ask your child's provider or nurse.

Procedures

Sedation for Procedures

Your child may need procedures such as spinal taps, bone marrow aspirates, biopsies, line placement, or scans that will require your child to lie very still for several minutes at a time. Your child may receive medication to put him/her into a light or deep sleep, depending on the procedure.

If sedation is required, your child will be unable to eat or drink for a period of time prior to the appointment (except for a small sip of water to take with the prescribed medication). If your child normally takes a medication that requires food (such as Prednisone or dexamethasone), bring the morning dose of the medication with you, along with a small snack, to give to your child after the sedation procedure.

How Child Life Specialists can help:

- **Medical play-** allows patients to learn and explore medical supplies and procedures.
- **Developmental play-** encourages fun, socialization, and play in the medical environment.
- **Diagnosis Teaching-** can help explain cancer diagnosis to your child and siblings at their developmental level.
- **Procedural or surgical preparation-** allows patients to ask questions and become familiar with equipment or procedure prior to it occurring. This helps decrease anxiety and misconceptions.
- **Distraction/ Support-** encourage fun or alternative focus during a medical procedure.
- **Sibling Support-** assists parents in supporting siblings throughout diagnosis.
- **Beads of Courage®-** a therapeutic arts in medicine bead program designed to support and strengthen children and families as they cope with a serious illness. Patients record, tell, and own their medical stories using colorful beads. All cancer patients are eligible for enrollment in this complementary program offered by your Child Life Specialist.



