

Websites: For Information and Emotional Support

National Cancer Institute

www.cancer.gov

**CureSearch: National Childhood Cancer
Foundation and Children's Oncology Group**

www.curesearch.org

Candlelighters Childhood Cancer Foundation

www.candlelighters.org

The Leukemia & Lymphoma Society

www.lls.org

People Living With Cancer

www.plwc.org

The American Cancer Society

www.cancer.org

Blood Cancer & Leukemia

www.leukemia-web.org

Dana Farber-Children's Hospital for Cancer Care

www.danafarber.org/pat/pediatric-care/

CancerCare, Inc.

www.cancercare.org

Gilda's Clubs

www.gildasclub.org

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A treatment *journal* for parents and kids



“Children are the anchors that hold a mother to life.”

-Sophocles

Sometimes, when you're stressed or busy or slightly anxious, it can be hard to remember everything you wanted to ask the doctor. Maybe you've been planning all week to ask a specific question, but once you walk into the waiting room, it flies right out of your head. Here are some suggestions that can help jog your memory.

important questions



*“There is no charm equal to
tenderness of heart.”*

-Jane Austen

When a child undergoes serious medical treatment, it can be a difficult time and a busy time. There is lots to remember: appointments, phone numbers, prescriptions, directions, and more.

This *Treatment Journal* was designed to help. It's an appointment calendar and an address book, with some medical definitions you might need, some encouraging quotes, and even a Games section to help keep your child occupied in medical offices and waiting rooms—all in one place.

We hope it is useful to you.



Pediatrician(s)

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Oncologist(s)

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

medical contacts

Surgeon(s)

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Nurse/Nurse Practitioner

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

medical contacts

Pharmacy

Name _____

Address _____

Tel# _____

Name _____

Address _____

Tel# _____

Emergency Contacts

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

Name _____

Address _____

Tel# Office _____

Other _____

Fax _____

Email _____

medical contacts

Primary Insurance

Provider _____

Provider _____

ID# _____

ID# _____

Group# _____

Group# _____

Customer Service Phone _____

Customer Service Phone _____

Website _____

Website _____

Secondary Insurance

Provider _____

Provider _____

ID# _____

ID# _____

Group# _____

Group# _____

Customer Service Phone _____

Customer Service Phone _____

Website _____

Website _____

medical contacts

Things you might want to ask your doctor

- What type of cancer does my child have?
- What are my child's treatment options?
- Which option do you think is best for my child, and why?
- What possible side effects are there?
- Which symptoms or side effects require immediate medical attention?
- Is there anything I can do to lessen the side effects?
- How long will the treatment take?
- How long will my child need to be in the hospital?
- If we're home, what should I do in case my child is running a fever?
- How will I know whether the treatment is working?

Things you might want to ask your doctor

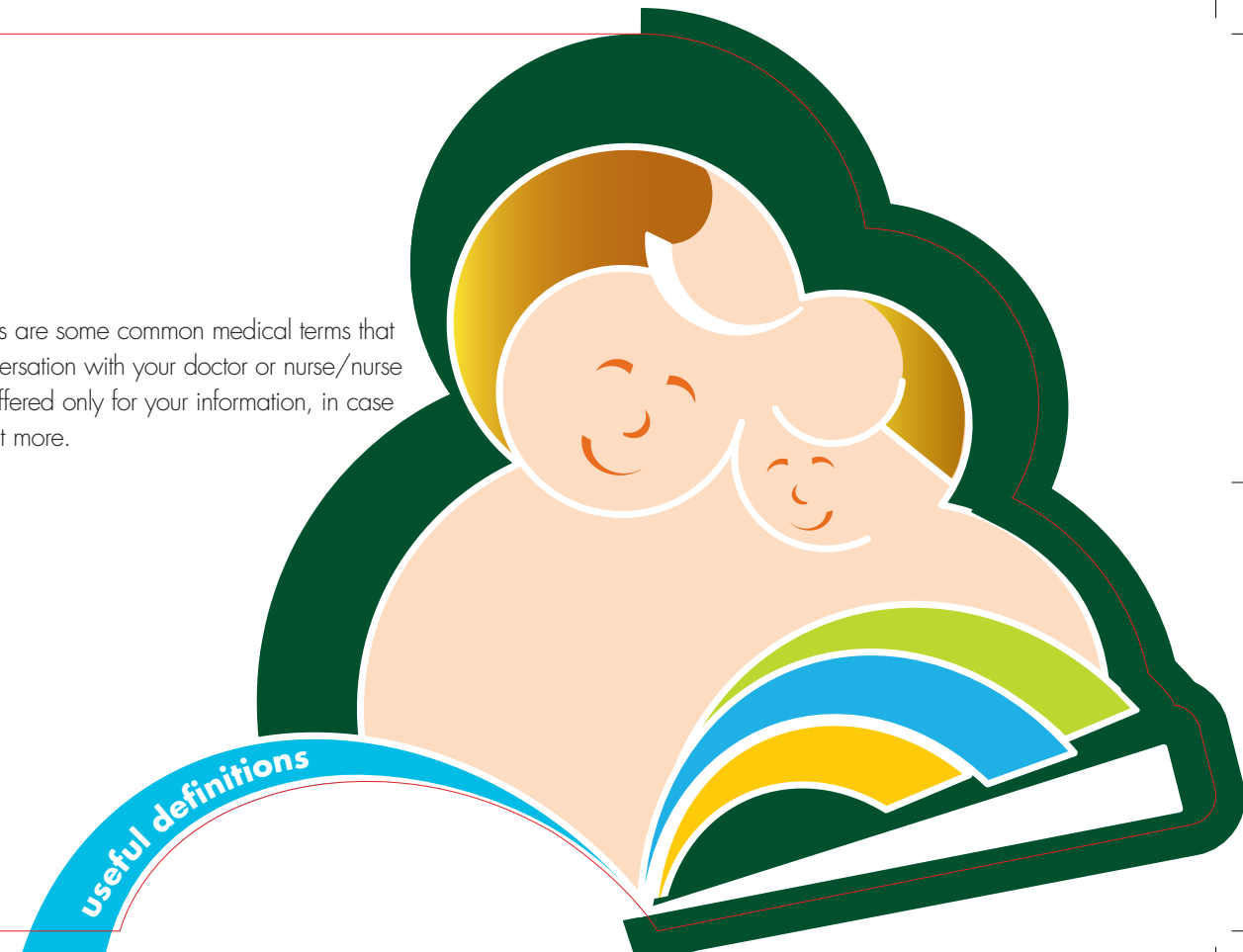
- Can my child do any of his/her usual activities?
- Is there any scientific information available on the chances of a full recovery from the type of cancer that my child has?
- If the tumor comes back after a first remission, what further treatment options are there? What are the goals of these additional treatments?
- Does the hospital or the local community have any resources or support groups that can help our family get through this?
- What support services are available to help my child cope with this disease?
- Do you have contact information for our doctors and the other health care providers my child sees?
- Will I need a new insurance referral?

important questions

“Nurture your mind with great thoughts. To believe in the heroic makes heroes.”

-Benjamin Disraeli

On the following pages are some common medical terms that could come up in conversation with your doctor or nurse/nurse practitioner. They are offered only for your information, in case you'd like to know a bit more.



Acute Lymphoblastic Leukemia (ALL) is a cancer of the white blood cells that results in too many immature white blood cells called lymphoblasts. White blood cells fight off infection and disease. Unfortunately, lymphoblasts can't fight off infection properly and they inhibit normal white blood cells from forming. Although people of any age can get ALL, the most commonly seen patients are between the ages of 3 and 5.

Acute Myeloblastic Leukemia (AML) is a cancer of the white blood cells. In most cases of AML, the body makes too many white blood cells called myeloblasts. These immature blood cells cannot fight infection as well as normal white blood cells do.

As more myeloblasts are made, they keep normal blood cells from growing. This can lead to infections, bleeding problems, anemia (loss of red blood cells), and can threaten major organs, such as the brain and spinal cord if not treated quickly.

Blood work measures the number of each type of blood cell. A small amount of blood can be taken from a vein in the arm, an IV catheter, or a simple finger prick. Tests for blood chemistry will show if there are abnormal chemicals in the body that could indicate health problems.

Bone marrow is a soft tissue found inside the hollow part of a bone. The marrow produces new blood cells, including two types of stem cells.

Bone marrow aspiration can show if your child's cancer is in remission and if new blood cells are being made. This is done by removing blood cells from the fluid part of bone marrow with a needle, usually from the hip bone.

Bone marrow biopsy can check for the presence of cancer cells in the bone marrow, and whether new blood cells are being created. For this test, a small piece of bone marrow with blood cells is removed.

Usually some kind of anesthesia or sedative is given to your child to ease discomfort during the procedure.

Chemotherapy is a course of treatment that uses powerful drugs capable of killing cancer cells, or at least slowing their growth.

Chronic Lymphocytic Leukemia (CLL) is a cancer of the white blood cells. When the body makes too many white blood cells, those cells cannot fight infection efficiently and they crowd out normal cells.

useful definitions

Chronic Myelogenous Leukemia (CML) is a cancer that causes the body to make white blood cells (called granulocytes) continually. Some of the bone marrow stem cells never mature. These immature stem cells take over the space in the bone marrow where red blood cells and platelets should be.

CT scans (sometimes called "CAT" scans) are painless. A CT scan takes 3D pictures and can show where the cancer is or if there are changes in the lymph nodes. CT scans can also show tumors, masses, and enlarged organs. The instrument that takes the pictures has a person-sized tunnel in it, and the patient will lay on a moveable table that slides into the tunnel.

Your child will probably not be allowed to eat or drink anything for a few hours before and may be asked to drink "contrast media," which helps picture clarity. CT scans are much clearer than any x-ray.

Hodgkin's Lymphoma is a cancer of the lymph system, which normally makes and stores the kinds of white blood cells (lymphocytes) that fight infection. With Hodgkin's lymphoma, these lymphocytes are abnormal, grow rapidly, and keep normal white blood cells from forming. These abnormal cells collect in the lymph nodes, causing them to swell, create pressure on, and harm other organs in the body.

Leukemia is cancer of the white blood cells. Blood cells are formed in bone marrow, which is inside the bone. Normal blood cells stay in the marrow only until they mature, and then they go out into the body. Cancer cells, however, stay in the bone marrow where they pile up. They also grow beyond normal size, clog up the bone marrow, and keep normal cells from developing.

Leukocytes are white blood cells.

Magnetic Resonance Imaging (MRI) is a test that uses a magnetic field to visualize pictures of organs and structures inside the body.

Sometimes an MRI can provide images that can't be seen on an x-ray or a CT scan. In order to have an MRI, your child will need to remove all metal objects (such as jewelry or hairpins) because the machine is actually a powerful magnet. Some people may be a little nervous inside the MRI machine, but the procedure is painless.

Neutropenia occurs when there is an abnormally low quantity of white blood cells, called neutrophils, in the bloodstream. Neutrophils are the main cells that fight bacteria, so when their numbers are sharply reduced, there is a greater risk of infection.

useful definitions

Non-Hodgkin's Lymphoma is a cancer of the lymph system, which is a group of tissues and organs found throughout the body. With non-Hodgkin's lymphoma, the body makes abnormal lymphocytes, which are cancer cells that have grown out of control. These cells collect and cause swelling in the lymph nodes.

PET scan is an imaging technique often used to find cancer and check organ functions. In order for the scan to be read clearly, a special "tracer" is injected intravenously. A camera records the tracer's signals as it moves through your child's body, and the resulting pictures are captured by computer.

Philadelphia (ph) chromosome is a chromosome that's found in the vast majority of people who have CML, and sometimes in people with ALL. This chromosome, which causes growth of abnormal blood cells, is an acquired abnormality. It's not inherited or passed along to one's child.

Platelets are blood cells that help stop bleeding.

Radiation therapy uses high-energy x-rays to kill cancer cells or to reduce the size of tumors.

Remission is the period when cancer cells can't be detected, and your child's body function is normal.

Spinal tap is also known as a lumbar puncture. While the lower back is numbed with a local anesthetic, a thin needle goes between the bones in the spine and draws out a small amount of fluid for examination. Testing will show if cancer cells are in the spinal fluid or near the brain.

The **Spleen** is an organ on the left side of the abdomen that removes worn-out blood cells. It's a useful but nonvital organ that sometimes becomes enlarged when cancer is present.

Stem cells, produced in bone marrow, are capable of becoming all the different kinds of blood cells. That's why stem cell transplantation is so valuable.

Stem cells are able to replace blood cells eliminated during chemotherapy or radiation therapy.

Tumor Lysis Syndrome (TLS) can occur during chemotherapy when cancer cells are killed off faster than the body can eliminate them. The kidneys can be overworked, and the normal chemical balance in the body can be thrown out of whack. If TLS is treated early on, organ damage can be avoided.

X-ray is probably the most familiar of the diagnostic imaging tools. X-rays are also used in CT scans, and can reveal tumors in organs, bones, the brain, or the spine.

useful definitions

*“We live in deeds, not years;
in thoughts not breaths; in feelings,
not in figures on a dial.”*

-Philip James Bailey

There might be many appointments to juggle in your child's life or hardly any. Whatever the case, this section is a good place to make note of them.



Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

Location: _____

Time: _____ Date: _____

appointments

“Happiness depends, as nature shows, less on exterior things than most suppose.”

-William Cowper

There are many symptoms your child may experience during the course of treatment. Here is a list to help you keep track of symptoms that commonly occur. There is also space for symptoms that are not listed.





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notes

“True hope is swift, and flies with swallow’s wings; kings it makes gods, and meaner creatures kings.”

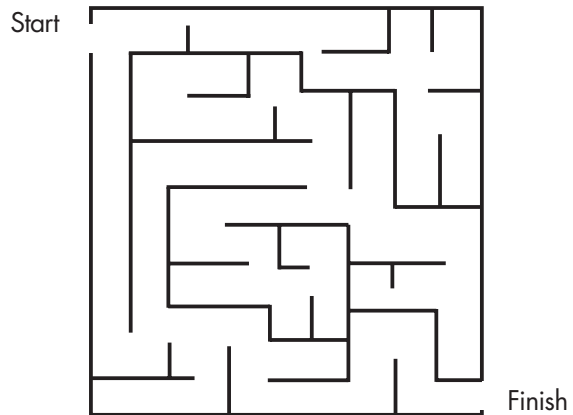
-William Shakespeare

Spending time in medical offices and waiting rooms can make even some adults impatient. So if kids need some distraction, it’s understandable. Quiet games can help pass the time. Aside from the mazes and Tic Tac Toe included here, all you need for Hangman or Battleship is paper and pencil. You can always bring along coloring books too or favorite stories to read.

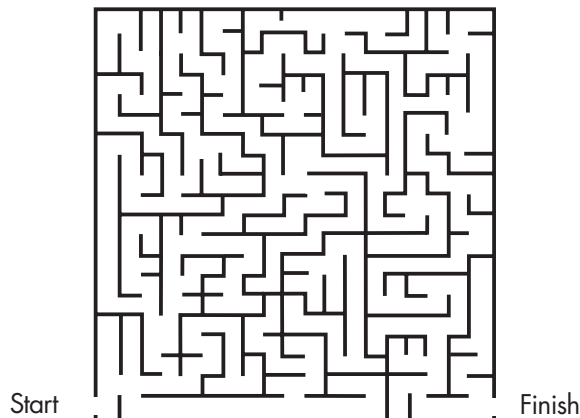


Maze Craze

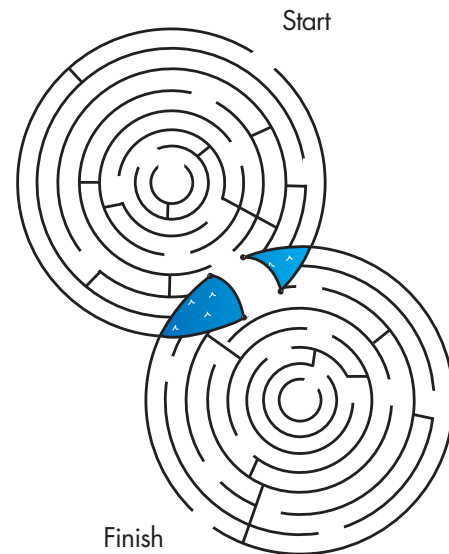
Easy



Hard

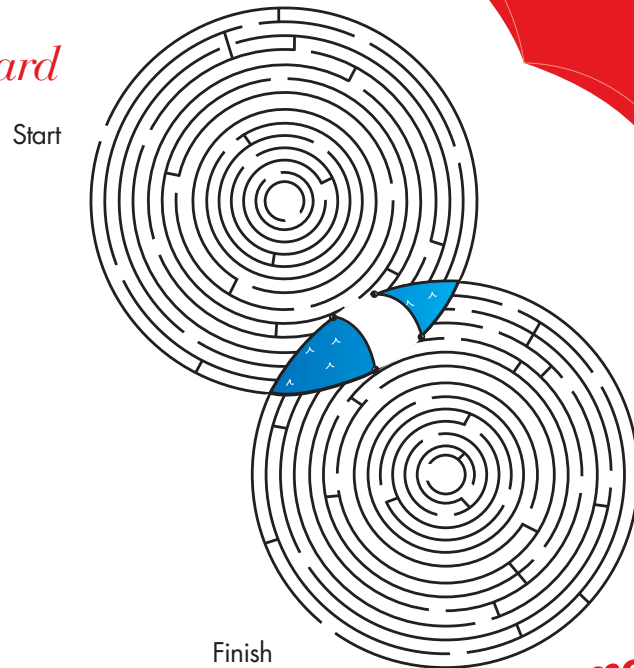


Easy



Maze Craze

Hard



games

