New Diagnosis Guide

Caring for Your Child at Home
Common Reactions at Diagnosis
Common Reactions at Diagnosis

- The first few weeks after diagnosis are particularly difficult for the whole family.
- Common responses include:
  - Distress
  - Isolation
  - Confusion
  - Anger
  - Upset
  - Irritability
  - Worry
  - Numb
  - Trouble sleeping
- Social Work and Child Life can partner with you to support your family.
About Cancer and its Treatment
What is cancer?

Cancer in children falls into one of 3 groups:

- Leukemias
- Lymphomas
- Solid Tumors
Leukemias

Leukemia are cancers of the blood forming cells.
Lymphomas are cancers of the immune system.
Solid Tumors

Solid tumors are cancers of the brain, bones, muscles, organs, and other tissues in the body.
How is cancer treated?

Each type of childhood cancer is treated differently.

Your child’s treatment may include one or a combination of the following:

Chemotherapy
Immunotherapy
Surgery
Radiation
Central Venous Line (CVL): PICC
Central Venous Line (CVL): External

INSERTION SITE

VEIN

CUFF KEEPS TUNNELED CATHETER IN PLACE

CATHETER COMES OUTSIDE CHEST

EXTERNAL CVL- CHEST
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The world's childhood cancer experts
Treatment Overview

- Record important treatment information on the Treatment Summary page.
- Keep this with you.
- Show it when needed, such as when visiting the Emergency Room.
Who to Call for Help
Cancer Center Phone Numbers

There is **ALWAYS** someone available to answer your questions, no matter the time of day or night!

**Buerger Center Oncology Clinic**

**King of Prussia Oncology Clinic**

**Voorhees, NJ Oncology Clinic**
Daytime Phone Numbers: Buerger Center

- **Phone Nurse:** 215-590-2299
  - 8:30 a.m. to 5 p.m.
  - Seven days a week
  - Including holidays

Before your first visit, you can see our clinic:
- A live tour or
- A video tour

Ask your bedside nurse for more information.
Daytime Phone Numbers: **KOP Clinic**

**Monday-Friday:**
- **KOP Nurse:** 267-425-3320
  - 8:00 a.m. to 4:30 p.m.

**Saturday and Sunday:**
- **Buerger Center:** 215-590-2299
  - 8:30 a.m. to 5 p.m

Before your first visit, you can see a video tour of the KOP Clinic. *Ask your bedside nurse for more information.*
Daytime Phone Numbers: VNJ Clinic

Monday-Friday:
• VNJ Nurse: 856-435-7502
  • 8:00 a.m. to 4:30 p.m.

Saturday and Sunday:
• Buerger Center: 215-590-2299
  • 8:30 a.m. to 5 p.m

Before your first visit, you can see a video tour of the VNJ Clinic. Ask your bedside nurse for more information.
After 5pm Phone Numbers

7 days a week:

- **Main Hospital:** 215-590-1000
  - ask for the Oncology Fellow On Call
  - Operator will ask for a call back number to reach you
  - If you don’t hear back from the Fellow after 15 minutes, call back.
When to Call for Help
Emergency Help

Call 911 immediately if your child:

- Is not breathing or has severe difficulty breathing
- Has skin and/or lips that look blue
- Is having a seizure
- Does not wake up after you have tried to wake them
When to Call for **Immediate** Help

<table>
<thead>
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**Fever:**

- **101.3 F (38.5 C)** even once
- **100.4 F - 101.2 F (38 C – 38.4 C)**
  - 3 times in a 24-hour period
  - Taken at least 2 hours apart

Do not wait until the clinic opens

Call right away!
Taking Your Child’s Temperature

- Have working thermometer
- Learn how to take child’s temperature
- Check child’s temperature if they feel warm or do not look or feel well
- Do not give Tylenol (acetaminophen) or aspirin or Motrin (ibuprofen)
- Do not take a rectal temperature

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When to Call for **Immediate** Help

**Buerger Center:** 215-590-2299  
**KOP:** 267-425-3320; **VNJ:** 856-435-7502  
**After 5pm:** 215-590-1000  
*Ask for the Oncology Fellow*

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**Trouble with breathing**

**Bleeding that does not stop within 5-10 minutes**

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**Do not wait until the clinic opens**
When to Call for Immediate Help

Buerger Center: 215-590-2299
KOP: 267-425-3320; VNJ: 856-435-7502

After 5pm: 215-590-1000
Ask for the Oncology Fellow

Change in behavior
Sudden change in vision
Severe or repeated headache

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New weakness

Uncontrolled pain

A break or leak in the central line

**Do not wait until the clinic opens**
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Repeated vomiting or diarrhea

Not able to drink fluids

Exposure to chicken pox or shingles

Call right away!

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If you are unsure or uneasy about *anything*, it is always better to call than not call!
Visiting the Emergency Room (ER)

Tell the ER staff about your child, including:

- Type of cancer
- Last treatment
- Fever requires immediate care, often including antibiotics
- No waiting in areas with other people who may be sick
- No rectal temperature
- No Motrin (Ibuprofen)
Managing Symptoms
Bleeding and Feeling Very Tired

Call if your child has any of these symptoms:

- Very tired
- Pale
- Dizzy
- Bad headache
- Bruising
- Small red dots on skin
- Bleeding from the nose, gums, or around the central venous line

Call immediately for bleeding that does not stop within 5-10 minutes
To Prevent Bleeding:

• Avoid rough play and contact sports

• Use a soft toothbrush

• Avoid giving aspirin or ibuprofen
Pain

Call 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, Diarrhea

- Use medicines given by your health care team
- Give sips of cool, clear liquids
- Offer small bites of foods that are easy to digest, such as:
  - Crackers
  - Rice
Dehydration

- **Call immediately if your child has:**
  - Dry mouth or lips
  - No tears when crying
  - Urinating less than normal
  - Dark urine
  - Repeated vomiting or diarrhea
  - Is not able to drink fluids
Call 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
Preventing Infection
Handwashing helps prevent infection

- Wash hands often with soap and water or use a hand sanitizer:
  - After using the toilet
  - Before caring for your child
  - Before preparing your child’s medicines
  - Before preparing your child’s food
Hygiene

- 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
Screen Visitors for Illness

- Check with friends and visitors before they arrive
- People can visit your child except if they have:
  - Fever
  - Runny nose
  - Cough
  - Diarrhea
  - Rash
  - Other symptoms of illness
  - Recently exposed to infection
Caring for Animals

- Your child should not clean:
  - Animal or bird cages
  - Aquariums
  - Cat litter boxes or animal waste

- If you live on a farm:
  - Talk with your health care team about safety tips for your child

Do not handle animal waste
Precautions During Treatment
Precautions During Treatment

- **Brush teeth regularly**
- **Call if exposed to chicken pox (varicella)**
- **Hold all vaccines, except the flu shot**
Precautions During Treatment

Take these precautions for **48 hours** after the last dose of chemo:

- **Wear gloves when handling waste**
- **Close the lid, flush two times**
- **Wash soiled clothes separately**
Giving Medicines
Giving Medicines

- For each medicine, you should know:
  - Medicine name
  - What it is for
  - When to give it
  - How to give it

Your nurse or a pharmacist will review all meds with you before you go home.
After you go home:

- Bring a list with your child’s current medications including name and dosage to the clinic, hospital, or ER
- Tell us when you need a refill
- Keep medicines locked in a safe place
Psychosocial Resources

- Every family has a **Social Worker** and a **Child Life Specialist** to support them.

**Social Work:**
- Provide emotional support
- Connect to resources: school, work, community, lodging and logistics, financial topics related to diagnosis

**Child Life Specialist:**
- Preparation, education and support before, during, and after procedures for you, child, and siblings
- Provide developmentally appropriate education regarding diagnosis and treatment
Brain Tumor and Shunt Precautions
Call **911** immediately if your child has a:
- Seizure *(and you have NOT been taught what to do at home)*

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**After 5pm:** 215-590-1000  
Ask for the Oncology Fellow

Call **immediately** if your child has:
- Severe or repeated headaches
- Repeated vomiting
- Extreme sleepiness
- Irritability
- Confusion
- Swelling or redness along the shunt tract
Wound Care
Wound Care

- Your nurse can show you how to care for the wound and change the bandage if needed.

- Keep the area clean and dry.

- Protect the wound until fully healed.
Review
Review

Let’s review who to call **during daytime hours:**

- Buerger Center Oncology Clinic
- King of Prussia Oncology Clinic
- Voorhees, NJ Oncology Clinic
Daytime Phone Numbers: Buerger Center

• Phone Nurse: 215-590-2299
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Questions
We are here to help!

For more information, please see the COG Family Handbook

https://www.childrensoncologygroup.org/index.php/cog-family-handbook
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