



FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



ACUTE LYMPHOBLASTIC LEUKEMIA (ALL)





The Cancer Support Community (CSC) has partnered with the Association of Community Cancer Centers (ACCC), Leukemia & Lymphoma Society (LLS), and Oncology Nursing Society (ONS) to develop this book for people impacted by acute lymphoblastic leukemia (ALL). It is our hope that it offers insight into understanding a diagnosis of cancer, making treatment decisions and coping with the emotional and practical challenges people with this type of cancer face. As you read, you will become part of a global cancer support community and find you are not alone.

Frankly Speaking About Cancer: Acute Lymphoblastic Leukemia (ALL)

Overview	4
Chapter 1: Diagnosis and Staging.....	7
Chapter 2: Treating Acute Lymphoblastic Leukemia	11
Chapter 3: How is ALL Treated?	16
Chapter 4: Managing Side Effects of ALL Treatment	25
Chapter 5: Coping with ALL	33
Chapter 6: Resources	46

Overview

WHAT IS ALL?

Acute lymphoblastic leukemia (also known as acute lymphocytic leukemia or ALL) is a type of cancer. Cancer is not one disease, but a collection of disorders that develop whenever something goes wrong inside a normal cell somewhere in the body that causes that abnormal cell to grow out of control. Unlike normal cells, cancer cells do not die but continue to reproduce.

ALL is a cancer of the blood and bone marrow. The bone marrow is the soft spongy middle of our bones that produces white blood cells (lymphocytes), red blood cells and platelets. The lymphocytes play a role in our immune system and protect us from infection.

Occasionally these cells undergo changes that make them grow out of control; they take over bone marrow and prevent it from producing normal blood cells. That's what leukemia is: cancer that begins in the immature white blood cells in the bone marrow.

There are four main types of leukemia, grouped for how fast they develop and the type of cell affected. Leukemia

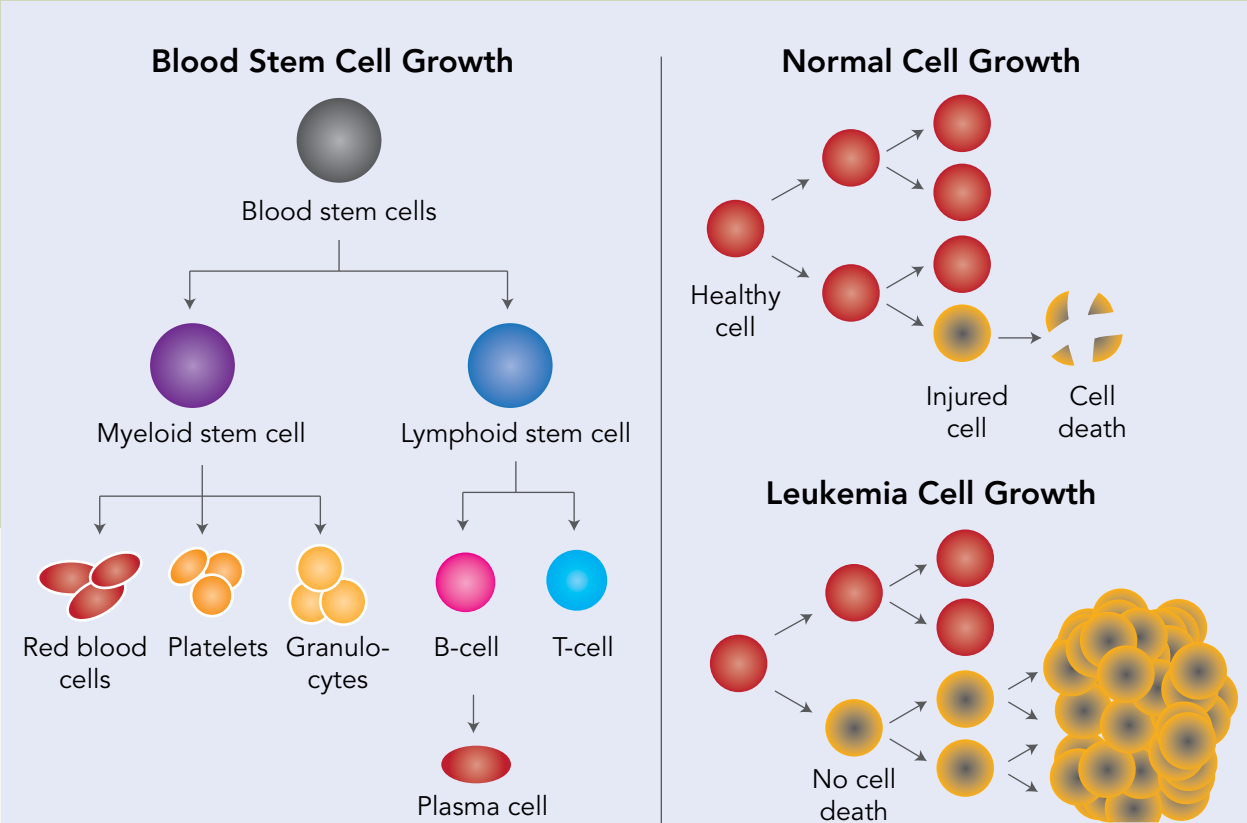
can be either **acute** (fast growing) or **chronic** (slow growing). With acute leukemia cases, the cancerous blood cells are still in their immature stage and cannot function normally in the blood. They multiply rapidly, making the disease get worse quickly. In chronic leukemia, the cancerous cells are more mature and they multiply less rapidly, making the disease progress more gradually.

If you are facing an ALL diagnosis, or being treated for this disease:

- Learn about ALL.
- Talk to your healthcare team.
- Ask questions.
- Think about getting your treatment in a facility that has expertise in treating leukemia.
- If you are an adolescent or young adult (AYA) look for a facility that has expertise treating AYAs.
- Take care of your physical, emotional, social, and spiritual needs.
- Talk to your health care team about getting the support you need right from the start.



Bone Marrow Cell Production



Either of the two types of white blood cells (**myeloid or lymphoid**), can turn into leukemia, so the disease is also named for which type of cell has become cancerous. In summary, the disease arises from the lymphoid stem cell line and the name ALL comes from:

A = Acute: the cells are growing very fast, in need of treatment right away

L = Lymphoblastic (also called Lymphocytic): the immature forms of lymphocytes

L = Leukemia: a cancer of the white blood cells, the cells that normally help fight infection

WHAT CAUSES ALL?

The short answer is that nobody knows what causes ALL. However, research has uncovered some intriguing new ideas about what is happening to normal bone marrow cells to make them turn into leukemia cells. The answers may lie in genetics.

All cancer comes from changes in the DNA inside a cell. Researchers have found several specific changes that can happen in the DNA of immature bone marrow cells (the ones that can turn into leukemia) that seem to make those cells grow abnormally, and make a person more likely to develop ALL. The disease develops from not a single genetic change, but several changes (or mutations) in the DNA occurring in the same cell that then multiply to millions of copies of the original mutated cell. Different DNA changes appear to mean different things in terms of what the expected outcomes will be and, often, what the recommended treatment will be.

It is important to note that these DNA changes happen spontaneously in immature blood cells, and are present only in the leukemia cells. While it is possible for people to inherit problem DNA from their parents, which increases their risk of developing

ALL (or other cancers), ALL is not considered to be an inherited disease and does not run in families. Certain exposures that cause changes in DNA can affect the risk for developing ALL, such as radiation, chemotherapy, or certain chemicals, but again, no one really knows what causes the genetic changes that lead to leukemia.

A SNAPSHOT OF ALL

- There are an estimated 382,000 people living with, or in remission from, all leukemias in the U.S.
- ALL represents 0.3 percent of all new cancer cases, and about 9 percent of all leukemias diagnosed in the U.S.
- It is estimated that there are about 5700 new cases of ALL each year
- ALL is most common in children, adolescents and young adults (15 to 39 years of age)
- The median age of diagnosis is 17
- About 74% of those diagnosed with ALL are less than age 20



Diagnosis and Staging

“The amount of information you are being asked to process over the first few days after diagnosis is unmanageable. What I try to tell families is that this isn’t the only time they are going to get to hear this, we will go over this many times. You don’t have to learn everything immediately.”

—Patrick Brown, MD, Johns Hopkins University

SIGNS AND SYMPTOMS

Many people will experience a variety of symptoms that may bring them to a doctor’s office before they are diagnosed. ALL symptoms tend to appear out of nowhere and get worse quickly. Keep in mind, your symptoms may be different than those of someone else with ALL. Some of the most common symptoms include:

- Feeling weak, extremely tired, dizzy or light-headed, or appearing abnormally pale. These symptoms can indicate anemia, caused by not enough red blood cells to deliver sufficient oxygen to the tissues of the body.
- Bruising or bleeding easily, especially frequent or severe nosebleeds and bleeding gums, which occurs when there is a lack of platelets in the blood.

- Fevers, recurring or long-lasting infections, such as in the upper respiratory tract or slow healing of minor cuts and abrasions.

These symptoms are caused by a deficiency in normal, working white blood cells, meaning that the body can’t fight off infections.

People with ALL may also have some non-specific symptoms, including weight loss, loss of appetite and night sweats. Less common symptoms are caused by leukemia cells traveling throughout the body and collecting in various places, which can include the lymph nodes, or inside joints, inside the liver and spleen, the chest cavity, the thymus (a small organ in front of the windpipe) or the brain and spinal cord. Some of these less commonly seen symptoms include: lumps under the skin (swollen lymph nodes), bone



and joint pain, respiratory problems, such as trouble breathing or coughing, and neurologic problems, such as headaches, seizures, vomiting, and trouble with balance.

HOW IS ALL DIAGNOSED?

A diagnosis of leukemia is made through standardized tests that look for specific hallmarks of the disease, such as too many white cells in the blood, and not enough red blood cells or platelets. If you have ALL, most of the white blood cells in your blood will be immature lymphocytes called “blasts” that shouldn’t normally be in the blood. The definitive step in diagnosis is to determine that the bone marrow contains many of these immature cells.

Complete Blood Count (CBC) and Peripheral Blood Smear

The CBC measures the number of white blood cells, red blood cells and platelets. A peripheral smear looks at the appearance of the cells to help diagnose leukemia. These tests are performed by drawing a blood sample.

Bone Marrow Tests

Even though blood tests may suggest that you might have leukemia, looking at the cells inside your bone marrow is the only way to be certain. This

test will also identify what type of leukemia you have and certain characteristics of that particular leukemia, both of which will help determine how to best treat the disease.

To remove the bone marrow cells, a needle is inserted into a large bone, usually the back of the hip bone, to remove a sample of the marrow. Two different types of bone marrow samples are needed. If the sample is liquid bone marrow, the test is called a **bone marrow aspiration**. If the sample is a solid piece of bone and bone marrow, the test is a **bone marrow biopsy**. Both tests are typically done at the same time.

Bone marrow aspiration/biopsy can be uncomfortable for many people. Talk to your health care provider about whether you should receive medication before the procedure to make it easier for you to tolerate.

Additional Tests

Once you receive a diagnosis of ALL, your doctors will do a series of further tests to get more information about your particular disease and begin planning the best course of treatment.

- **Detailed testing** to look for any chromosome changes that can help



predict a patient's outcome and response to treatment.

- **Spinal Fluid Tests** to determine whether the leukemia has spread to the spinal cord and spaces around the brain. Samples are collected through a spinal tap (also known as a lumbar puncture).
- **Imaging** to look for infections or spread of leukemia beyond the blood and marrow to other organs.

MAIN FACTORS THAT AFFECT TREATMENT OPTIONS

Your prognosis once diagnosed with ALL depends on what type of ALL you have (the subtype), your age and some other characteristics that can be determined through lab tests.

Subsets of ALL

ALL can be divided into different groups, or subtypes based on:

- The type of lymphocyte (B cell or T cell) that the leukemia cells came from (refer to diagram in the Overview chapter)
- The DNA changes in the leukemia cells
- How mature the leukemia cells are

Each subtype of ALL has a different prognosis. The differences that determine why some people do better after treatment than others are known as prognostic factors. A lot of research has been done on identifying **prognostic factors** for ALL, and these results help doctors plan the type and amount of treatment they give to a patient.



QUESTIONS TO ASK ABOUT YOUR DIAGNOSIS:

What type of leukemia do I have? How was that determined?

Will more tests be needed to confirm the diagnosis? Are there any risks from these tests?
How soon will I know the results?

How much experience do you have treating this type of leukemia? How many of your patients have been around my age?

What are the results of the different tests? What do these results mean?

What factors might affect my outlook?

What resources are available in the hospital and the community to help me?

Are there brochures or other printed material that I can take with me? What websites do you recommend?

What happens next?



Treating Acute Lymphoblastic Leukemia

“As recently as the early 1960s, ALL was a fatal disease. There were no effective treatments and what was offered to patients was pain management and transfusions. It really is one of the biggest success stories in medicine the transition that now close to 90 percent of young patients with ALL can be cured from their disease, and the cure rates for older people with ALL are going up as well.”

—Patrick Brown, MD, Johns Hopkins University

Cancer doctors (oncologists) use a combination of drugs to kill ALL cells by targeting the fast-growing cancer cells. Some of the most complex chemotherapy combinations and treatment schedules used in the whole field of oncology are used to treat ALL.

The good news is that there has been great progress made in recent years in finding drug combinations to fight the different types of ALL, and most people do well with treatment.

The goal of treatment is to bring about complete **remission**: no more leukemia cells in your blood or bone marrow. This isn't the same as a cure, but it's a necessary step towards that goal. Long-term survival from ALL is considered to be complete remission that lasts at least five years.

The number of people achieving long-term survival is increasing every year.

MAKING A TREATMENT PLAN

Because of the acute nature of ALL, treatment usually begins as soon as possible after diagnosis. If time permits, you should try to get a second opinion. Having another perspective can help you understand what is happening and should help you feel more confident in making decisions about your treatment.

Soon after you are diagnosed, your health care team will begin discussing your options for treatment. Your options will be based on: what subtype of ALL you have, your age, your general level of health and whether it has spread to other parts of your body like the brain or spinal fluid.



In general, ALL treatment takes two years for females and three years for males. However, most of the therapy can be done as an outpatient, and the majority of the therapy is spent on a maintenance phase. A maintenance phase allows you to return to many of the things you did before your diagnosis. Your team will work with you to construct a treatment plan. It is helpful to be written as a calendar, mapping out each phase of therapy, what types of therapies you will receive, what responses you would expect to see and what the side effects may be.

“If you don’t understand a process or a name that your healthcare team has thrown out, the only way to gain understanding is to ask them to put [it] in laymen’s and relevant terms for you. There is nothing you can’t ask. This is your life and the life of your loved one so don’t feel like you are inconveniencing anyone by asking questions.”

—Felicia Hardaway, Caregiver

TREATMENT DECISION-MAKING

The Treatment Team

ALL needs to be treated by a whole team of professionals from a range

of specialties. Some of the team members may include:

- Hematologist-Oncologists
- Oncology Nurses
- Nurse Practitioners or Physician Assistants
- Social Workers
- Patient Navigators
- Case Managers
- Oncology Nutritionists
- Financial Advisors
- Patient Advocates
- Physical and Occupational Therapists
- Child-Life Specialists
- Psychiatrists, Psychologists, or other kinds of trained counselors
- Chaplains or other spiritual support

“I always tell my patients that it is a joint effort. We work together. We work as a team. You tell me what works for you and what doesn’t work for you. You need to speak up and make sure you have your voice heard.” — Van Huynh, MD, Children’s Hospital of Orange County



The Importance of a Caregiver

Caregivers are people who provide help to, or arrange help for, relatives or friends who are ill or disabled. Help can be physical, emotional, spiritual, financial, or logistical. Some caregivers may live with the person but others may not. Caring for someone who has a serious disease is not easy. People with cancer and the people who care about them face many problems and challenges. Coping with these issues can be easier with information and support.

Caregiving can be a full-time job itself. Caring for someone with cancer can lead to work-related issues such as missed days, low productivity, and work interruptions. Some caregivers need to take unpaid leave, turn down promotions or lose work benefits. The stress of caring for someone on top of worrying about keeping your job can be overwhelming. Dealing with these issues is important to both employers and employees.

Caregivers are often so focused on taking care of their loved ones that they neglect their own mental, emotional and physical health. That is why caregiver support groups are a vital resource to assist caregivers. Caregivers often face numerous issues,

including struggling to maintain a normal life. In addition, caregivers may feel depressed at times. In-person and online support groups are a great place for people to share concerns and obtain help, and may help caregivers feel less alone.

“It is hard to imagine a young adult going through ALL without at least one solid caregiver, if not a whole group to be there to assist. It doesn’t matter how independent you are, when you are fatigued and have chemo-brain, you need somebody there.”
—Meghan Fitzgibbons, MSW,
Patient Navigator for the Ulman
Cancer Fund for Young Adults



HONESTY IS THE BEST POLICY

To ensure that your care is the best it can be, you have to be honest with your treatment team. That includes awkward topics such as drug use (legal or otherwise) and sexual practices. For example, using marijuana can increase your risk of developing a fatal fungal infection. If you are sexually active, it is important to use a barrier contraceptive to protect your partner. It is also important to disclose whether you are sticking to your treatment regimen. If you have trouble obtaining medications or taking them as prescribed, talk to your treatment team about options.

“We are not here to judge you; we just want to give you the best care we can. We just ask that you be honest with us. Some of the things you take and do can really affect your treatment.”

—Van Huynh, MD, Children’s Hospital of Orange County





In August of 2010, Kristin Clan Hopper was diagnosed with Acute Lymphoblastic Leukemia. Her initial journey with treatment evolved over the next 4 years and then her cancer relapsed in 2014. Having exhausted all standard treatment protocols, her medical team began to seek clinical trial options available for her and Kristin was enrolled in her first clinical trial using a combination of chemotherapies. This was when her oncologist informed her about CAR-T (Chimeric Antigen Receptor T) cell therapy as another clinical trial option. There was little information for her to read and learn about CAR-T cell therapy in 2014, but with limited options left for Kristin, the prospect of a novel treatment was exciting for her. “It made so much sense using your own immune system to fight cancer, as clearly, my body was building up a resistance to the chemotherapies and I was being left with very toxic side effects, many of which I still have today.”

For Benny Juarez, Kristin’s caregiver, he shared her excitement at the prospect of another treatment that could bring hope after all other treatments had failed. CAR-T cell therapy treatment is intense and requires a strong commitment from both the patient and caregiver. For Benny, he knew the commitment he needed to make. “You need to be there 24/7 when the patient

is going through treatment, so for myself I did have to put my career on hold.” He also knew that communication with the medical team was incredibly important. “There’s so much being thrown at you at once, so it’s important to take a notebook and take detailed notes. It’s important to reach out to the medical team, explain side effects that you might have written down, because something very small could be very, very important to them. And don’t be afraid to ask questions.”

Benny knew that caring for Kristin was his primary focus, but he also knew that there would be an impact on him. “As a caregiver, it’s a long road and a long journey, and it’s not very easy. Hearing about the treatment and the side effects and actually being there when these are happening, it’s challenging. So it’s important to reach out to your network, communicate with your friends and family when you’re having a hard time, and take care of yourself. I remember there were times I would spend weeks in the hospital and going outside and breathing fresh air, well it’s rejuvenating and clears your head for the next journey.” Today there is a lot of information available to prepare patients and families for CAR-T cell therapy.

“People have been through this before, people understand what you’re talking about and they’ll be able to give you advice and suggestions on how to cope and manage the stress associated with the treatments.”

Kristin’s sister had bracelets made that said “Choose Hope.” Benny has been wearing one since 2014. “I don’t know why. I just haven’t really taken it off. It’s a part of me now.” Together, Kristin and Benny chose hope.

How is ALL Treated?

Patients do better when we stay on track with their care plan. The more you ask questions, understand your illness and treatments, and follow the team’s instructions, the better things will go.”

—Thomas LeBlanc, MD, Duke University

In general, the initial ALL treatment is intense for the first six to eight months, followed by a prolonged period of lower-intensity maintenance treatment. Overall, the average ALL patient needs to be treated between two and three years, with most of that time in maintenance. The main treatment is chemotherapy, which uses medicines or drugs to kill leukemia cells. Other supportive treatment you might need includes biological therapy, blood transfusions, platelet transfusions, radiation therapy, steroids, and antibiotics.

Recent research has shown that AYAs (aged 15 to 39) could tolerate and have optimal outcomes using the same intensive strategy that has been used in children. So even though you may be treated by an adult doctor (a hematologist-oncologist), you likely will be treated with what is called a “pediatric protocol,” which is a higher intensity regimen than the adult protocol.

PHASE 1: REMISSION INDUCTION—GETTING RID OF ALMOST ALL THE CANCEROUS CELLS

The aim of the first phase of treatment is destruction of all leukemia cells. You are considered to be in complete remission when there are no more leukemia cells easily seen in the bone marrow (less than five percent of the cells are the immature cells, or “blasts”) and you have no symptoms of the disease. You will probably need to stay in the hospital for about two or three weeks for this stage of treatment.

The pediatric protocol calls for a combination of drugs, which will be either in a pill, given as a shot under the skin or into a muscle, or injected directly into a vein through a central catheter (a tube inserted into a blood vessel in the chest). Examples of central catheters are Hickmans and Port-a-Caths. The typical induction regimen includes multiple drugs, some of which are chemotherapy, while others work



through different actions. Your doctor will decide which drug or drugs will work best for you.

You might also receive drugs delivered into your cerebrospinal fluid, the fluid that surrounds the brain and spinal cord. This type of drug delivery is called intrathecal chemotherapy. If you also have disease in your central nervous system, you may also get radiation to the brain and/or spine, which uses x-rays or other high-energy beams to kill leukemia cells. Even if there is no leukemia detected in the spinal fluid, it is still important to give intrathecal chemotherapy to reduce the risk of having a relapse there later.

SPECIAL CASES

- **Males.** ALL cells can hide in the testicles, which makes it harder to eliminate completely from the body. For this reason, the pediatric protocol currently calls for males to have one additional year of therapy. This may change in the near future, as researchers are investigating whether that extra year is necessary.
- The **Philadelphia chromosome** is a specific finding in the genes of the patient's white blood cells. The presence or absence of this

chromosome is a major factor for your doctor to determine your treatment plan. If your ALL has the Philadelphia chromosome (often abbreviated to Ph+), you may be given biological therapy in addition to chemotherapy.

PHASE 1B (IF NECESSARY): RETREATMENT

If you are not in remission after initial treatment, you will need more chemotherapy. Your doctor may decide to use a different combination of drugs than the first round, or to intensify and/or prolong the initial treatment.

PHASE 2: CONSOLIDATION THERAPY— MAKING SURE ALL DOES NOT RETURN

Once you are in remission, you will still need more treatment to ensure that the cancer doesn't come back. Leukemia cells could still be hiding in very low numbers somewhere in your body and ALL could return without further treatment. This phase usually lasts for a few months.

In the consolidation phase of treatment, you may have:

- More chemotherapy—often the same drugs as used for induction.



- A stem cell transplant from a donor or, rarely, from your own blood-forming stem cells. This treatment, also known as a bone marrow transplant, replaces your diseased cells in your bone marrow with healthy blood stem cells.

PHASE 3: MAINTENANCE THERAPY—KEEPING ALL AWAY

This is the longest phase of treatment, designed to keep your leukemia in remission. In maintenance, you will usually be given low dose chemotherapy and short courses of steroids for up to 2 years.

PHASE 4 (IF NECESSARY): TREATMENT RESISTANCE/RELAPSE—TREATING ALL THAT DIDN'T FULLY GO AWAY OR RETURNS

Sometimes leukemia cells will still be in the blood even after a full course of treatment. If your leukemia comes back after remission, it is called a relapse.

In relapse, your doctor will discuss the options available to you. You might need to receive more chemotherapy, either the same or different drugs.

You might be a candidate for newer approved or investigational drugs, a clinical trial, or a bone marrow or stem cell transplant. Treatment of relapsed and resistant ALL is often more

intensive than for newly diagnosed disease. However there are a number of newer targeted therapy options that are less toxic or have different toxicities than chemotherapy which may be used to treat relapse.

Immunotherapy treatment uses the patient's own immune system to see and help kill cancer cells. There are currently a number of approved immunotherapy options available for consideration. These newer options are not for every ALL patient and discussion with your oncologist will help determine if any are the best choice for your treatment plan.

Scientists have identified mutations in genes that predict a high likelihood of relapse, which can help doctors tailor treatment intensity appropriately. In general, 80% to 90% of adults will achieve complete remission, but around half of them relapse. The cure rates vary with subtype of ALL and other factors. Relapse rates tend to be higher the older the person is at time of diagnosis.

MEASURABLE RESIDUAL DISEASE (MRD) TESTING FOR ALL

Checking for measurable residual disease (MRD) is part of routine testing for both adults and children living with ALL. MRD refers to the small number of cancer cells that remain in your body during and



after cancer treatment. It is sometimes called minimal residual disease.

MRD testing is so sensitive that it can find 1 cancer cell in 100,000 healthy cells. It may even be able to detect 1 cancer cell in 1 million healthy white blood cells. Other lab tests may not detect these cancer cells that remain after treatment, and you may not show any signs or symptoms of cancer.

BENEFITS OF MRD TESTING

Knowing your MRD levels helps your doctor determine how well your treatment for ALL is working. It helps predict the risk of your cancer returning. Checking for MRD can also help confirm and monitor remission. Knowing how much MRD is present in your body allows treatment to be tailored to your unique needs. This gives you the best chance of achieving complete remission.

UNDERSTANDING MRD RESULTS

Testing for MRD tells your doctor whether there are cancer cells remaining in your body. MRD-negative means that there are no traces of detectable cancer left. People who are MRD-negative may live longer without disease than those who are MRD-positive. Although testing negative for MRD is the goal, it is

possible to test MRD-negative but still have your ALL return.

MRD-positive means that some cancer cells are still present. If you test MRD-positive, your health care team may suggest consolidation treatment. This uses immunotherapy or chemotherapy to remove the remaining leukemia cells. MRD results may also show whether you'd benefit from stem cell transplant.

TESTING TIMELINES

The timing of MRD testing depends on your unique situation. For example, your doctor may recommend MRD testing:

- After the final cycle of a planned combination therapy
- After stem cell transplant
- During treatment to confirm the depth of remission
- At the 1-year point of maintenance therapy
- At regular intervals after treatment is completed

You may need more than one MRD test, so be sure to ask that your blood or bone marrow be sent to the same lab that handled your previous MRD tests. Using the same lab will help you and your care team make accurate comparisons about your MRD status over time.



QUESTIONS TO ASK ABOUT MRD TESTING

- Why do I need to have an MRD test? How was that determined?
- When and how often should I have an MRD test?
- What does an MRD-positive or an MRD-negative test result mean for me?
- How will MRD results affect my treatment plan?
- What types of MRD tests are available to assess my ALL? How do they vary in sensitivity and accuracy?
- How much does MRD testing cost, and is it covered by my insurance? Is financial assistance available?
- Are there brochures or other printed materials about MRD testing that I can take with me? What websites do you recommend?
- What happens next?

FACTS ABOUT TESTING FOR MRD

- MRD testing is standard for pediatric and adult patients living with ALL.
 - MRD can predict effectiveness of your treatment after the induction phase of ALL treatment.
 - MRD testing requires blood or bone marrow samples.
 - A local or general anesthetic will be given if your test requires a bone marrow sample.
 - There are 3 techniques available to determine your MRD status. These highly sensitive techniques are:
 1. Flow cytometry
 2. Polymerase chain reaction (PCR)
 3. Next-generation sequencing (NGS)
- Flow cytometry checks for abnormal proteins. PCR and NGS identify cancer cells based on genetic mutations.
- MRD test results take between 1 day to several weeks depending on the technique used.
 - MRD testing shows either a negative result (no measurable cancer cells found) or positive result (cancer cells are present).
 - MRD test results guide the future course of treatment.



CAR T CELL THERAPY

Approved by the Food and Drug Administration (FDA) in 2017, CAR T Cell therapy is one way to use the body's natural defenses to fight cancer. It is called CAR T Cell therapy because a lab-made protein, called a chimeric antigen receptor (CAR), is added to the patient's own T cells, which are a type of white blood cell. The CAR protein helps the T cells target cancer cells to be killed and helps train your immune system to attack the cancer. Now more than 150 centers in the U.S. offer CAR T cell therapy treatment

for ALL. Your oncologist may not be part of a cancer center that offers this option and may need to refer you to a center that does. CAR T cell therapy is designed to be a one-time treatment. It is a complex treatment option and will require a caregiver to be with you 24 hours a day, 7 days a week (24/7), for 4-8 weeks. Thorough discussion with your oncologist will guide you in your decision to pursue CAR T cell therapy. For more detailed explanation regarding CAR T cell therapy refer to *CAR T Patient And Caregiver Guide* at www.CancerSupportCommunity.org/CARTGuide

CLINICAL TRIALS

Researchers and doctors are always looking for new treatments for cancer and new ways to combine existing treatments. New therapies are tested in clinical trials that determine whether these new treatments and interventions are safe and effective for the prevention, diagnosis, or treatment of cancer.

The clinical trial process is required before the Food and Drug Administration (FDA) approves a new treatment. There are currently thousands of trials going on all over the world. Each study has specific conditions a person must meet to participate. Participation is always

voluntary and participants may choose to leave the study at any time.

The resources below can help you find clinical trials, and you and your doctor can talk about if one is right for you:

Cancer Support Community
www.CancerSupportCommunity.org/ClinicalTrials

Cancer.net
www.cancer.net/research-and-advocacy/clinical-trials

Leukemia and Lymphoma Society
www.lls.org/treatment/types-of-treatment/clinical-trials

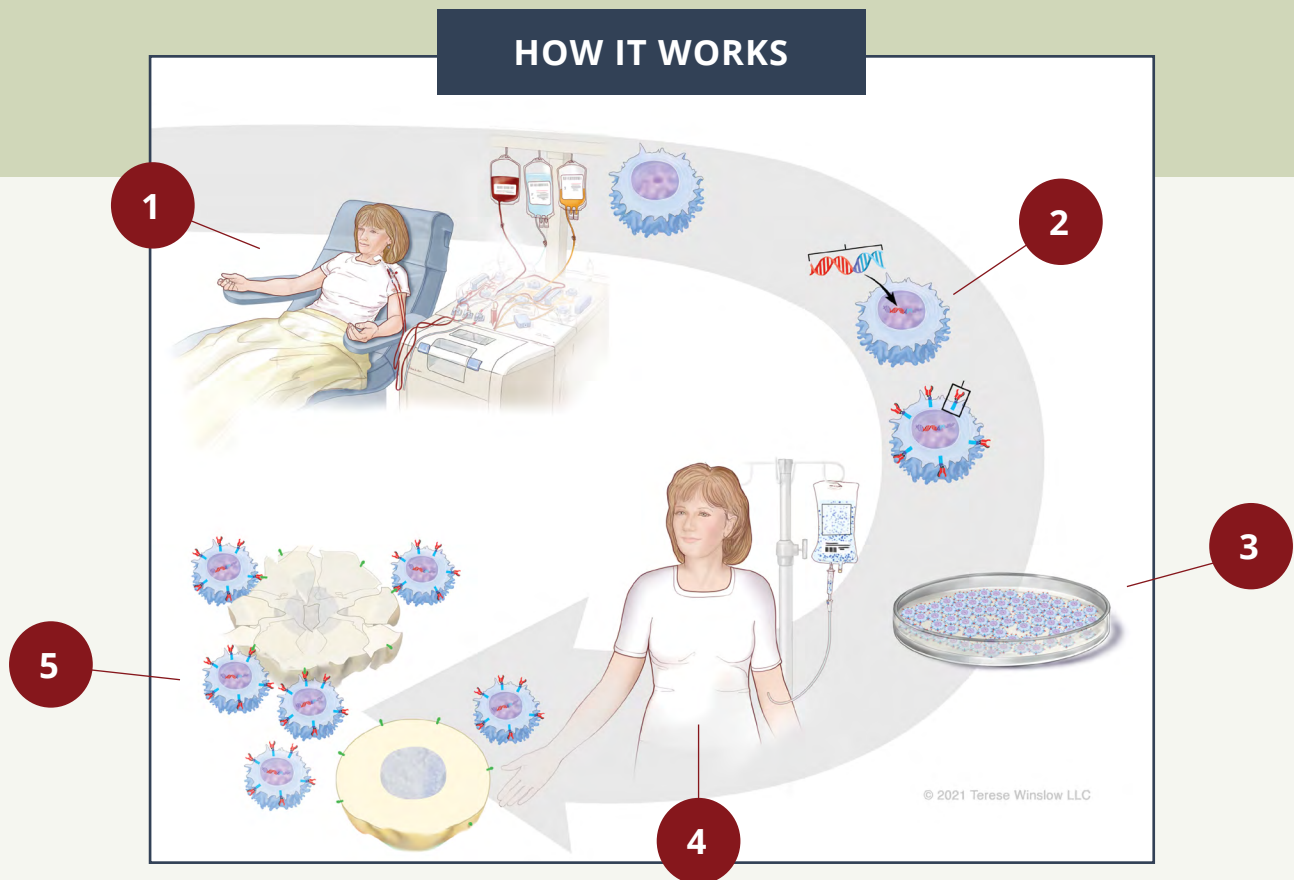
National Cancer Institute
www.cancer.gov/about-cancer/treatment/clinical-trials



What is CAR T Cell Therapy?

CAR T cell therapy, or chimeric antigen receptor T cell therapy, is one way to use the body's natural defenses to fight cancer. It is called CAR T cell therapy because a lab-made protein in a CAR protein is added into the patient's own T cells. The CAR protein helps T cells target cancer cells to be killed.

Each patient's CAR T cell infusion process is personalized, created from their own cells. CAR T cell therapy is designed to be a one-time treatment. CAR T cells can remain in the body and continue to be active for a long period of time. Some patients who have responded to CAR T cell therapy remain in remission after several years.



1. Blood is removed from the patient to get the T cells T cells are collected from your bloodstream in a procedure called apheresis and sent to the lab. The T cells may be frozen and kept in a special temperature-controlled storage unit until you are ready to receive treatment.

2. CAR T cells are made in the lab CAR proteins, which act like cancer-cell tracking devices, are then added to your T cells. Now your T cells are CAR T cells.

3. Millions of CAR T cells are grown The new CAR T cells continue to grow in the lab until there is enough for your treatment.

4. CAR T cells are infused into the patient Once the CAR T cells are ready, they are infused back into your bloodstream. You may get a brief course of chemotherapy (referred to as conditioning chemotherapy) before getting the CAR T cell infusion. This is done to destroy regular T cells and give the CAR T cells more room to operate.

5. CAR T cells bind to cancer cells and kill them Once the CAR T cells are back in your bloodstream, they attack your cancer.

TESTICULAR RELAPSE

For men and boys with ALL, there is a risk that leukemia cells can spread to the testicles. If you have any swelling or lumps in your testicles, you must let your doctor know immediately. If the cancer has returned in the testicles, you will require more treatment, either chemotherapy or radiation therapy.

FOLLOW-UP

It is important to follow up with your oncologist on a schedule. This will probably be monthly for the first year, with less frequent appointments as you move further out from completing of your treatment. Your doctor will do tests to look for any signs of leukemia or long-term side effects, which can possibly last for the rest of your life. Be sure to mention any changes you have noticed. Ask your oncologist what symptoms to be on the lookout for. If

symptoms occur, report them promptly.

Questions to ask about follow-up:

- How long will it take me to recover from my treatment?
- Are my treatment-related side effects permanent?
- When will I be able to go back to work?
- When can I take up my usual sports, hobbies, and activities again?

“I always remind my patients that everyone is different. The percentages given for cures are just predictions, based on age, some genetics of the cancer cells (some variations are actually more favorable) and how patients respond to cancer therapy.

—Van Huynh, MD, Children’s Hospital of Orange County

RISK STRATIFICATION

There are now predictors that tell doctors how likely a patient’s disease is to relapse. That information is sometimes used to dial up or dial down the intensity of the chemotherapy a person receives. For low-risk patients, the first few months of intensive chemotherapy are not that intense at all. Some people do not need to be hospitalized and their treatment can be given as outpatient. For high-risk patients, their first few months of chemotherapy are intensive enough to require admission to the hospital for treatment due to the monitoring that is required and the side effects they experience. Intermediate-risk patients fall in between these low and high-risk extremes.



QUESTIONS TO ASK ABOUT TREATMENT:

What are my treatment options?

What are the side effects of treatment?

What treatment plan do you recommend? Why? Is a pediatric or adult protocol better for me? Can you provide me with more information on the research that supports this treatment plan?

What is the goal of each treatment you recommend? What are the risks and benefits of each?

Does this hospital (or center) offer the best treatment for me?

Are there other doctors I need to see? Is there time for a second opinion? If so, can you suggest someone?

What clinical trials would be available for me? How do I find out more about them?

How soon do we need to start treatment?

How long will treatment last? Where will it be done?

What do you expect the treatment to achieve? How will we know whether the treatment is working?

Who will be part of my health care team, and what does each member do? Who will be coordinating the overall treatment?

What can I do to protect myself from infection during and after treatment?

Are there any particular activities I should do—or avoid—to take care of myself while on this treatment?

When should I call the doctor or hospital if there is a problem while at home?

What symptoms should I look out for while being treated?

What is my prognosis?

What are the chances that my leukemia will come back after I have been treated?
What will we do if the treatment doesn't work or if the leukemia comes back?

How much will the treatment cost? How can I find out how much my insurance company will cover?
Who can help me with financial concerns?

Where can I get help dealing with my feelings?

Are there supportive services or support groups that I can get involved in to help me through the treatment process?

Does the cancer center or hospital provide counseling services? Are they free or is there a fee?

How do I get practical help at home?

Is there transportation to take me to doctor or hospital appointments if I need it?

Who can advise me on money matters or help with insurance benefit claims?

Can this therapy affect my fertility?

Will my sex life be affected?



Clarissa Schilstra doesn't remember the first time she was diagnosed with ALL. She was two years old. She went through two and a half years of chemotherapy and was in remission until June of 2007 when a broken subway escalator on her 13th birthday trip to New York City revealed that she couldn't keep up with her friends and family when climbing the stairs, finding herself out of breath and exhausted far more easily than usual. A doctor's visit determined that she had relapsed, and she began another two and a half years of chemotherapy.

A major challenge as a teen with cancer was finding other young people experiencing what she was going through. Clarissa found peers through a week-long camp for cancer patients and survivors sponsored by Johns Hopkins Hospital. "It was an incredible experience because it was the first time I was around a group of people who understood what it was like to be living the life I was living," she says. "We are dealing with different things than children or adults are."

She was a camper there for three summers and trained to be a counselor, which she did for two summers after that.

Realizing the importance of the experience of peer support, Clarissa started writing a blog for teens and young adults with cancer and published a book about it: *Riding the Cancer Coaster: Survival Guide for Teens and Young Adults* (which you can learn more about on her website www.teen-cancer.com). Her goal was to help readers understand aspects of cancer and its treatment that aren't often discussed, such as how going through cancer affects friends and family and the social challenges of being away from school. "Writing about my experiences and processing my treatment through writing was really helpful in my efforts to reflect on it all and learn from the challenges," she says.

Clarissa is now focused on trying to address some of the social and emotional challenges she experienced as a young person with cancer, through her research as a PhD Candidate at the University of New South Wales, in Sydney, Australia. Her research aims to better understand the ways in which cancer treatment affects teenagers' and young adults' social well-being. She also hopes to find ways to better support young people's social and emotional needs from diagnosis through survivorship.

"Focusing on how I can try to have a positive impact on the cancer treatment and survivorship experiences of other young people with cancer has given me a sense of empowerment and purpose, which has helped me to cope with my own experiences, such as the late effects I have experienced over time."

Managing Side Effects of ALL Treatment

“Your life after ALL diagnosis is going to be different. You will probably experience some side effects, but there will be a health care team that will support you through all of them. Eventually you can go back to school or work and you start to have a new ‘normal.’”

—Van Huynh, MD, Children’s Hospital of Orange County

Most cancer treatment is aimed at killing fast-growing cancer cells. But because most drugs are not specific to cancer cells, they can affect any cells in your body that grow quickly. The unwanted damage to healthy cells is what causes side effects.

Side effects are unpredictable. Different types of treatments and dosages can cause varying side effects. The level of side effects you might experience will also depend on your individual body, your general health, and your age. Some side effects can appear almost as soon as treatment begins, and others can appear months or even years later.

The good news is that research is continuing to uncover ways to lessen side effects, and people who are treated for ALL now are less likely to have long-term effects than people treated in the past. It is also important to remember that many cancer treatments will

decrease symptoms caused by ALL—so you may feel better and your quality of life may actually improve during treatment.

The immediate side effects that come while you are having treatment for ALL, or soon after you complete it, may include:

- From reduced red blood cell counts, known as **anemia**: tiredness (fatigue), dizziness, weakness, headaches, pale coloring
- From low platelet counts, known as **thrombocytopenia**: easy bruising, unexplained bleeding, small red or purple spots on the skin, known as **petechiae**
- From decreased white blood cell counts, known as **neutropenia**: increased risk of infection, especially respiratory, bladder, blood (known as sepsis) and around the eyes, nose,



mouth, genital and rectal areas and catheter sites

- From damage to hair follicles: hair loss, known as **alopecia**, ranging from thinning to complete loss (while most often associated with hair on the scalp, all body hair can be affected)
- From damage to gastrointestinal tract: mouth and throat sores, dry mouth or changes in taste, loss of appetite, nausea and vomiting, diarrhea or constipation
- From nerve damage, known as **peripheral neuropathy**: numbness, tingling, burning sensations, discomfort or weakness in hands or feet
- From damage to the reproductive system: women's periods usually stop and men may stop producing sperm. Sometimes there is permanent infertility as a result of treatment. For females, you should discuss with your doctor whether you should consider ovarian suppression with or without egg preservation. For males, you should discuss whether you should consider sperm banking. These decisions should be made before starting treatment.

Most of these side effects go away soon

after treatment is finished. If serious side effects occur during treatment, that type of chemotherapy may have to be reduced or switched to another drug.

Just because a side effect is common does not mean it is guaranteed to occur. Most people undergoing ALL treatment do not experience all of these side effects, and the ones they do may be mild. The most important thing you can do is to let your health care team know when you experience side effects, as there are many treatments available to lessen side effects. Some of these options include:

- Drugs to prevent nausea and vomiting
- Drugs or transfusions to increase the numbers of platelets and red blood cells
- Antibiotics to prevent an infection or prevent it from becoming a serious infection
- Drugs that help the body eliminate the contents of killed tumor cells that can spill into the blood and cause further side effects
- Drugs for pain and discomfort
- Self-care techniques to prevent or decrease severity of mouth sores, skin breakdown, infections and fatigue





Twenty-six year old Brendan McGeown spent most of his adolescence being treated for ALL and what he learned is that staying upbeat can go a long way to making the experience better. He was 14 when signs and symptoms of fatigue, bruising, and paleness went unnoticed for quite some time. It wasn't until he had what felt like flu-like symptoms did he visit a doctor and have blood work that revealed a diagnosis of ALL.

He began treatment in February 2009 and relapsed soon after finishing treatment, in July 2012. After another three years, he finished treatment in January 2015. Although Brendan experienced side effects from chemotherapy and a number of infections, he says "completing treatment was a marathon of mental endurance just as much as it was physical".

"I still attribute taking the journey day by day to being able to stay positive and conquer the small achievements along the way."

A key release from all he was going through was heading to the beach to take photos. "There, I didn't have to worry about treatment, relapse, school, or

anything like that. It was just a complete break from stress," he says. During his treatment he tried to stay engaged and understand what was going on with his care. He constantly asked questions of the nurses, seeking to learn more. "I feel fortunate to have been under the care of such a caring team of nurses and physicians. I always felt that because I received such amazing care, I wanted to try to provide that for other patients and/or families who are going through similar circumstances."

In 2017 Brendan became a nursing assistant for the Hematology/Oncology department, on the very unit where he received care, the same unit where he works today after completing his Bachelor of Science in Nursing degree. "Being part of the unit where I was treated is an amazing feeling. I have encountered situations where sharing my story has been used as a source of strength and to let patients know they are not alone."

Now living in Tustin, Calif., Brendan married his number one source of support in nursing school, Selyna, in March 2021. He still goes in for regular check ups but doesn't focus on his diagnosis. "On a daily basis, I try not to let the idea of relapse enter my mind, and I try not to introduce excess worry into my life. I feel living without that fear allows me to live a less stressful life and always keep a positive outlook."

And although he doesn't have quite the time for photography as he once did, when the opportunity arises, he takes advantages for a photo day trip. "Photography is still a creative outlet for me that allows peace and freedom from worry."

“I don’t think I realized that my treatments may have impacted the internal structures of my body in a way that I can’t see and that it might manifest in various new problems as I get older, like lower back problems or requiring extra time on tests. You must remain informed and active in your care as a survivor—get regular physical exams through a primary care provider, have an annual visit with a long-term survivorship specialist, and most importantly, to listen to your body—to ensure your long-term wellbeing.” —Clarissa Schilstra, two-time ALL survivor

LONG-TERM SIDE EFFECTS

ALL requires a very long treatment regimen, with strong chemotherapy drugs that can leave lasting effects for many years, even for the rest of your life. These long-term side effects can show up months or years after your treatment has finished. Most long-term survivors don’t have serious late effects, but it is important to catch any problems early to be able to treat them.

Here are some of the more common long-term side effects seen after treatment for ALL. Your risk of developing any of them depends on many factors, especially the specific treatment that you receive. You and your doctor should discuss the possibility of these occurring, what to look out for and if anything can be done to prevent them. After treatment, follow-up is critical to be able to catch any of these late effects and to figure out ways to help you.

Learning problems. This is especially common if you receive radiation therapy or intrathecal chemotherapy into your spine. These therapies kill leukemia in your central nervous system, but can also cause problems to the brain, such as Attention Deficit Disorder, Attention Deficit and Hyperactivity Disorder or general academic difficulties. People who experience this do not have any reduction in their IQs, but are slower at processing information. If it is suspected that you suffer from this problem, a neuropsychiatric evaluation is usually the next step, and possibly meeting with a psychologist. There are several things that can be done to address these learning abilities, including developing an Individual Education Plan (I.E.P.) to make up for this deficit if you are still in school. An I.E.P. allows you to get certain accommodations in work or school.



Bone and joint problems. Steroids are a common part of leukemia treatment, but they can lead to damaged bones and joints or osteoporosis (thinning of the bones). Mild to moderate osteoporosis can be treated with medication and exercise, but if severe bone or joint problems occur, you may need to stop steroid use and be referred to an orthopedic surgeon.

Heart problems. Certain chemotherapy drugs can sometimes cause heart problems. Your doctor will likely have you undergo an echocardiogram, a simple and painless test to check heart function, before beginning therapy. This makes it easy to see if there is any decreased function after therapy. Your doctor may arrange for a consultation with a cardiologist, a doctor who specializes in care of the

heart. After therapy, you may have a follow-up echocardiogram to assess heart function, as the cardiotoxic effects of some chemotherapy may not be seen until several years after treatment.

Another cancer. Around 5% of people receiving certain chemotherapies will have an increased risk of developing acute myelogenous leukemia (AML) later in their lives. Even less frequently, some people who have been cured with ALL therapy will develop non-Hodgkin's lymphoma or other cancers. Discuss this with your health care team so you can better understand what this means for you.

Infertility. Some chemotherapy drugs, radiation therapy to certain parts of your body or a stem cell transplant can increase your risk of becoming infertile.

“I took steroids on and off over a six year period. I had been told of potential issues caused by steroids, but never thought that it could happen to me. While working through my second year of treatment for my relapse, tests showed that I had avascular necrosis, or dead bone tissue caused by a lack of blood flow. My left hip was to a point where I would end up needing a total hip replacement. My right hip was caught at an early enough stage that there were other options. Being at a young age, hip replacement is a difficult option because it will affect your activity level going forward, so early detection is key to maintaining other options.” —Brendan McGeown, two-time ALL survivor



CARING FOR YOUR SKIN

Sometimes treatment for ALL can lead to side effects that affect your skin. Some people can experience rashes and skin breakdown as well as sores in the mouth and the buttocks that can result in serious infections, if not treated early. It can be awkward to let someone examine the private and sensitive areas of your body, but skin checks are important. It is vital to pay attention to your skin and let your health care team know right away if you experience any changes.

HAIR LOSS

Most chemotherapy (and radiation to the head) can cause you to lose hair. It is not a guarantee, though. Some people only experience thinning. Keep in mind that the hair loss is temporary. Your hair will grow back after eight to nine months when you are on maintenance therapy. It may be slightly different—in texture or color—than it was before. There are a few options to think about when dealing with hair loss:

- First, consider cutting your hair short before it falls out, which will make thinning and hair loss less noticeable and may make the transition to having no hair easier.
- Consider shaving your head, which will eliminate shedding and patchy hair loss. It can also make your scalp feel less itchy and irritated.
- You will want to protect your scalp from sun and keep your head warm when your hair thins or falls out. Think about getting some hats and scarves.
- If you want to look into getting a wig, have your doctor write a prescription for a cranial prosthesis, which may be covered by your health insurance.



QUESTIONS TO ASK ABOUT SIDE EFFECTS:

What are the possible side effects of this treatment, both in the short term and the long term? How long will they last? Is there anything that can be done to reduce them? Are there any complementary therapies that may help me cope with cancer treatment?

When should I contact my doctor about my side effects? Who specifically should I contact?

Could this treatment affect my ability to become pregnant or have children in the future? If so, should I talk with a fertility specialist before treatment begins? Is there even time to do this?

(For females): Should I consider ovarian suppression, and potentially preserving or freezing my eggs?

(For males) Should I consider sperm banking?

Will I have any hair loss? If so, when will my hair grow back? Who can I speak to about getting a wig if I want one?

“I received two weeks of radiation therapy, which I was told wouldn’t make me sick at all but made me sicker than my heaviest chemotherapy. It was an example of how treatment can affect people differently and how even if your doctors tell you that you are going to end up feeling one way, you could feel less or more. Being prepared for that can help a lot.” —Clarissa Schilstra, two-time ALL survivor



FERTILITY

There are an increasing number of options available to address the risks to fertility for many of the therapies that would be given to someone with ALL:

- Men and boys after puberty can bank sperm that can be frozen and cryopreserved so that if they do have fertility issues later, there are options available for artificial insemination and in vitro fertilization.
- Women and girls after puberty can take medications that suppress the menstrual cycle during treatment, which can potentially be protective of fertility. More procedures are becoming available where patients can have pieces of their ovaries removed and have eggs frozen for use later.

Although these options are available, in general, they can be quite costly (more so for females), and it may not be covered by insurance. However, there are financial assistance programs that can help with the cost (more details about this in the next section).

A complication for decision-making is that there is such a small window of time between being diagnosed with ALL and needing to begin treatment. It can become an ethical dilemma, especially for women: “would I rather go through fertility preservation processes, delaying treatment when I know it really needs to start as soon as possible for the best chance at success?” Only you can decide the right choice for you, based on your risks.



Coping with ALL

“It is crucial to have a support person along with you to hear the information being discussed. When you are hearing tough information on your own you don’t hear everything that is being said, and often one person hears something differently than the other.”

—Cara Kramer, Pediatric Oncology RN, The Johns Hopkins Hospital

BEING EMPOWERED

Facing a cancer diagnosis at any age is understandably a shock. A cancer diagnosis can be difficult to cope with, both from a practical and an emotional standpoint. Especially with ALL, you may have become ill suddenly and have to start making decisions right away about a very long treatment process.

It is normal to feel confused, scared and overwhelmed. In addition to the rollercoaster ride of emotions you may experience and the physical limitations caused by fatigue or pain, there are a number of practical issues you will have to figure out. You may have to sort out how to pay for treatment, who you tell about your condition and how much to tell.

This section contains tips about things you can do to make the cancer diagnosis and treatment process smoother, and point you in the right direction for assistance for many of the issues that are

going to come up. Just remember you don’t need to sort everything out at once. And there are people who can help you every step of the way.

LINE UP YOUR CAREGIVER

The first thing to consider is enlisting someone to help you keep everything straight and to help with logistics, such as transportation to get to appointments. The primary caregiver for young adults tends to be a parent or a spouse, but it could be anyone who is dedicated to supporting you emotionally and helping you stay on task with all the things you have to manage.

You may find that your caregiver wants to do everything for you. This is a delicate balance, but for you to maintain strength through treatment and recovery, you need to do as much as you can for yourself every day. You will have to learn to say politely, “Thank you, but no thank you, I need to do that for myself.” It is critical to your recovery that you play an active role.



PROFESSIONAL HELP

If you have been assigned a patient navigator (sometimes called a nurse navigator), use them as much as possible! If you haven't been assigned one, ask your health care team to help you get one. Patient navigators are people dedicated to helping guide people through the complex health care system and they are an incredibly valuable resource for you and your family.

They come from many different backgrounds, and there is almost no limit to what a patient navigator can assist you and your family with, but some of them include:

- Explaining medical care and treatment options
- Communicating with the health care team
- Accompanying patients to appointments
- Aiding caregivers
- Helping with insurance issues
- Managing medical paperwork

Cancer centers must now provide patient navigation services. If you are being treated in a place that does not provide one, call the CSC's Cancer Support Helpline at 1-888-793-9355. The Helpline is staffed by community navigators, resource specialists, and

Helpline counselors. You can also live chat with a Helpline Counselor at www.CancerSupportCommunity.org/Helpline

LEARN ABOUT ALL

It is important to be well-informed with the correct information about ALL so that you can make good decisions about your treatment and recovery.

We include a number of reputable sources of information in the Resources section.

Of course, you will likely go to the internet to search for information about your condition. Just be careful of how you interpret what you find. The field of ALL research and treatment moves very quickly, so anything more than a couple years old will almost certainly be outdated. When you find information on the internet, here are some things to keep in mind:

- Check the date
- Stay with credible organizations (we provide many in the Resource section)
- Most importantly, discuss what you find with your health care team

COMMUNICATE

Good, open communication with your health care team is critical to your treatment and recovery. If you are a



young adult, you may have to stand up for yourself and make sure your opinions are heard.

Many times caregivers, who are often also parents, fall back into the role of wanting to shield their children from any harm and can launch into overprotective mode. Understand that it comes from a place of love, but you are an independent person who will make decisions about how you handle your health yourself.

“We encourage all of our patients to educate themselves, and if they are looking online to consider what they are looking at: when people post, they usually are posting their really good experiences and really bad experiences. You are not seeing 90 percent of what is out there; you are only seeing a small percent of the worst and best cases.” —Cara Kramer, Pediatric Oncology RN, The Johns Hopkins Hospital

As emphasized throughout the other sections:

- Don't be afraid to ask questions or let your team know if you are experiencing side effects or struggling with the emotional impact of your cancer.
- Make a list before your appointment of the issues you want to discuss.

- Take someone with you to your appointments to help listen and respond to what happens.

TALKING TO OTHERS

After a cancer diagnosis, your friends and family naturally want to help. The problem is, most of the time they don't really know how best to help. Sometimes even huge support networks can fade away over time, which can be hard because you will need support throughout the months and years of treatment and recovery. Alternatively, you may have people around you who might have the best of intentions, but who are really uncomfortable with the topic of cancer, so they don't do anything. They just disappear, which can be very hurtful and understandably make you feel very isolated.

Either way, experts say that the best thing a newly diagnosed patient can do is take charge of your support network from the very beginning, teaching your friends and family what you need from them. How do you do this? Primarily by being upfront with your loved ones.

Some ideas include telling them that you may declare “no cancer” days when you don't feel like discussing the topic: don't mention the word, just go about normal daily life and not think about cancer for a while. Other days, maybe



you need someone to just listen to how challenging treatment has been or how tired you are. You can decide if you want a specific time you want to discuss it.

If you know what you need, it is useful to be specific. Ask someone for a meal, to watch your children, to give you a ride or just be there to listen. CSC's **MyLifeLine.org** is an online platform that allows you to communicate with people in your life about topics like these.

Ideally, you will have a social worker or patient navigator to help you with the process of communicating with your loved ones. If you don't, there are reputable sources listed in the Resources section that can help.

Another topic of concern for anyone with ALL, but especially among young adults, is dating: how to tell a partner or casual date about your diagnosis (and later, history) of cancer. The answer is up to you, but it is a good idea to discuss it with others and work out your "script" about your version of events to feel comfortable with who you decide to tell, and when and how you tell these people.

REACH OUT

Oftentimes the people around you, no matter how much they love you and no matter how much you convey to them, may not be able to directly relate to what you are experiencing. Experts encourage

making connections with others facing the same problems that you are— it could be through in-person support groups or activities, and also through online support groups. These people understand what you are going through. Those who are further along than you are can be incredibly useful to ask about what to expect and get tips and advice about what helped them get through it. However, remember that everyone's experience is different and yours might be better or worse.

One of the biggest things I work through with young adults with cancer is isolation, trying to get them to connect with other people, hopefully with other people who have cancer to normalize that experience. A lot of times their peers have not encountered serious illness before, so they don't really know how to handle it." —Meghan Fitzgibbons, MSW, Patient Navigator for the Ulman Cancer Fund for Young Adults

SEX/INTIMACY

Sex is a very important part of many people's lives, but it's an area that patients and caregivers don't often ask about and health care providers don't usually bring up. It is important for



you to be able to be intimate with your partner, whatever that might look like and however it may need to be adapted (for example, risk of infection or bleeding, fatigue, and pain may need to be taken into account).

In general, there are few physical limitations to having ALL that affect intimacy, but if you are nauseated or fatigued you understandably may not be interested. You should be sure to keep your partner in the loop about how you are feeling.

If you are neutropenic (have an abnormally low number of white blood cells in your blood), you are at higher risk of contracting infections—and this includes sexually transmitted diseases (STDs). It is important that both you and your partner get tested and continue to use protection to prevent contracting an STD. For females, intercourse can also lead to a higher risk of getting a urinary tract infection, so you should talk to your provider or nurse about strategies to decrease this possibility. Also, it is best to avoid anal intercourse while neutropenic due to the risk of causing skin tears, which could lead to a serious infection.

Contraception is critical while you are undergoing treatment. The drugs you are being given to kill the leukemia cells can cause genetic abnormalities to

sperm cells and can be very dangerous to an unborn child. Barrier contraceptives, such as condoms, are the best form of contraception while undergoing chemotherapy to prevent even the slightest chance of exposing your partner to the drugs. In addition, the use of a second kind of contraception may be recommended to ensure that you or your partner does not get pregnant.

“There are things you can do to minimize the financial impact of cancer. It does place a burden on you as a patient and your caregivers or family members to really address some things, to shop around and make some choices, but it can mean the difference between filing for bankruptcy or not.”

—Joanna Morales, Esq., CEO, Triage Cancer

FINANCES AND INSURANCE

“Financial toxicity” refers to the out-of-pocket costs that negatively affect a person’s life.

Cancer is expensive to treat, and a cancer diagnosis can be a particularly heavy burden for younger people who may not be employed, or if they are working, have not been in the workforce as long and don’t usually have the savings that older people do. Young adults of course



span a variety of life situations, from still living at home and attending school to being employed in the workforce with a family of their own. Below are some of the general financial issues to consider when dealing with a diagnosis of ALL, no matter what your situation is.

The first thing you can do is recognize that treating ALL can have out-of-pocket costs, even if you have insurance.

- Make a list of your current necessary expenses, and write out a budget for that
- Figure out what expenses you could reduce or eliminate
- Apply for financial assistance programs if you qualify

If you are working, you may need to take time off work and figure out how to replace the lost wages. Here are some of the things for you to consider:

- Do I qualify for disability insurance programs purchased through insurance companies (not very common with young adults)?
- Is something available through my employer as part of my benefits?
- Do I live in a state that offers state disability insurance?
- Is my medical condition severe enough that I would qualify for long-term benefits through the Social

Security Administration? (If so, note that this process often takes multiple applications to be approved, and can expire so you might have to re-apply)

If you are in school, you may need to take a leave of absence. Questions should include:

- How will this impact my student loans?
- Can I get a forbearance?
- If I am not going to return to school, can I get my student loans dismissed?

HEALTH INSURANCE COVERAGE

Many people diagnosed with ALL may need to pull back from work and school, if not completely stop for a period of time. This can create additional stress if that is where your health insurance comes from. The first thing to do when you receive a cancer diagnosis is to make sure you have insurance.

Next, ensure that you have adequate coverage and figure out how to use it properly to reduce out-of-pocket costs.

Many young adults are not insured, but the Affordable Care Act (ACA) makes it possible for many more to obtain reasonably priced insurance. The questions you should consider will depend on your situation regarding insurance.



If you have insurance through your school:

- How is my insurance impacted if I take a leave of absence?

If you have insurance through a parent, ACA allows children to stay on their parent's plan until age 26:

- What are options to continue access to health insurance coverage if/when I age out of ACA?

If you are insured through your employer:

- How do I keep my coverage if I am taking time off work?
- What is the cost of COBRA (Consolidated Omnibus Budget Reconciliation Act), which is a continuation of your benefits you received at work? (COBRA continuation coverage is often more expensive than the amount you paid as an active employee— often much more)

If you have no income:

- What does my state offer as part of a Medicaid program? More than half of states adopted the expansion of health coverage to low-income individuals as part of the ACA. This is based on income level and applications are open year-round.

A young adult can get access to

insurance through the ACA's annual Health Insurance Marketplace (www.healthcare.gov). This is offered every year, usually beginning November 1 and going until mid-December, for coverage that begins on January 1 of the next year. This is the time when you can enroll in a new insurance plan, switch plans or make changes to your existing plan.

“Switching to a better insurance plan through the Marketplace can make a huge difference. Paying a hundred dollars more a month for a monthly premium can mean thousands of dollars saved in the end because of ongoing medical expenses.”

— Joanna Morales, Esq., CEO, Triage Cancer

If you don't enroll in a health insurance plan by the end of January, you can't enroll in a plan for that year unless you qualify for a Special Enrollment Period. You qualify for a special enrollment period 60 days following certain life events that include losing your health insurance.

Something to consider even if you have insurance: often these plans are bare bones, with high co-payments and deductibles. You may have coverage, but it might not be that great. It is always worthwhile to compare your options even if just to find out that you have



good coverage. Until you see what is out there, you won't have any perspective on that.

TOOLS TO HELP COMMUNICATE YOUR WISHES

Caregivers and health care workers can find it awkward to begin a conversation about making decisions should you become unable to do so for yourself. As unpleasant as the topic is, having a plan in place is a good idea for anyone of any age or situation.

Nobody ever knows in advance if they will be seriously injured or become suddenly ill and unable to make decisions about their health care.

The best way to convey what your wishes are is through written information saved as a document called an **advance healthcare directive**. These legal documents are helpful to yourself and your caregivers. Most of these documents can be prepared for free without the use of a lawyer. Provide a copy to your doctor and to the hospital so that it is part of your health record.

Having conversations about death and dying, or becoming incapacitated, does not signal that the end is near or negate hope for the future. Quite the opposite, it can be an opportunity to discuss with loved ones your personal goals, values and beliefs, let them know the care

and treatment you would prefer and to convey to them any information you would want to make sure they know. Something to consider: some people plan a social event around the topic of death and dying to discuss how to take charge of some of the issues around life ending.

“The way I like to explain it to my patients is: any one of us could walk out the door and be hit by a car and may need somebody to make decisions for us. Honestly it is in everybody's best interest to have an advance directive whether you have cancer or not.” —Cara Kramer, Pediatric Oncology RN, The Johns Hopkins Hospital

It can be an empowering activity to think through all of these issues and put down your wishes in writing. No matter what you decide, know that even if you became unable to make decisions for a while, you would resume making your own choices when your health improves. A free, simple, secure way for anyone to complete an advance directive can be found here: www.MyDirectives.com

MANAGING EMOTIONAL HEALTH

Dealing with a cancer diagnosis can be stressful. It can cause a rollercoaster ride of emotional ups and downs. You may



experience issues related to family and friendship roles, self-esteem, body image, finances, and other day-to-day activities.

If you start to find that your ups and downs have become extreme and severely interfere with your ability to function, or worry seems to be consuming your life, the most important thing you can do is to reach out for help. Treating your emotional health is just as important as treating your physical body. The following are some ideas for taking care of your emotional health.

FIND THE POSITIVE

Even though the experience of a cancer diagnosis and treatment can seem pretty negative, it can help to find the nuggets of good in life. The trick is finding positive things: appreciating the health care staff, getting to know other patients that could become good friends who you never would have met otherwise, challenging yourself to overcome the obstacles life has placed in your path and recognizing that people learn a lot and may be enriched by adversity.

SLOW DOWN AND BE IN THE MOMENT

It is very easy to become overwhelmed when trying to plan for the future and contemplating an endless list of what-ifs. Concentrating on what you can do

today and dealing with what comes at you one day—or even one hour or one minute—at a time is a really useful technique. The idea of being in the moment, or mindfulness, has come a long way in recent years, and has been scientifically proven through imaging studies to change how the brain functions. Yoga and meditation are great ways to improve mindfulness. Meditation can be as simple as sitting still for 10 or 20 minutes, while focusing on your breathing or on a repeated word or phrase of your choosing.

LEARN SKILLS FOR RELAXATION

Learning to relax is a skill you have to work at, but it can help with many aspects of life that cause stress. Find what works for you, whether it be listening to music, yoga, or meditation. It may also be a physical activity, such as a walk or gentle swim.

“It is a shock to the system to get a cancer diagnosis and have your life turned upside down. It is a normal response to an abnormal situation for patients to have depression and anxiety. We have ways to help this, specialists to help with the emotional and mental health aspects of cancer diagnosis and treatment.” —Pat Brown, MD, Johns Hopkins University



FOCUS ON WHAT YOU CAN CONTROL

When you get a diagnosis such as ALL, a lot of things during treatment and even afterward are going to feel out of your control. It can be helpful to focus on what you can control. You make decisions every day. You can decide to go out as much as you can. You can decide to meet friends for lunch. You can decide to slow down and be in the moment.

“During treatment, I really enjoyed watching comedies that made me laugh and took my focus off of everything that was going on around me, but that didn’t require any energy on my part. It was a coping mechanism for me when I physically couldn’t do very much and was also really helpful because the laughter made me more positive overall.” —Clarissa Schilstra, two-time ALL survivor

GIVE YOURSELF A BREAK

Learning to live with uncertainty is a big adjustment. Realize that the waves of emotion you will experience are normal. There will be good days and there will be bad days. Give yourself permission to have a down day, and get back on track the next day.

“I’ve been doing support groups since 1999, and I have seen time and again that the people who are actively seeking something positive inside of the negative tend to have a better quality of and outlook on life.”

—Lora Hays, Director,
Clinical & Hospital Administration,
Cancer Support Community
Central Indiana

BODY IMAGE AND IDENTITY

A particular concern for many people with a cancer diagnosis is how it is going to affect the way they look. This usually comes into play after the crisis mode of treating cancer, when you are left to pick up the pieces and see how things have changed such as hair loss, weight loss or gain, or scars or skin changes from radiation therapy. To help cope with body image changes, do things that make you feel good about yourself. Engage in a form of physical activity that you enjoy most days of the week. Eat healthy foods that help you feel energized. Wear clothing styles that accentuate what you like the most about your body. Anything you can do to find comfort and confidence in your body can help. One way may be learning some acceptance and viewing them as victory scars.



It is important to speak with your health care team or other individuals you trust if you find yourself isolating yourself because of these changes.

MOVING FORWARD

Treatment for ALL takes a frustratingly long time. But give yourself time to recover. Move back into your normal life at the speed that works for you. You get to decide how quickly you return to school or work and who you tell about your absence (and how much).

With a disease like ALL that could possibly come back someday, you will have to keep up with your follow-up appointments. In that time you may also wonder how long you have to live. It's frightening to imagine a different future than you originally planned for yourself. It can also be difficult to talk about such painful topics. Don't hold these feelings in—it's important to have someone you can talk to about your fears so that you can deal with them in an effective way.

PARTICIPATING IN SUPPORT AND ADVOCACY

Some people who have had cancer find that they want to share what they learned or provide support to others who are going through the same experience. Others may be interested in working to change laws or policies to

help more people. There are many ways you can become involved in the ALL support and advocacy community. A good starting point is to talk with the people or organizations that helped you. People just like you can be important sources of support for others or voices for change. Possible ways you may become involved include:

Help others through peer support.

People with ALL often learn and get comfort from others who have had the disease. Ask about answering support telephone lines, helping with in-person support groups, or providing support online. Reach out to support organizations or hospital staff to learn more.

Become an advocate. Advocacy is about standing up, being visible, and being heard. It is about promoting change and not accepting the status quo. Take a public stand for those causes and issues that matter to you. You can advocate for changes to disability or insurance laws or increases in government funding for ALL research. Advocacy can involve making phone calls, sending emails, signing petitions, writing letters or articles or visiting government offices.

Become a patient advocate.

There are many ways to be a patient advocate. Some are similar to providing



peer support but focus on helping groups of people, not individuals. For example, you could work with local hospitals to make sure people are getting the care, treatment and support they need. Being a patient advocate can also mean working with researchers to help set up clinical trials, making sure that the recruiting process is appropriate and ensuring that the patient's point of view is considered. People who have had cancer are also sometimes needed to sit on government committees or review grant proposals from a patient perspective.

FINDING HOPE

Your sense of hope can change over time. You may hope for many things in your life. Perhaps you hope for recovery of your physical and emotional health, for peace in your relationships, for good communication with your health care

team, or for a way to come to terms with ALL and its place in your life. By doing important things such as taking steps to improve your level of physical activity, your diet, your relationships and your emotional health, you are improving the quality of your life. Never be afraid to hope; just remember what you hope for may change.

People affected by cancer sometimes hear that they need to have a positive attitude to beat their cancer. Do not expect to be positive all of the time; however, trying to view things from a positive perspective as much as possible can improve your general well-being. Finding productive ways to express your feelings is helpful and can keep your stress level down.

QUESTIONS TO ASK ABOUT FOLLOW-UP CARE:

- What are the chances that my leukemia will come back after I have been treated? What about another type of cancer?
- What follow-up tests will I need, and how often will I need them? Can any of these be done closer to where I live?
- What symptoms should I watch for? If I develop any of these symptoms, whom should I call?
- Will I have trouble getting health insurance because of the cancer?
- Can you recommend any support groups or other resources that can help me with survivorship issues?





Philip Ahn had a really busy summer before beginning high school, filled with football practice and trips abroad, but the week before school began he had started to feel feverish and really run down. Although a doctor visit had diagnosed him as having some kind of infection requiring an antibiotic, he wasn't getting better and nearly fainted during his first week in high school. A different doctor recognized petechiae, tiny red spots that indicate bleeding, and she said it could be a symptom of cancer. A blood test soon revealed that he had ALL.

Philip, then 14 years old, was immediately admitted to the hospital for intense chemotherapy and radiation therapy for two months.

"That was one of the toughest times for me personally," he recalls. "I was confused and angry and all I wanted was to get out of the hospital and start high school."

"All of my experience with leukemia brought on a very big perspective change," Philip says. "I am always grateful for good health because I understand how difficult life can be with cancer."

He hopes to share his experience and help others. Now 26 years old, Philip is completing his Master's degree in nursing at Columbia University with hopes to later become a Nurse Practitioner.

"What I want to tell anyone going through what I went through is: 'What you experience and learn will carry you the rest of your life. Once getting through all this, make the most of every moment.'"

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge.

To access any of these resources below call 1-888-793-9355 or visit www.CancerSupportCommunity.org

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET and Sat-Sun 9am - 5pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at

www.CancerExperienceRegistry.org

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate



GENERAL CANCER INFORMATION & SUPPORT

AMERICAN CANCER SOCIETY
800-227-2345
www.cancer.org

AMERICAN SOCIETY OF CLINICAL
ONCOLOGY'S CANCER.NET
888-651-3038
www.cancer.net

ASSOCIATION OF COMMUNITY
CANCER CENTERS
301-770-1949
www.accc-cancer.org

CANCER CARE
800-813-4673
www.cancercare.org

CRITICAL MASS
512-553-3556
www.criticalmass.org

LEUKEMIA & LYMPHOMA SOCIETY
800-955-4572
www.lls.org

NATIONAL CANCER INSTITUTE
800-422-6237
www.cancer.gov

NATIONAL CENTER FOR COMPLEMENTARY
AND ALTERNATIVE MEDICINE
888-644-6226
www.nccih.nih.gov

NATIONAL COMPREHENSIVE
CANCER NETWORK
215-690-0300
www.nccn.org/patients/

NATIONAL INSTITUTES OF HEALTH
www.clinicaltrials.gov

ONCOLOGY NURSING SOCIETY
866-257-4ONS (866-257-4667)
www.ons.org/contact

STUPID CANCER
877-735-4673
www.stupidcancer.org/

THE ULMAN CANCER FUND FOR
YOUNG ADULTS
888-393-3863
www.ulmanfund.org/

FINANCIAL AND LEGAL ASSISTANCE

CANCER AND CAREERS
646-929-8032
www.cancerandcareers.org

CANCER LEGAL RESOURCE CENTER
866-843-2572
www.thedrhc.org/cancer/

CENTERS FOR MEDICARE AND
MEDICAID SERVICES
800-633-4227
www.cms.gov

HEALTHCARE.GOV
www.healthcare.gov

PATIENT ADVOCATE FOUNDATION
800-532-5274
www.patientadvocate.org

PATIENT ACCESS NETWORK FOUNDATION
866-316-7263
www.panfoundation.org

TRIAGE CANCER
424-258-4628
www.triagecancer.org



SO THAT NO ONE FACES CANCER ALONE®

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C., and across the nation.

**For more information, visit www.CancerSupportCommunity.org
or call the toll-free Cancer Support Helpline at 888-793-9355**



FRANKLY SPEAKING
ABOUT CANCER: ACUTE
LYMPHOBLASTIC
LEUKEMIA (ALL)
PROGRAM PARTNERS



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