

**CHILDREN'S
ONCOLOGY
GROUP**

The world's childhood
cancer experts

Family Handbook

New

Diagnosis

Guide

Provided through
the generosity of

 **St. Baldrick's**
FOUNDATION
Conquer Childhood Cancers

Acknowledgements

EDITORS

Jeneane Sullivan MSN, RN
Kathryn Tomlinson BSN, RN

REVIEWERS

COG Group Chair, Peter Adamson MD
COG Nursing Steering Committee, Wendy Landier PhD, RN - Chair
COG Hematology/Oncology Committee, Naomi Winick MD - Chair
COG Patient Advocacy Committee, Kristy Sharif - Chair
COG Behavioral Science Committee, Leanne Embry PhD - Chair

GRAPHIC DESIGN

Anne Moertel

MEDICAL ILLUSTRATIONS

Terese Winslow

Special thanks to the St. Baldrick's Foundation for their generous support of printing and production-related costs.

DISCLAIMER AND NOTICE OF COPYRIGHT

The information and content provided in the *Children's Oncology Group Family Handbook New Diagnosis Guide* is made available for informational purposes only for children and their families affected by cancer. While the Children's Oncology Group strives to provide accurate and up-to-date information, the information may be out of date or incomplete in certain respects. Please do not rely on this information and seek the care of a qualified medical professional if you have questions regarding a specific medical condition, disease, diagnosis or symptom. The information and content presented herein is not intended to replace the independent clinical judgment, medical advice, screening, health counseling, or other intervention performed by your (or your child's) health care provider. Please contact "911" or your emergency services if this is a health emergency. No endorsement of any specific tests, products, or procedures is made herein.

The *Children's Oncology Group Family Handbook New Diagnosis Guide* is proprietary to the Children's Oncology Group (©2018).

THE CHILDREN'S ONCOLOGY GROUP

Family Handbook

New Diagnosis Guide

**CHILDREN'S
ONCOLOGY
GROUP**

The world's childhood
cancer experts

COPYRIGHT 2018 © CHILDREN'S ONCOLOGY GROUP
ALL RIGHTS RESERVED WORLDWIDE

Introduction

This guide was written for patients and families learning about a new cancer diagnosis. If you are an adolescent or young adult with cancer reading this guide, we welcome you. Information that you see directed toward “your child” will be information about your care.

The diagnosis of cancer brings changes to your life and the lives of your whole family. Each family has ways to cope with stressful experiences. Many families have told us that their child’s diagnosis brings feelings of fear, anger, sadness, and guilt. Having these feelings during this stressful time is normal. You are not alone.

You are getting a lot of information right now. You are being asked to learn about medical topics and care when you are likely feeling overwhelmed. This ***New Diagnosis Guide*** was created to help you focus on the most important information that you need right now, in this time just after your child’s diagnosis. By working with your health care team and taking one step at a time, you will learn what you need to know to care for your child. This guide is an introduction to your learning. Your health care team will continue to review important information with you throughout your child’s treatment. Always feel free to ask questions of any member of your health care team.

Children of different ages understand and react differently to cancer and its treatment. Your child’s personality, coping style, support system, treatment plan, as well as age or developmental level will affect how your child copes with cancer. Often parents have a hard time telling their child about cancer. From years of experience, we know that not telling your child the truth can be harmful. Children can quickly sense when something is wrong. They need to know they can trust their parents to always tell them the truth. There are members of your health care team who are available to help you talk with your child about their diagnosis and can help you and your child cope through counseling, financial assistance, and access to resources. Talk with your health care team about your needs so that you get the right support.

DOWNLOAD ONLINE

In addition to printed copies, the *Children’s Oncology Group Family Handbook* and *New Diagnosis Guide* can be found at childrensoncologygroup.org/cog-family-handbook, as well as downloaded from the website onto any e-reader.

Treatment Overview

Ask your doctor or nurse to complete this form.

PATIENT NAME

DIAGNOSIS

TREATMENT WILL LIKELY INCLUDE

- Chemotherapy (medicines to kill cancer cells)
- Immunotherapy (medicines to boost the body's ability to fight cancer)
- Radiation therapy (high energy x-rays to kill cancer cells)
- Surgery (operation to remove tumors)
- Other

TREATMENT SCHEDULE

Treatment will start with

Treatment will last

TREATMENT LOCATION

- Treatments will happen in the hospital (spend the night)
- Treatments will happen in the clinic (come during the day and go home the same day)

MY HEALTH CARE TEAM

Doctor(s)

Nurse(s)

Other(s)

HOW TO CONTACT MY HEALTH CARE TEAM

Daytime

After Hours

Oncology Clinic

Inpatient Unit

Home Care Company

Other

About Cancer and its Treatment

What is Cancer?

Cancer is one name for a group of diseases. Each type of cancer has its own name, treatment, and prognosis (chance of responding to treatment). Cancer in children can generally be divided into three groups:

- **Leukemias** (cancers of the blood-forming cells)
- **Lymphomas** (cancers of the immune system)
- **Solid tumors** (cancers of the brain, bones, muscles, organs, or other tissues in the body)

How is Cancer Treated?

Each type of childhood cancer will be treated differently, depending on what doctors have found to be the best treatment for that type of cancer. Your child may receive one or a combination of the following treatments at different times in their therapy.

CHEMOTHERAPY

Chemotherapy is medicine that treats cancer by stopping cells from growing, or by destroying cells. Chemotherapy can be given in a number of ways including:

- by mouth
- as an injection (shot)
- into a vein
- into the spinal fluid

Talk to your health care team about the ways your child's chemotherapy will be given.

IMMUNOTHERAPY

Immunotherapy uses the immune system (infection fighting cells) or medicines made in the laboratory from immune cells to fight cancer. Immunotherapy can be given:

- By mouth
- Into a vein

Talk to your health care team about how your child's immunotherapy will be given.

RADIATION THERAPY

Radiation therapy delivers high energy x-rays that damage and destroy rapidly growing cells, such as cancer cells.

SURGERY

Different types of surgery are used to treat cancer. Sometimes, taking out the tumor may be the only treatment needed. Usually chemotherapy, immunotherapy, or radiation is also used to kill any cancer cells still in the body.

CENTRAL VENOUS LINES (CVLS)

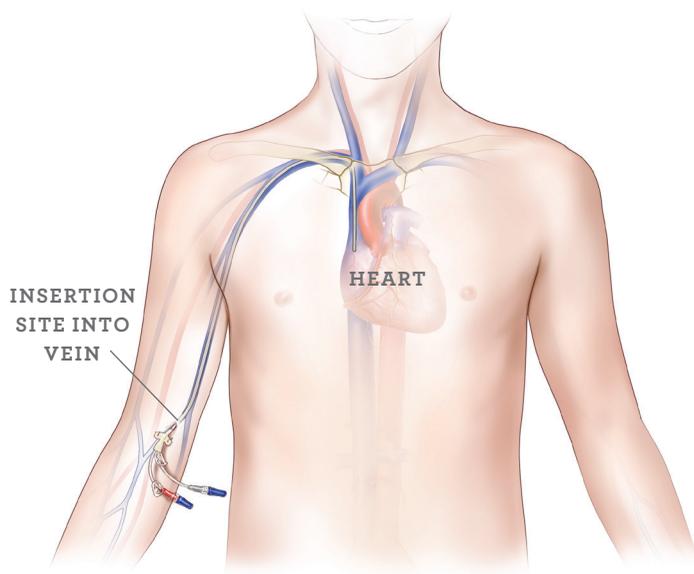
A central venous line provides a safe way to give medicines, including chemotherapy, through a vein. The different types of central venous lines are pictured on the next page.

If your child has a PICC (peripherally inserted central catheter), or external CVL, your nurse will teach you how to care for this line at home. If your child has a port, you may be asked to apply a numbing cream on the skin over the port before your child comes to the clinic or Emergency Room. The cream can help make putting the needle in the port easier for your child. Check with your child's nurse to see if this is something your child will need.

What is a Clinical Trial?

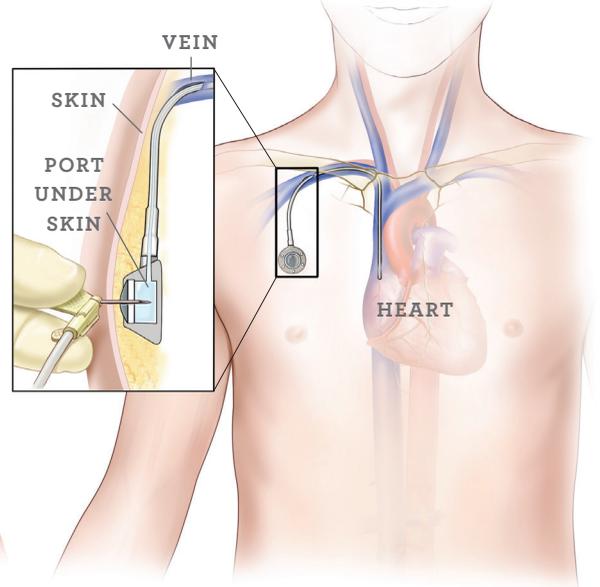
Clinical trials are research studies done to help the health care team understand more about diseases, like cancer, and how best to treat them. The progress that has taken place in treating childhood cancer has been made possible through clinical trials and the children, adolescents and young adults who participate in them.

The Children's Oncology Group (COG) is the largest pediatric clinical trials group in the world. The COG has treated more children with cancer than any other organization. Doctors, nurses, and other experts around the world are working to continually improve treatments for children with cancer. Your doctor and health care team will let you know if there are clinical trials available for your child. Some clinical trials are about treatment and some are about ways to support children with cancer. You may always choose whether or not your child will be part of a clinical trial. If you choose to be part of a clinical trial, you will need to give your permission first. This is called informed consent. A member of your health care team will explain this to you. After permission is given, you will get a copy of the signed consent form explaining the clinical trial. Talk with your health care team to learn more.



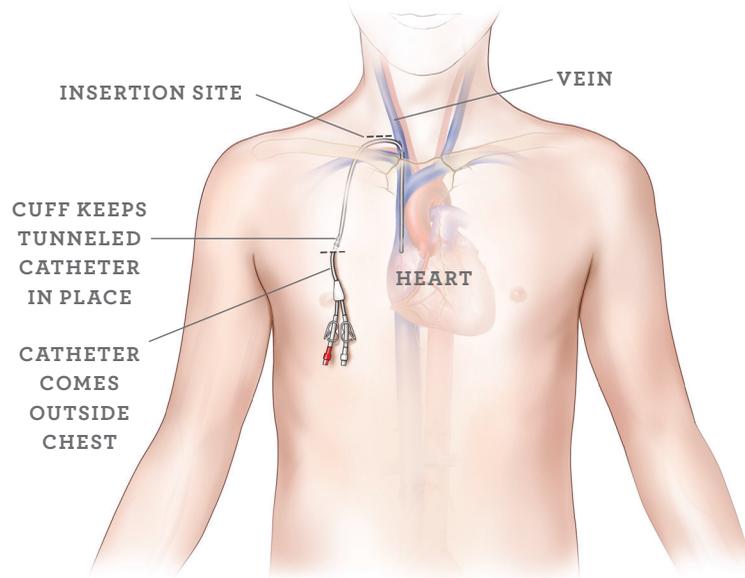
PICC

© 2011 TERESE WINSLOW LLC



PORT

© 2011 TERESE WINSLOW LLC



EXTERNAL CVL-CHEST

© 2011 TERESE WINSLOW LLC

When to Call for Help

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

Call Emergency Services (“911” in the U.S. and Canada) immediately if your child:

- is not breathing or has severe difficulty breathing
- has skin and/or lips that look blue
- is having a seizure (and you have **NOT** been told that a seizure can be managed at home)
- does not wake up after you have tried to wake them (loss of consciousness)

Call your health care team immediately (do not wait until the clinic or office opens) if your child has:

- fever (temperature of _____ or higher)
- chills (shivering)
- trouble with breathing
- bleeding that does not stop within 5 to 10 minutes
- change in behavior or level of consciousness (such as being very sleepy, very irritable, or not making sense when talking)
- sudden change in vision
- severe or repeated headache
- new weakness of the face, arm, or leg
- uncontrolled pain
- a break or leak in the central venous line (CVL)
- repeated vomiting or diarrhea
- not been able to drink fluids
- exposure to chickenpox or shingles

*If you are unsure or uneasy about anything,
it is always better to call than not call!*

Visiting the Emergency Room (ER)

If your child has a fever or other emergency, your health care team may tell you to go to the Emergency Room.

When you arrive in the Emergency Room, tell them:

- your child's type of cancer
- date of your child's most recent cancer treatment
- results of recent blood tests
- your child must be seen right away for a fever and given antibiotics promptly
- your child cannot wait in an area with other people who may be sick
- your child cannot have an enema, suppository, or rectal temperature

Ask your health care team for a letter that explains your child's diagnosis and possible needs in the Emergency Room. Bring this letter with you any time you take your child to any Emergency Room.

A Treatment Overview page is included in the beginning of this guide. You can use it to record your child's diagnosis and important treatment information, as well as who to call for help. Take the Treatment Overview page with you when you visit the Emergency Room.

Fever

A fever may be a sign of a serious infection. Children who receive cancer treatment are at high risk for getting serious infections. If your child has a fever and does not get medical care right away, your child could get very sick and this could be life-threatening.

- Call your health care team immediately if your child has a fever. Do not wait for the clinic to open.
- Do NOT give your child aspirin (salicylate), acetaminophen (Tylenol®), or ibuprofen (Motrin®, Advil®, and Pediaprofen™) unless you are told to do so by your health care team.

Sometimes an infection can occur without fever. Any time your child has chills or you are concerned that they do not look well, even if there is no fever, **call your health care team immediately**. Do not wait for the clinic to open.

If your child becomes ill or has a fever, there is a chance your child will need to be admitted to the hospital for antibiotics and care.

TAKING YOUR CHILD'S TEMPERATURE

- Make sure that you have a thermometer at home that works, and that you know how to use it.
- Take the temperature if your child feels warm to touch or does not look or feel well.
- Take the temperature as you have been taught by your health care team. Do not take a rectal temperature as this could cause bleeding or infection.

Managing Symptoms

Our goal is to keep your child safe and feeling as well as possible during treatment. By understanding the side effects of treatment, you will know how to support your child and when to call the health care team for help. **It is always OK to ask for help** if your child is not feeling well or is uncomfortable, whether your child is in the hospital or at home.

BLEEDING AND FEELING VERY TIRED

Chemotherapy can lower your child's blood counts. This can cause bleeding or make your child feel very tired. Call your health care team if your child:

- is very tired, pale, or complains of headache or dizziness
- is bruising more easily than usual
- has small red dots on the skin
- has bleeding from the nose, gums, or around the central venous line

Call your health care team immediately if your child has bleeding that does not stop within 5 to 10 minutes.

To prevent bleeding, your child may need to:

- avoid rough play and contact sports
- use a soft toothbrush
- avoid taking aspirin or ibuprofen during times when the blood counts are low

PAIN

Pain in children with cancer can be from many causes. Cancer cells in the body can cause bone or tissue pain. Some side effects of cancer treatment, such as mouth or skin sores, can be painful. Recovering from some surgery can also be painful. Call your health care team if your child has:

- new or increasing pain
- pain that is not getting better with the pain medicines you have been given to use at home

NAUSEA, VOMITING AND DIARRHEA

Cancer therapy can cause nausea and vomiting. You may be sent home with medicines to give at home to help with nausea and vomiting. Follow the instructions carefully. If your child has nausea or vomiting, you can also offer sips of cool, clear liquids or small bites of foods that are easy to digest, such as crackers or rice.

Diarrhea (frequent, watery stools) can sometimes happen as a result of cancer therapy.

Vomiting and diarrhea can place your child at risk for dehydration (not enough liquid in the body). **Call your health care team immediately** if your child has signs of dehydration, which may include:

- dry mouth or lips
- no tears when crying
- urinating less than normal
- dark urine
- has repeated vomiting or diarrhea
- is not able to drink fluids

CONSTIPATION

Constipation is when a child has hard stools (bowel movements) that happen less often than usual. Chemotherapy (such as vincristine) and other medicines (such as pain medicines) can cause constipation. Follow the instructions for any medicines you are given to help with constipation at home. Call your health care team if your child has:

- a change in their regular bowel movement pattern (not as often, not as much)
- pain when having a bowel movement
- hard stool even after giving medicine for constipation

HAIR LOSS

Some kinds of cancer therapy may cause hair loss or thinning of the hair. Hair loss may begin 7 to 10 days after the treatment has started. Hair on other parts of the body may also be affected. Some children and parents prefer to cut the hair as short as possible when the hair starts to fall out. Hair will usually grow back when the cancer treatments become milder, or when treatment is finished.

Preventing Infection

Whether at school, home, or in your community, your child will be exposed to germs. We all have germs on our skin and in our mouth and intestines (gut). Germs can also be found in the environment and in people with infections. Children being treated for cancer cannot fight germs as well as healthy children. It is very important to take steps to prevent infection.

HYGIENE

The most important way to prevent infection is to keep your hands clean and to help your child do the same. To prevent the spread of germs from one person to another, encourage your child, family members, and visitors to:

- wash hands often with soap and water and/or use a hand sanitizer

It is especially important to wash hands after using the toilet and before:

- caring for your child
- preparing your child's medicines
- preparing your child's food

It is also important to remind your child:

- not to share cups, water bottles, or eating utensils with other people
- not to share a toothbrush with anyone
- to bathe or shower regularly, as instructed by your health care team

SCREEN VISITORS AND FRIENDS FOR INFECTIONS

We encourage your child to continue to have visitors, including other children. Be sure to ask ahead of time if the visitor or friend is sick or has been exposed to an infection. Anyone who has a fever, runny nose, cough, diarrhea, or rash should not visit your child.

CARING FOR ANIMALS

If your family has a pet, your child should not clean animal cages (such as a bird cage or turtle aquarium), empty cat litter boxes, or deal with animal waste. Animal waste may carry germs that can spread to your child. If you live on a farm, talk with your health care team about any additional safety measures that may be needed when working with animals.

Precautions During Treatment

DENTAL CARE

Keep your child's teeth, mouth, and gums clean. Your child should brush their teeth after each meal and before bed with a soft toothbrush and toothpaste. Check with your health care team before taking your child to the dentist.

VACCINATIONS

Some vaccines should not be given while your child is receiving treatment. Flu shots are usually recommended for your child and all family members. Talk to your health care team before your child receives any vaccines.

VARICELLA (CHICKENPOX OR SHINGLES) EXPOSURE

If your child has been in contact with anyone who has the chickenpox or shingles, **call your health care team immediately**. It is possible your child will need to get a medicine to protect against chickenpox. For this medicine to work, your child must get it as soon as possible after contact.

CHEMOTHERAPY SAFETY

Chemotherapy leaves the body through urine, stool, and vomit. Because of this, while your child is receiving chemotherapy and for 48 hours after the last dose, it is important to take the following precautions:

- Wear disposable nitrile gloves (available at most drug stores and pharmacies) when handling your child's body waste (urine, stool, vomit) or items soiled with waste. Always wash your hands after taking off the gloves.
- Close the lid and flush twice after each time your child uses the toilet.
- Wash clothes or bed linens that have been soiled with body waste separately from other laundry using hot, soapy water. Then wash them again with your regular laundry.
- If soiled clothes or bed linens cannot be washed right away, keep them in a sealed plastic bag.
- Dirty items that are not soiled with body waste can be touched and washed as usual.

- If your child is in diapers, wear disposable nitrile gloves when changing diapers and seal the soiled diapers in a plastic bag before disposal.
- When possible, women who are pregnant or breastfeeding should avoid touching a child's body waste during and for 48 hours after the child receives chemotherapy. If it is necessary for a pregnant woman to handle soiled items during this time, they should wear disposable nitrile gloves.

Other Precautions

CENTRAL VENOUS LINE EMERGENCY CARE

If your child has a PICC or external central venous line, never use scissors near the line or dressing. If you see a break or leak in the line, clamp the line above the break right away. Call your health care team and take your child to the hospital or clinic to have the line fixed.

PRECAUTIONS FOR PATIENTS WITH BRAIN TUMORS AND/OR SHUNTS

If your child has a brain tumor or a shunt, **call your health care team immediately** if your child has:

- Severe or repeated headaches
- Repeated vomiting
- Extreme sleepiness
- Irritability
- Confusion
- Swelling or redness along the shunt tract

Call Emergency Services ("911" in the U.S. and Canada) immediately if your child has a:

- Seizure (and you have **NOT** been told that a seizure can be managed at home)

POSTOPERATIVE/WOUND CARE

If your child has had surgery, the nurse can show you how to care for the wound and to change the bandage if needed. Generally, it is important to keep the area clean and dry, and to protect the wound from stress (such as rough activities) until it is fully healed.

Giving Medicines

It is important to understand the reason for each of your child's medicines, and how to give each of them correctly. The main types of medicines are for:

- Treatment of cancer (some children will take these medicines at home)
- Prevention of complications (such as infection)
- Management of symptoms (such as pain and nausea)

Before you go home, you will receive a list of your child's medicines. Be sure that you know:

- The name of each medicine
- When to give the medicine
- What each medicine is for
- How to give the medicine
- How much medicine to give

Your child's nurse can show you how to give each of the medicines to your child. Talk with the nurse to plan a time to practice giving the medicines to your child before you go home. It is also best to pick up your child's medicines from the pharmacy before you go home so that you can review them with the health care team. If you are not able to pick up the medicines before you go home, be sure you know where to get the medicine, and what to do if the pharmacy is unable to get any of your child's medicines for you.

If your child has trouble taking medicines or cannot swallow pills, tell your child's nurse or doctor. They can help you find the best way to give the medicine to your child. Your nurse or child life specialist may also be able to help your child learn and practice how to swallow pills. Talk to your nurse or doctor about what to do if your child vomits a dose of medicine at home.

After you go home:

- Bring your child's medicines and medicine list with you each time you come to the clinic, hospital, or Emergency Room.
- Let your doctor or nurse know right away when your child's supply of any medicine is running low.
- Keep your child's medicines locked in a safe place, out of reach of children and pets.

