

ADULTS LIVING WITH

*Acute Lymphocytic/  
Lymphoblastic  
Leukemia (ALL)*

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# Adults Living with Acute Lymphocytic/Lymphoblastic Leukemia (ALL)

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*Acute lymphocytic/lymphoblastic leukemia (ALL) is a cancer of the blood and bone marrow. ALL is rare, with less than 6,000 cases diagnosed in the United States each year.*

ALL starts from lymphocytes, the early version of white blood cells found in bone marrow (the spongy tissue inside bones where blood cells are made). ALL is a type of leukemia that can progress quickly if not treated.

Symptoms of ALL can include fatigue, fever, weakness, lightheadedness, recurrent infections, bruising, shortness of breath, bone pain and bleeding problems.



## Treatment Options

### Chemotherapy

Chemotherapy drugs, given intravenously (through a needle into a vein) or in pill form, can destroy cancer cells. Chemotherapy has long been an effective treatment for ALL and continues to be an important treatment option for many patients.

Chemotherapy treatment for ALL typically begins with “induction” (initial) chemotherapy, a series of treatments in which a combination of drugs is used to destroy the majority of the leukemia cells and bring blood counts to normal levels.

Following induction chemotherapy, a longer course of “consolidation” therapy is used to destroy any remaining leukemia cells that may still exist, but cannot be detected through standard testing.

Induction and consolidation chemotherapy treatment often combine two or more drugs, as this seems to be a more effective approach than administering one drug alone (known as “monotherapy”).

The types of chemotherapy most often given to treat ALL in these two phases include:

- **Vincristine.** Vincristine (Oncovin, Marqibo, Vincasar PFS) prevents microtubules within the cell from dividing and replicating, which ultimately results in the death of cancer cells.

- **Anthracyclines.** Anthracyclines (doxorubicin, daunorubicin) are a type of antibiotic used to treat many types of cancer; they are designed to damage the DNA in cancer cells, causing those cells to die.
- **Cytarabine.** Cytarabine (Cytosar-U, Ara-C) is an “antimetabolite,” which prevents cancer cells from dividing.

Based on the patient’s individual circumstances, the induction phase of chemotherapy may also include cyclophosphamide (Cytoxan), pegylated-asparaginase (PEG-asparaginase), etoposide (VP-16) and rituximab.

After consolidation therapy, patients with ALL generally receive maintenance therapy, a less intensive course of chemotherapy designed to delay or prevent a relapse. Maintenance therapy typically consists of a combination of methotrexate and 6-mercaptopurine (6-MP), both of which are antimetabolites, in combination with vincristine and prednisone, a corticosteroid that controls inflammation in the body.



During each phase of chemotherapy, people with ALL may receive “prophylaxis” treatment to prevent leukemia cells from spreading to the central nervous system (the brain and the spinal cord). In prophylaxis treatment, chemotherapy drugs—such as methotrexate or cytarabine—are injected into the fluid that covers the spinal cord. Prednisone may also be included as part of this therapy.

Additionally, the antimetabolite chemotherapy nelarabine (Arranon) is used for the treatment of patients with T-cell acute lymphoblastic leukemia (T-ALL) whose disease is refractory (has not responded to at least two chemotherapy regimens), or has relapsed (recurred) following treatment.

## Targeted Therapy

Targeted therapy focuses on specific cell mechanisms thought to be important for the growth and survival of cancer cells.

About 25 percent of adult patients with ALL have a chromosomal abnormality (the “Philadelphia chromosome”) which forms BCR-ABL, a new “fusion” gene. Cells with the BCR-ABL gene make an abnormal protein that fuels the growth of cancer cells.

Drugs, called tyrosine kinase inhibitors (TKIs), have been developed to attack this protein. TKIs are taken in pill form and include imatinib (Gleevec), dasatinib (Sprycel) and ponatinib (Iclusig).

Studies have shown that adding a TKI to chemotherapy helps patients go into remission after treatment and can also help keep the leukemia from recurring.

## Stem Cell Transplant

A stem cell transplant is a procedure in which diseased bone marrow is replaced with healthy bone marrow. It is an important treatment option for some people with ALL.

In an allogeneic transplant, stem cells (blood cells that divide to make new blood cells within the bone marrow) are harvested (removed) from the blood or bone marrow of a donor. Donors are often a close relative such as a brother or sister, but sometimes can be an unrelated volunteer who has compatible bone marrow.

The person with ALL is given high doses of chemotherapy or radiation to destroy as many leukemia cells as possible. The stem cells are then “infused” (transplanted) into the body, where they travel to the bones and begin rebuilding bone marrow.

To prevent the rejection of donor cells and to ensure the transplanted cells do not cause an autoimmune disease such as graft-versus-host disease (GVHD), immunosuppressive drugs (cyclosporine, tacrolimus, others) are typically given for a period of time after the transplant.

Many older people are not able to tolerate the high doses of chemotherapy that are used in stem cell transplants. In that case, a “reduced-intensity” transplant may be performed. In this procedure (also called a mini-transplant), lower doses of chemotherapy are given, potentially with radiation. The patient then receives allogeneic (donor) stem cells.

To determine if a stem cell transplant is the right treatment approach, doctors weigh a number of factors, including the risk of recurrence if a transplant is not performed and how well the leukemia has responded to prior treatment approaches. Age and general physical health are also taken into consideration.

## Immunotherapy

Our immune system is constantly working to keep us healthy. It recognizes and fights against danger, such as infections, viruses and growing cancer cells. In general terms, immunotherapy uses our own immune system as a treatment against cancer.

### *Monoclonal Antibodies*

The U.S. Food and Drug Administration (FDA) has approved two monoclonal antibodies, a type of immunotherapy, for the treatment of B-cell precursor ALL:

- **Inotuzumab ozogamicin.** In August 2017, the FDA approved inotuzumab ozogamicin (Besponsa) for the treatment of adults with relapsed or refractory B-cell precursor ALL. Inotuzumab ozogamicin works by targeting CD22, a protein found on the surface of this type of cancer cell.



- **Blinatumomab.** In 2017, the FDA approved blinatumomab (Blincyto) for the treatment of adults with relapsed or refractory B-cell precursor ALL. In March 2018, the FDA extended the approval of blinatumomab to treat individuals with B-cell precursor ALL who are in remission but still have minimal residual disease (MRD). Blinatumomab works by attaching to the CD19 protein on leukemia cells and the CD3 protein found on certain immune system cells, which improves the ability of the immune cells to attack the leukemia cells and helps to prevent relapse.

### **CAR T-Cell Therapy**

In August 2017, the FDA approved the immunotherapy tisagenlecleucel (Kymriah) for the treatment of certain patients with ALL. Tisagenlecleucel, a chimeric antigen receptor (CAR) T cell therapy, uses a patient's own T-cells (a type of white blood cell) to target cancer cells that are positive for the CD19 protein.

Tisagenlecleucel is intended for children and young adults up to the age of 25 who have B-cell ALL that is refractory, meaning that it has not responded to standard treatments, or has relapsed (recurred) at least twice.

CAR T-cell therapy follows a specific process:

- Blood is drawn from the patient via an intravenous catheter (a flexible tube).
- The T-cells are isolated from the rest of the blood.
- In a laboratory, the T-cells are genetically modified to produce CAR T-cells that will recognize cancerous cells.

## The Importance of Clinical Trials

**Clinical trials are the standard by which we measure the worth of new treatments and the quality of life of patients as they receive those treatments. For this reason, doctors and researchers urge people with cancer to take part in clinical trials.**

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things that you should know:

- Often, people who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

- The T-cells are expanded to number in the hundreds of millions and infused back into the patient.
- The CAR triggers the modified T-cells to attack the CD19-positive cells.

# Treatment Side Effects

All cancer treatments can cause side effects. It's important that you report any side effects that you experience to your health care team so they can help you manage them. Report them right away—don't wait for your next appointment. Doing so will improve your quality of life and allow you to stick with your treatment plan. It's important to remember that not all patients experience all side effects, and patients may experience side effects not listed here.

## Side Effects of Chemotherapy

The side effects of chemotherapy depend on the type and dose of drugs given and the length of time they are used. They can include:

- Hair loss
- Increased risk of infection (from having too few white blood cells)
- Easy bruising or bleeding
- Changes in memory or thinking
- Peripheral neuropathy (numbness or tingling in hands and feet)
- Inflammation of the pancreas and liver
- Damage to the bones called avascular necrosis

## Side Effects of Targeted Therapy

Targeted therapy drugs don't have the same effect on the body as do chemotherapy drugs, but they can still cause side effects. Common side effects of targeted therapy include rashes, problems with blood clotting and wound healing, diarrhea, liver problems (such as elevated liver enzymes) and high blood pressure.

## Side Effects of Immunotherapy

Immunotherapy travels through the bloodstream, helping to prompt an immune response. Because it may attack healthy cells as well as cancer cells, certain side effects may be experienced, including fatigue, decreased appetite and digestive tract symptoms. The management of these potential side effects is discussed in the next section of this booklet.

CAR T-cell therapy has its own specific potential side effects, including:

- **Cytokine-Release Syndrome (CRS).** The infusion of CAR T-cells into the body results in the production of large numbers of cytokines (molecules that help cells communicate), which can cause the immune system to become excessively active. This can lead to CRS, with symptoms such as high fever and flu-like symptoms. These side effects can be controlled and reversed with cytokine-blocking drugs and steroids.
- **Changes in cognition.** Some changes in cognition (thought processes) ranging from mild to severe can occur within several days of CAR T-cell therapy. The symptoms are often treated with steroids and are almost always reversible.



- **B-cell aplasia.** CAR T-cell therapy destroys normal as well as cancerous B-cells, which can cause B-cell aplasia (low numbers of B-cells), in which the body is less able to make the antibodies that protect against infection. Immunoglobulin replacement, administered intravenously, can be used to treat or prevent infection.

## Managing Digestive Tract Symptoms

### *Nausea and vomiting*

- Avoid food with strong odors, as well as overly sweet, greasy, fried or highly seasoned food.
- Nibble on dry crackers or toast. These bland foods are easy on the stomach.
- Having something in your stomach when you take medication may help ease nausea.
- Many effective medications for nausea and vomiting have been developed in recent years; talk to your doctor about whether any may be right for you.



### *Diarrhea*

- Drink plenty of water. Ask your doctor about using drinks such as Gatorade which provide electrolytes as well as liquid. Electrolytes are body salts that must stay in balance for cells to work properly.
- Over-the-counter medicines such as loperamide (Imodium A-D and others) and prescription drugs are available for diarrhea but should be used only if necessary. If the diarrhea is bad enough that you need medicine, discuss it with your doctor or nurse.
- Choose foods that contain soluble fiber, such as beans, oat cereals, oranges and flaxseeds. High-pectin foods such as peaches, apples, oranges, grapefruit, bananas and apricots can also help to avoid diarrhea.

### *Loss of appetite*

- To help maintain your weight, eating small meals throughout the day is an easy way to take in more protein and calories. Try to include protein in every meal.
- To keep from feeling full early, avoid liquids with meals or take only small sips (unless you need liquids to help swallow). Drink most of your liquids between meals and focus on liquids that have nutritional value.
- Keep high-calorie, high-protein snacks on hand such as hard-boiled eggs, peanut butter, cheese, ice cream, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna or trail mix.
- If you are struggling to maintain your appetite, talk to your health care team about whether appetite-building medication could be right for you.

## Managing Fatigue

Fatigue (extreme tiredness not helped by sleep) is one of the most common side effects of many cancer treatments. If you are taking any medications, your doctor may lower the dose of the drug or drugs, as long as it does not make the treatment less effective. If you are experiencing fatigue, talk to your doctor about whether taking smaller doses is right for you.

There are a number of other tips for reducing fatigue:

- Take several short naps or breaks.
- Take short walks or do some light exercise, if possible.
- Try easier or shorter versions of the activities you enjoy.
- Ask your family or friends to help you with tasks you find difficult or tiring.

There are also prescription medications that may help, such as modafinil. Your health care team can provide guidance on whether medication is the right approach for your individual circumstances.

## Managing Pain

There are a number of options for pain relief, including prescription and over-the-counter medications. It's important to talk to a member of your health care team before taking any over-the-counter medication to determine if they are safe and whether they will interfere with your treatments.

## Communicating With Your Health Care Team

As you manage your cancer, it's important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and get to know the members of your health care team, including doctors, nurses, nurse practitioners, physician assistants, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

**Start a health care journal.** Having a health care journal or notebook will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Keep a diary of your daily experiences with symptoms related to your illness or treatment. You can separate your journal or notebook into different sections to help keep it organized.



**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific and brief as possible.

**Bring someone with you to your appointments.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person who accompanies you can serve as a second set of ears. He or she may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, such as a smart phone or tablet, ask if you can use it to take notes. Writing notes will help you review the information later.

Remember, there is no such thing as over-communication.



## CancerCare's Free Support Services and Programs

**It is very difficult to receive a diagnosis of cancer, and adjusting to the necessary changes in your life can be challenging.**

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system, and provide information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit [www.cancercare.org](http://www.cancercare.org).

You will likely also build your own personal support network, comprised of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.

## MORE ABOUT ALL

# Frequently Asked Questions

### **Q: Should a person diagnosed with ALL seek a second opinion?**

A: At the time of diagnosis, it makes sense to seek a consultation from a major cancer center or a group of physicians who are experts in managing ALL. Another time to seek a consultation or second opinion is if the cancer is not responding to treatment and/or if a change in treatment is warranted. Discussions can include possible changes in treatment approaches and whether participation in a clinical trial should be considered.

### **Q: If I am being treated for ALL during flu season, should I get a flu shot?**

A: Flu shots are not “contraindicated” for people undergoing treatment for ALL (meaning that the shots are generally safe), but their effectiveness can be reduced by the treatment being received. There are other measures that can reduce the risk of a viral illness, such as frequent hand-washing and avoiding people who have (or are just getting over) a cold. It is also important that family members and close companions of those receiving any type of cancer treatment get flu shots to prevent catching and passing on the flu to the person in treatment.

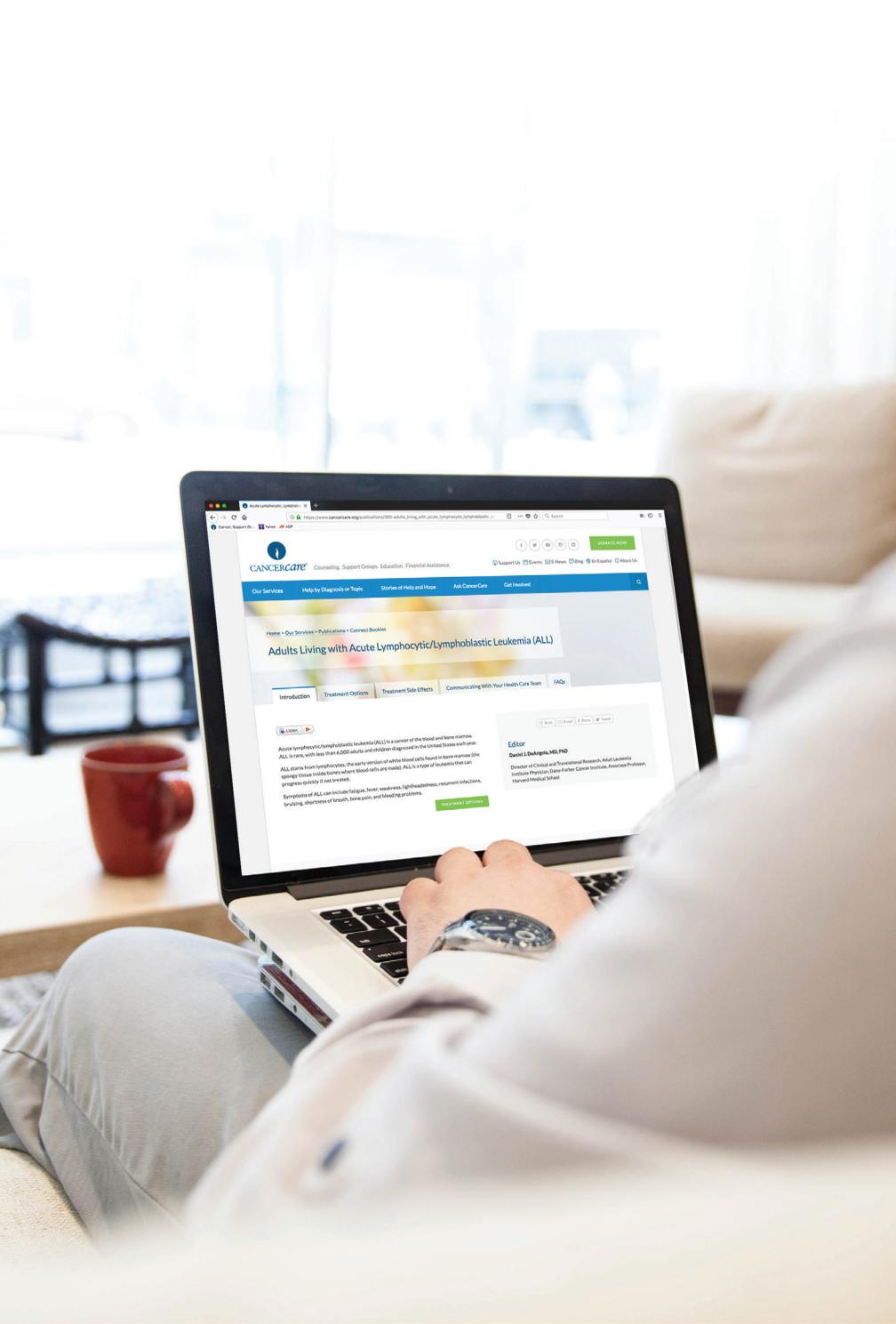
### **Q: What is a treatment summary and why is it important?**

A: A treatment summary, sometimes called a “shadow chart,” is a document you create and which remains in your possession. Maintaining your own records allows you and your family members instant access to the specifics of your diagnosis and treatment. A treatment summary should include:

- Your name and date of birth.
- Date of diagnosis.
- Name, affiliation, and contact information of the doctor who gave the diagnosis.
- Prescribed therapy/therapies; include dates started and stopped and dosages when appropriate.
- Dates and types of post-diagnosis testing, and the results.
- Other medication and supplements you are taking.
- Names, affiliations and contact information of all members of your health care team.

Talk to your doctor or a member of your health care team about your intention to create a treatment summary, and ask them what else they suggest be included. Take your treatment summary with you when you visit any doctor, not just your oncologist.





## Resources

### **CancerCare®**

800-813-HOPE (800-813-4673)  
www.cancercares.org

### **American Cancer Society**

800-227-2345  
www.cancer.org

### **Be the Match® Patient Services**

800-627-7692  
www.bethematch.org

### **Blood & Marrow Transplant Information Network**

888-597-7674  
www.bmtinfonet.org

### **The Bone Marrow Foundation**

800-365-1336  
www.bonemarrow.org

### **Cancer.Net**

Patient information from  
the American Society of  
Clinical Oncology  
888-651-3038  
www.cancer.net

### **National Cancer Institute**

800-422-6237  
www.cancer.gov

### **Cancer Support Community**

888-793-9355  
www.cancersupportcommunity.org

### **National Coalition for Cancer Survivorship**

877-622-7937  
www.canceradvocacy.org

### **The Leukemia & Lymphoma Society**

800-955-4572  
www.lls.org

### **Leukemia Research Foundation**

847-424-0600  
www.allbloodcancers.org

### **CLINICAL TRIALS WEBSITES**

#### **EmergingMed**

www.emergingmed.com

#### **National Cancer Institute**

www.cancer.gov

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