

### Educating Yourself

It can be tempting to jump on the internet and research everything you can about your child's cancer. Please remember that the internet is not regulated so you may come across a great deal of misleading information. Doctors want you to be educated about your child's cancer and they will probably provide a folder of information along with your child's treatment plan. If you are anxious to do more research please talk to your doctors to determine which websites they recommend. Start by visiting your hospital's website. If you are having trouble understanding any of the information, talk to the doctor or support staff as it is of vital importance that you understand your child's illness and treatment.

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*"I utilized the internet a lot to find information but would caution parents to be careful to filter what they read. Being a nurse, I was able to do that some, but still found some information to be not entirely accurate and certainly not helpful in terms of trying to find answers for Lauren's diagnosis. I continue to be amazed at how little there is out there about children with special needs and leukemia (or any cancer)".*

*– Tammy*

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*"As you know we were very honest with Sarah, and didn't keep any of the "facts" from her. With the help of the Child Life Specialists, we explained things on her level as they came. It helps to take it a piece at a time as it comes. You have to be truthful so that they will trust you".*

*– Dianne*

### Educating Your Children

Gabe's My Heart believes that education is the cornerstone to helping children through their cancer journey. Child life staff and psychologists are trained to help you educate your child about everything they can expect from cancer treatment. Always refer to them first as they are trained to deal with children of all ages in the hospital setting. They know what is available in the way of books, toys or DVD's to help you and your child understand specific cancer issues. If you ask they will be happy to suggest some age appropriate methods of teaching your child.

The educational needs of children vary greatly by age, there is a great need to educate young children as they feel lost and confused. If you can find a way to explain their treatment in a non threatening way, it can be a great relief for the whole family. Chemo Duck is a great tool for educating young children on their own level. Children need to feel control over their situation. If you can help them to express themselves through play therapy and educate them with suitable tools everyone will be more comfortable and content.

When children are familiar with their environment and know what to expect they are less likely to resist treatment.

Offer age appropriate instruction to assist them in understanding what is happening to them and why. Older children will have questions and doubts. Older children should be given as much information as you feel they can take. Answer their questions as honestly as you can, and do not be afraid to tell them you do not know all the answers. Older children should still be encouraged to express themselves and in return you should feel able to be honest about some of your emotions

#### In a nutshell:

- Talk to the Child Life Specialists
- Take it a piece at a time from the beginning
- Keep it age appropriate
- Tell the truth or be as honest as you can
- Use all the resources available

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*"We found it very helpful to write down exactly how we were going to explain it to her".*

*– Scott and Jennifer*

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*"The Candelighter's have very good resources to educate the parents and to help with explaining to children. Use all the resources available. Look to the Child Life Specialists first".*

*– Unknown*

### School and Homebound School

Talk to hospital support staff about contacting your child's school. They will be able to assist you in preparing any necessary paperwork. The hospital will assist you in developing an education plan for your child. This will depend on your child's diagnosis, and doctor's advice. Because you are facing so many changes as a family, it is nice to keep as much of your normal routine as possible. Most doctors agree that it is in the child's best interests to attend regular school as much as possible while in treatment. However, there may be times when you require a homebound teacher. For prolonged hospital visits there are education options available.

There are many useful guidebooks for educating children with cancer. Ask your child life specialist to recommend some.

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*"The Homebound program was wonderful. She spent the second half of kindergarten and the first half of first grade in the program. A teacher would come to the house twice a week for 1 1/2 hours. We set up a room in the house to be the classroom, which made it easier for her to focus. The homebound teacher would even come to the hospital if she had been admitted".*

*– Scott and Jennifer*

## BLOOD COUNTS FOR BEGINNERS

The term blood count refers to the number of blood cells you have in your body.

**There are 3 different kinds of blood cells:**

- Red blood cells
- White blood cells
- Platelets

Bones are hollow on the inside. The hollow section is filled with a liquid substance called bone marrow. This bone marrow is where blood cells are made.

- Some of the stem cells become red blood cells
- Some of the stem cells become white blood cells
- Some of the stem cells become platelets

We measure your blood cells by doing a complete blood count (CBC). A CBC means a drop of blood is drawn and the laboratory counts how many red blood cells (including hemoglobin), platelets, and white blood cells are in the blood.

### Red Blood Cells

Red blood cells pick up oxygen from the lungs and carry it to all the other cells of the body. The cells use oxygen as fuel. Red blood cells also give your skin its color. The way we measure the red blood cells is by measuring the hemoglobin.

Hemoglobin is the protein that makes up the red blood cells. So what is a normal hemoglobin? Normal hemoglobin level is greater than 11 grams. Most people are okay with a hemoglobin above 8 grams.

When the hemoglobin level is below 8 grams, cells are not receiving enough oxygen. Your body may begin to feel differently. Your heart must also pump harder.

**When your hemoglobin is less than 8 grams you may:**

- Feel more tired
- Have a headache
- Feel dizzy
- Look pale
- Have pale lips
- Feel short of breath with activity

Young children cannot tell us these things. They may be more irritable and tired than usual. When the hemoglobin level drops below 8 grams, your doctor will decide if you should receive a blood transfusion to make you feel better, and to lessen the strain on the heart.

### Platelets

The second type of blood cell is called a platelet. Whenever you are cut, platelets form a clot or scab to stop the bleeding. Platelets also prevent you from bleeding even when you are not cut. They also line the walls of our tiny blood vessels called capillaries to prevent us from having blood leak out of them even when we are not injured.

Normal platelet count is above 150,000. Most people are fine with a platelet count above 40,000. When the platelet count drops below 10,000, you are at greater risk for bleeding.

## BLOOD COUNTS FOR BEGINNERS

What can happen with a low platelet count? The risk of bleeding is serious when the platelet count drops below 10,000. You bruise easily, develop nosebleeds, bleed from your gums, or bleed from blood draws or IV sticks. The most dangerous area to bleed is within your brain. This is an EMERGENCY! When the platelet count drops below 20,000 your doctor will decide if a platelet transfusion should be given to you.

### Signs of a low platelet count:

- Easy bruising
- Easy bleeding (gums, blood draws, IVs)
- More frequent nosebleeds
- Severe headache or mood changes
- Petechiae

Petechiae are small red dots that can appear anywhere on the skin when your platelets are low. They are a sign that the tiny blood vessels called capillaries do not have enough platelets to prevent blood from leaking out. Babies and younger children can develop them around their eyes if they have been crying hard.

### White blood cells

There are many different kinds of white blood cells. All of them have the same function: FIGHT INFECTION. Normal white blood cell count is 5,000-10,000. This is the total white blood cell count (WBC).

### Causes of low white blood cells can include:

- Laboratory error, viral infections (bacterial infections usually raise the white blood cell numbers)
- Certain diseases of the blood and effects of chemotherapy

The WBC includes all the different kinds of white blood cells. It is also important to know your DIFFERENTIAL. Differential means the counts of each of the different kinds of white blood cells. These are some of the many different kinds of white blood cells you have in your body. Neutrophil, band neutrophil, monocyte, lymphocyte and basophil neutrophils are the only white blood cells that are able to fight BACTERIAL infections.

**How many NEUTROPHILS are enough?** A neutrophil count over 1,000 gives you enough to fight off most bacterial infections. Neutrophils below 1,000, you are at greater risk for bacterial infection. When the neutrophil count is below 500, you are at serious risk of infection.