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

- **8:30-5:00pm, 7 days a week (including Holidays):**
  - Oncology Phone RN: **215-590-2299**
- **After 5pm:**
  - Main Hospital: **215-590-1000** and ask for the Oncology Fellow On Call
- **If your child will be going to one of our suburban locations:**
  - Voorhees: (856) 435-7502
  - KOP: **267-425-8800**

An **Oncology RN** will answer your questions and/or connect you with the member of the team who can best help you.

This phone number is to be used when you are no longer in the hospital. While an inpatient, please talk to your RN about any questions to help you contact a member of the Oncology team.
Common Reactions at Diagnosis

- First few weeks after diagnosis are particularly difficult, a roller coaster of emotions.
- Most families adjust over time.
- Common emotional responses for children, parents, and siblings include:
  - Distress is expected and normal
  - Feeling confused, upset, worried, numb, isolated
  - Behavioral changes, such as irritability and sleep problems, are common.
- Connect with others who can help, such as family and friends, parent support groups, and your child's social worker.

Treatment: Chemotherapy

Medication that treats cancer by stopping cells from growing or by destroying cells.
- By mouth
- Into a vein
- Under the skin
- Into the spinal fluid

Treatment: Radiation

- Delivers high energy beams that destroy rapidly growing cells, like cancer cells.
- Given by itself or in combination with other therapies, like chemo or surgery.
Effects of Treatment on the Bone Marrow

- **Bone Marrow**: spongy tissue inside bones
- Factory where blood cells are made
  - Red blood cells
  - White blood cells
  - Platelets

Blood Counts

- **LOW COUNTS**: Chemotherapy and Radiation can lower the number of blood cells the bone marrow makes.

  - Blood counts are checked with a blood test: **Complete Blood Count (CBC)**

When do blood counts drop?

- **7 to 10 days** after chemo
- A **CBC** will be checked often during this time
- It is not unusual for treatment to be **delayed** for low counts
- The time it takes blood counts to rise depends on your child's treatment, typically **2-3 weeks**
White Blood Cells (WBCs)

- Fight Infection
- No obvious sign that a WBC count is low

Absolute Neutrophil Count (ANC)

- Neutrophils: type of WBC that fight bacteria
- ANC: total # of neutrophils in WBC count
- A low ANC increases the risk of infection

<table>
<thead>
<tr>
<th>ANC</th>
<th>Risk for Infection</th>
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<tbody>
<tr>
<td>Lower than 500</td>
<td>Highest</td>
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<tr>
<td>500 to 1000</td>
<td>Moderate</td>
</tr>
<tr>
<td>More than 1000</td>
<td>Lower</td>
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</tbody>
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Red Blood Cells (RBCs)

- Carry oxygen to the body
- Hemoglobin is the most important part of red blood cells
- Chemo may cause a drop in Hemoglobin
- Anemia: Hemoglobin
- RBC transfusion is given when hemoglobin is low

Signs of a Low Hemoglobin

CALL if your child has any of these signs:

- Headache
- Tiredness
- Shortness of breath
- Fast heart rate
- Pale skin or gums
- Dizziness

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Platelets

- Help stop bleeding by forming clots
- Chemo may lower the platelet count
- A low platelet count increases the risk of bleeding
- Platelet transfusion is given for a low platelet count

Signs of Low Platelets

CALL if your child has any of these signs:

- Bleeding
- Petechiae
- Bruising
- Blood in poop
- Blood in vomit

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Ways to Avoid Bleeding

- Do NOT:
  - Take a rectal temperature
- Do NOT:
  - Give an enema/suppository
- Do NOT:
  - Give aspirin or ibuprofen (Motrin, Advil)
- Use a soft toothbrush
- Ask the Oncology team about activity restrictions your child may have if platelets are low
If your child needs a Red Blood Cell or Platelet transfusion, the Oncology Team will talk to you about this process.

Sign of Infection: FEVER

Fever for a child with cancer can be a life threatening emergency!
You need to call clinic/fellow immediately!

Sign of Infection: FEVER

• When to call:
  • 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 give Tylenol until you’ve called.
If your child has a fever...

- Call ASAP!
- You will have to bring your child to the Clinic or the closest Emergency Department
- The Oncology Fellow will alert the ED that your child is coming
- Tell the ED staff that your child is an Oncology patient. You will be taken to an isolation area

What to expect in the Clinic/Emergency Department

- Complete Blood Count (CBC)
- Blood Culture
- IV Antibiotics

Central Lines

A catheter that provides a safe way to deliver treatment by connecting with a large, central vein.

- Port: Internal line
- Broviac: External line
- PICC: External line
- Medcomp: External line
**Signs of a Central Line Infection**

CALL if your child has any of these signs:

- Shaking or chills when the central line is flushed
- Fever
- Pain
- Redness
- Swelling
- Pus at the site

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**Bacterial Infections**

- Bacterial infections can happen anywhere in the body
- Children receiving chemotherapy are at risk for a certain type of pneumonia
- Bactrim (Co-trimoxazole) is given to help prevent this type of pneumonia

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**Chicken Pox & Shingles**

- If your child has been exposed to a person with chickenpox or shingles, CALL as soon as possible
- Both are contagious diseases caused by a virus
- Do NOT come into the clinic waiting room
- Treatment:
  - Possible need for IV medication
Fungal Infections

- Fungal infections can spread to the blood
- **Thrush**: type of fungal infection
  - White spots or coating on the **tongue and inside of the mouth**
- Fungal infections can develop in the **diaper area**
- Treatment:
  - Skin creams
  - Oral or IV medicines

Other Signs of Infection

**CALL** if your child has any of these signs:

- Chills
- Cough
- Trouble breathing
- Diarrhea
- Pain
- Red, irritated skin

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The best way to prevent infections is **good hand washing**!
**Preventing Infection**

- Ask visitors if they have been sick within the last 48 hours
- Do **NOT** allow anyone to visit who has:
  - Fever
  - Cough, Runny Nose
  - Vomiting, Diarrhea
  - Rash
- Ask your healthcare provider about specific restrictions for your child

**Environment**

- Cleaning
- Pet care

**Dental Care**

- Talk with your oncology team before going to a dentist

**Skin Care**

- Keep skin clean and moisturized
- Use sunscreen, especially if on Bactrim
- Watch for breaks in the skin and signs of infection

**Immunizations**

- No immunizations during treatment
- Siblings may receive routine immunizations
- Your child and all family members should get the Flu Shot!
**Nausea & Vomiting**

- Medications are used before, during and after chemo/radiation to decrease nausea & vomiting
- **Call if any of the following occur:**
  - Your child is throwing up and nausea medications are not helping
  - You see blood in vomit
  - You child is not able to drink due to nausea

**Mouth Sores**

- “Mucositis”
- Can cause infection
- Good mouth care decreases bacteria and lessens the chance of infection
- **Call if your child experiences:**
  - Mouth/throat pain
  - Not drinking enough liquids

**Diarrhea**

- Frequent, loose, or watery bowel movements
- **Call for > 5 stools in 24 hours**
  - Encourage drinking
  - Check skin in diaper area for irritation
**Dehydration**

- When liquid output (vomit, stool) is more than liquid intake (drinking)
- **Caused by:**
  - Fever
  - Vomiting
  - Diarrhea
  - Drinking less because of mouth sores or nausea
  - Ask your nurse how many ounces your child should drink each day

**CALL** if your child has any of these signs:

- Pees less than 5x/day
- Dark pee
- Dry skin, lips
- Increased sleepiness
- Lack of energy

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**Constipation**

- Hard bowel movements that are infrequent or difficult to pass
- Most children have a bowel movement every 1 to 3 days
- **Causes:**
  - Medicine
  - Decreased liquids
  - Decreased activity
- **Call if your child:**
  - Has not had a BM in 3 days
  - Has pain when having a BM
  - Has hard stool
- **NEVER** give enemas or suppositories
Weight Gain or Weight Loss

**Weight Gain** is often a result of **steroids**:
- Causes Increased Hunger
- Temporary Side Effect

**Weight loss** may be a result of:
- Loss of appetite
- Nausea
- Mouth sores

If you are concerned about your child's weight, ask to speak with a member of the **Oncology Nutrition staff**

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Your Child and School

- **Return to school** is incredibly important for:
  - Helping your child engage in normal activities
  - Maintaining peer relations and support
  - Continuing academic progress

- **School** is not all or nothing. There are options:
  - Tutoring while in the hospital
  - Intermittent homebound instruction when your child is home but cannot attend school
  - 504 Service Plan for accommodations or an Individualized Education Plan (IEP) when your child returns to school

- **Talk to your Social Worker** to initiate a school reentry plan.

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Communicating About The Diagnosis

- It is important to be honest with your child about his/her cancer diagnosis and treatment using words your child can understand.

  - **Your Child Life Specialist** can:
    - Help you talk to your child in a developmentally appropriate way
    - Educate patients and other family members about your child's cancer diagnosis and treatment
    - Provide resources about diagnosis, hair loss, being hospitalized, procedures, getting a port, etc.

- We encourage continued, open, and honest communication.
Each newly diagnosed family is assigned:

- **Social Worker**
  - Addresses your psychosocial needs including emotional support
  - Provides resources such as help with transportation, meals, school reentry, etc.

- **Child Life Specialist**
  - Provides education on your child’s diagnosis
  - Helps you and your child cope with emotional stress and anxiety associated with a cancer diagnosis and treatment

- **Teacher**
  - Through the Hospital School Program
  - Provides for your child's education needs during inpatient admission and outpatient treatment

Also available as needed to provide support:

- **Oncology Chaplain**
- **Psychologists**
- **Art Therapists**
- **Music Therapists**

For additional information go to: http://www.chop.edu/service/oncology/resources-for-families-of-children-with-cancer/