

4 UNDERSTANDING BLOOD CANCERS AND TREATMENT OPTIONS

Visit www.LLS.org/CaregiverWorkbook to access all chapters and worksheets.

Types of Blood Cancer. Leukemia, lymphoma, myeloma, myelodysplastic syndromes (MDSs) and myeloproliferative neoplasms (MPNs) are types of cancer that can affect the bone marrow, blood cells, lymph nodes and other parts of the lymphatic system. Each category of blood cancer also contains different subtypes. Blood cancers affect people of all ages, races, and genders. Blood cancers can be acute (severe and sudden) or chronic (long term).

Leukemia. Leukemia begins in a cell in the bone marrow. The cell undergoes a change and becomes a type of leukemia cell. Once the marrow cell undergoes a leukemic change, the leukemia cells may grow and survive better than normal cells. Over time, the leukemia cells crowd out and/or suppress the development of normal cells. The rate at which leukemia progresses and how the cells replace the normal blood and marrow cells are different with each type of leukemia.

Subtypes of leukemia include

- Acute lymphoblastic leukemia (ALL)
- Acute myeloid leukemia (AML)
- Chronic lymphocytic leukemia (CLL)
- Chronic myeloid leukemia (CML)

Lymphoma. “Lymphoma” is the name of a group of blood cancers that develop in the lymphatic system. The two main types are Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL).

Hodgkin lymphoma has characteristics that distinguish it from other diseases classified as lymphoma. It is characterized by the presence of Reed-Sternberg cells. These are large, cancerous cells, named for the scientists who first identified them, found in Hodgkin lymphoma tissues. With proper treatment, HL can be cured in most patients.

Non-Hodgkin lymphoma (NHL) is a diverse group of diseases distinguished by the characteristics of the cancer cells associated with each disease type. NHL subtypes can be either indolent (slow growing) or aggressive (fast growing). Most people with NHL have a B-cell type of NHL (about 80-85 percent). The others (about 15-20 percent of NHL patients) have a T-cell type or a natural killer (NK)-cell type of lymphoma. Some patients with fast-growing (aggressive) NHL can be cured. For patient’s with a slow-growing type of NHL, treatment may keep the disease in check for many years. It is important to know the patient’s exact subtype of NHL because different types of NHL require different treatment.

Some of the subtypes of NHL include

- Diffuse large B cell lymphoma
- Follicular lymphoma
- Burkitt lymphoma
- Cutaneous T-cell lymphoma
- Mantle cell lymphoma

“In a perfect world, I would love to not have anything to do with LLS and have anything to do with multiple myeloma. I would have been perfectly okay not ever having experienced this, but I feel like because we did and the way that we did, there has to be a reason; and if that reason is for me to help other people so that, you know, when they hear the words, ‘multiple myeloma,’ they don’t feel as completely sucker-punched as I was.”

—Kimberly, caregiver and wife of Elijah, who passed from myeloma

Excerpt from July 2018 “No Playbook for Caregiving: Kimberly’s Story” podcast episode on *The Bloodline with LLS* (www.LLS.org/TheBloodline)

Myeloma. Myeloma begins in the bone marrow. It is a cancer of plasma cells (also called “plasma B cells”), a type of white blood cell. Myeloma has several forms. They are

- Multiple myeloma—the most common form. More than 90 percent of people with myeloma have this type. Multiple myeloma affects several different areas of the body.
- Plasmacytoma—a single site of myeloma cells evident in the body, such as a tumor in the bone, skin, muscle, or lung

Myeloma is characterized by how rapidly or slowly the disease progresses. The disease is grouped accordingly. Those groups are

- Asymptomatic (or smoldering) myeloma progresses slowly and the patient has no symptoms, even though he or she has the disease.
- Symptomatic myeloma has related symptoms, such as anemia, kidney damage and bone disease.

Myelodysplastic Syndromes (MDSs). Myelodysplastic syndromes comprise a group of diseases of the blood and bone marrow, with varying degrees of severity, treatment needs and life expectancy. An MDS may be primary (de novo) or treatment-related.

Myeloproliferative Neoplasms (MPNs). Myeloproliferative neoplasms are types of blood cancer that begin with an abnormal mutation (change) in a stem cell in the bone marrow. The change leads to an overproduction of any combination of white cells, red cells and platelets. Types of MPNs include

- Myelofibrosis
- Polycythemia vera
- Essential thrombocythemia.



For more information about blood cancers, speak one-on-one with an Information Specialist who can provide you with accurate, up-to-date disease, treatment and support information. Call **(800) 955-4572**.



You can also visit www.LLS.org/DiseaseInformation or www.LLS.org/webcast to find more disease-specific information.

The Patient’s Diagnosis. Write down your loved one’s exact diagnosis and the stage of his or her disease in the spaces below for future reference. It’s important for all healthcare providers to be given the specific diagnosis, such as “chronic lymphocytic leukemia,” not just the more generalized term “leukemia.” Take the patient’s medical records to all of his or her appointments with new healthcare providers and to any emergency room visits.

Questions to Ask Members of the Healthcare Team

- What is the patient’s exact diagnosis?
- What is the stage of the disease?

Learning About Treatment Options. After your loved one is diagnosed with a blood cancer, he or she will work with members of the healthcare team to determine the best treatment plan. Treatment options vary for the different types of blood cancer. Your loved one's choices depend on his or her specific diagnosis, age, cytogenetic analysis (an examination of the chromosomes in the bone marrow, blood and lymph node cells), overall health and other factors.

The patient's treatment plan might include

- The watch-and-wait approach
- Chemotherapy or other drug therapies
- Radiation therapy
- Immunotherapy
- Stem cell transplant
- Blood transfusion
- Palliative care
- Clinical trials
- A combination of any of the above.

Surgery can be, but usually isn't, a part of treatment for cancers that involve the blood and marrow.

Your loved one may ask you to participate in the process for choosing a treatment plan. You can help in some of the following ways:

- Research and collect information on the patient's diagnosis and suggested treatment options.
- Be the patient's second set of ears or offer to take notes at appointments.
- Help the patient find a blood cancer specialist for a second opinion if the patient would like a second opinion.
- Help the patient keep a running list of questions to ask members of the healthcare team.
- Be a sounding board for the patient to discuss each treatment option.

Remember, ultimately, the treatment decision is up to the patient. In an open discussion, you can share your perspective with the patient. Be respectful and supportive of the patient's decision, even if you disagree with the choices he or she is making.

Researching Treatment Options. Caregivers often become the primary "researchers" for disease information and support in an effort to assist the person with cancer and to help him or her better understand the disease, treatment options and side effects. Be wary of information found online. Always check to make sure the information is provided by a reliable source.

FACT

"Palliative care" is not just end-of-life care. Palliative care can also be used, alongside curative treatment, to help manage side effects and improve the patient's well-being.

TIP:

Pack a tote bag with items to make waiting rooms and treatment days more bearable. Bring a book, magazine, puzzle book, a music player and headphones, or a journal and pen to entertain yourself and your loved one. Pack a sweater or blanket since treatment centers can be chilly. Add snacks and a water bottle. And, don't forget a phone charger!



LLS offers free materials and services designed to simplify this search for information and support. Call an Information Specialist at **(800) 955-4572**.



Visit www.LLS.org/treatment to learn more about specific treatments.

Side Effects. Side effects of treatment are often a top concern for both patients and caregivers. Reactions to treatment vary from patient to patient. Reactions also vary depending on

- The treatment and/or types of drugs used
- Drug or radiation dose amounts
- The duration of the therapy regimen
- Whether the patient has some other health condition, such as diabetes or kidney disease.

Unfortunately, treatments that damage or destroy cancer cells may also affect normal cells and may cause side effects. Side effects from cancer treatment can be either short term or long term. Some side effects improve or disappear when treatment ends, while others may show up after treatment ends, sometimes even years later.

Questions to Ask Members of the Healthcare Team

Ask the healthcare team the following questions about side effects:

- What side effects are common with this treatment? Can you provide a written list?
- What side effects or signs require a trip to the emergency room?
- Whom should I call if the patient begins to experience a side effect?
- Is there any risk to me, as the caregiver, from this treatment?
- What side effect or signs prompt a call to the healthcare team?

It is best to address side effects right away, and there are medications and palliative care options available to help manage some side effects. You can also manage some side effects by making changes to the patient's food choices and daily habits. Talk to the members of the healthcare team before making any changes.



For more information about side effects, visit www.LLS.org/booklets to view, print or order the free LLS booklet *Understanding Side Effects of Drug Therapy*.

Watch and Wait. The watch-and-wait approach involves closely monitoring a patient's condition without giving any treatment until disease characteristics, signs and/or symptoms appear or change. Some people, with their doctor's care and guidance, can manage their blood cancer—depending on the disease—for years using a watch-and-wait approach. It is usually recommended for patients who are in early stages of indolent (slow-growing) disease or some chronic forms of blood cancers.

As part of the watch-and-wait protocol, the doctor will monitor the patient's condition for disease progression with regular physical examinations and lab tests. The patient won't take any drugs or undergo any forms of treatment during this period. The patient can avoid drug treatment and its potential side effects until they are needed. The watch-and-wait approach is based on studies that indicate early treatment for some patients, in some situations, isn't beneficial.

The patient following the watch-and-wait protocol must visit the doctor regularly so the doctor can check for any health changes, specifically monitoring whether the disease status remains stable or starts to progress. The doctor monitors the patient's test results to decide when it is time to start treatment and to determine the best treatment option. Depending on the disease, the doctor may advise the patient to begin treatment if the patient has

- Lymph nodes that are getting larger
- Newly affected lymph nodes
- Bone or other organs that have become affected by cancer
- A low blood cell count
- A relatively rapid increase in the number of lymphocytes in the blood
- A spleen that's increasing in size
- Worsening anemia.

Caregiver Responsibilities During Watch and Wait. You may feel uncomfortable because you know that your loved one has cancer, yet is not receiving treatment right away. Rest assured that the watch-and-wait approach is the standard of care for people whose disease is not progressing quickly, is not widespread and who have no symptoms.

Your caregiver responsibilities during this time may be limited to accompanying your loved one to checkups and providing emotional support. You can also help him or her watch for new symptoms and make sure that they are reported to the healthcare team right away.

Chemotherapy. Chemotherapy (chemo) is the use of strong drugs or chemicals, often given in combinations or administered at intervals, to kill or damage cancer cells. Chemotherapy drugs are often called “anticancer agents.” Chemotherapy can produce long-term remission (no sign of illness) or outright cure for many people, depending on the type of cancer and its extent.

Not all chemotherapy treatments are the same. Certain chemotherapy drugs are used only for certain disease types. All chemotherapy drugs interfere with cancer cells' ability to grow or multiply, but different groups of drugs harm cancer cells in different ways.

Chemotherapy may be combined with radiation therapy or stem cell transplant.

Chemotherapy can also damage healthy cells and cause side effects. Side effects of chemotherapy can include appetite changes, nausea and vomiting, diarrhea, constipation, mouth sores, hair loss, anemia, skin changes, fertility problems, and problems with concentration and focus. Ask members of the healthcare team what to expect and alert them to any new or worsening symptoms.

How Is Chemotherapy Administered? Chemotherapy and other drugs are often given in combination with each other and can be given in different ways. The method of administering the drug is based on the actual disease diagnosed and the agent's effectiveness. Commonly used methods of administration include

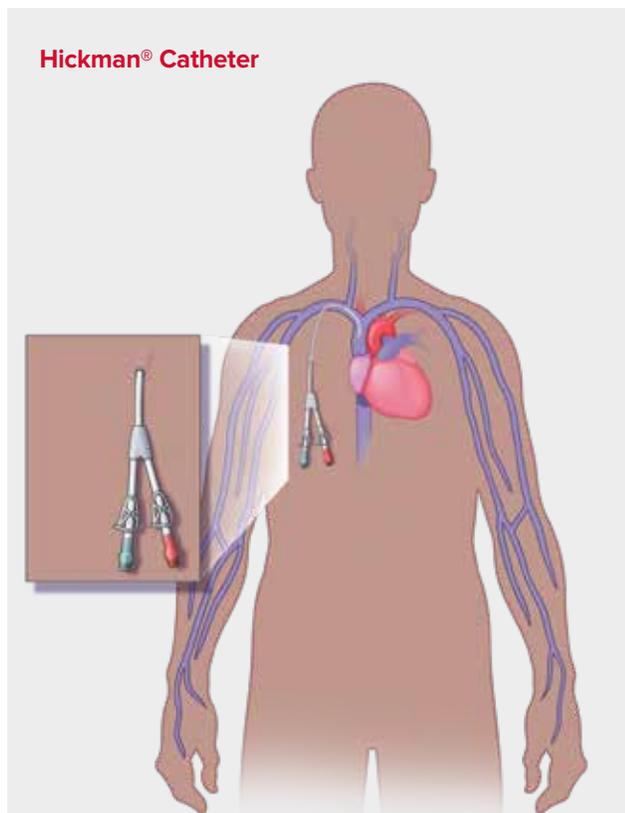
- Intravenous (IV) (into a vein)
- Oral (PO) (by mouth as a pill, liquid or capsule)
- Intramuscular (IM) injection (into a muscle)
- Subcutaneous (SC) injection (under the skin)
- Intrathecal (into the cerebrospinal fluid [CSF]).

How Patients Receive IV Treatment. Certain medications irritate the veins and make repeated IV placement difficult. Many patients find that chemotherapy drugs can be given more conveniently and comfortably through a line or catheter that can stay in place longer than a regular IV.

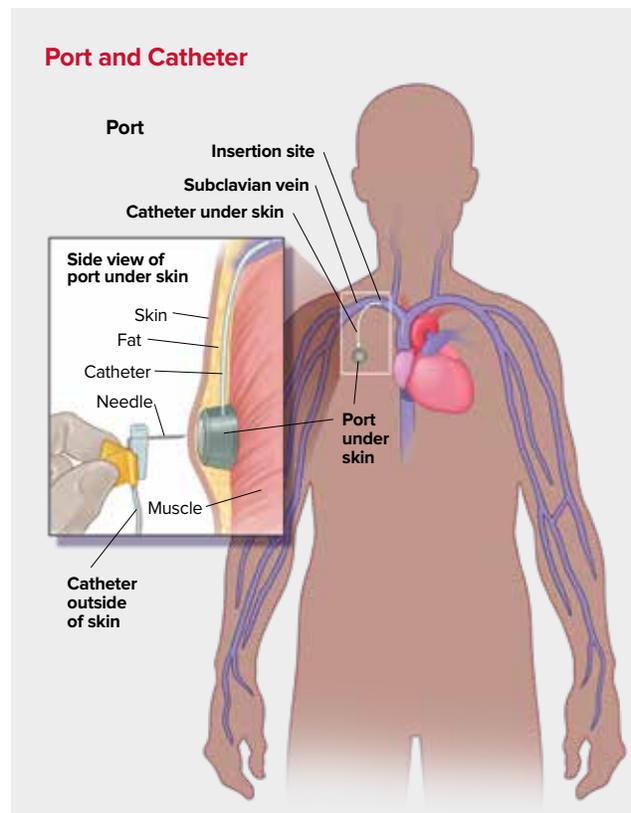
- PICC line: PICC or PIC line is short for percutaneously (under the skin) inserted central venous catheter. This type of IV catheter is inserted through the skin and into a vein in the arm. The doctor uses a guide wire to thread the PICC line through the vein until it reaches the superior vena cava, a large vein above the heart. Needlesticks are made through a capped self-sealing valve on the end of the catheter.
- Central line: A thin tube that is put under the skin and threaded into a large vein in the chest. The central line stays firmly in place. It is also called a “catheter.” It can remain in place for weeks or months. See picture below on the left.
- Port: This is a small device attached to a central line. The port is surgically placed under the skin of the chest. After the site heals, no dressings are needed and no special home care is needed. To access the vein, the nurse puts a needle through the skin into the port. A numbing cream can be put on the skin before the port is used. See picture below on the right.

These devices can be used to administer chemotherapy drugs, other drugs, blood cells or blood products, fluids, or nutrition. They can also be used to take blood samples for lab tests.

After the device is in place, the healthcare team will explain how to clean and care for the central line. Talk to the healthcare team about the best way for your loved one to receive treatment.



Hickman® Catheter: An example of a type of central line.



Port: A port used with a central line.

Caring for a Central Line, PICC Line or Port. Since these devices can sometimes stay in place for months, you and your loved one will need to know how to care for the device at home.

If your loved one has a central line, PICC line, or port, the site will need to be cleaned and monitored for infection or other issues such as blood clots (thrombosis). Hospital or clinic staff will show you and your loved one how to clean and care for the device. Signs of infection include

- Redness
- Pus
- Warmth to the touch
- Bad smell
- Increased pain
- Fever.

Let the healthcare team know immediately if you notice these symptoms. Although blood clots often have no symptoms, pain, redness, and discoloration can also be signs of a blood clot. An ache in the shoulder or jaw could also be a sign of a blood clot. Talk to the healthcare team about your loved one's risk for blood clots and what to do in an emergency situation.

Any long-term device will also need to be flushed periodically. The healthcare team will provide a plan for how to flush the device, as well as how often this must be done.

Additional Care and Use of Devices. Depending on your loved one's specific treatment plan and needs, it's possible that you, as the caregiver, will also need to learn how to use the device to administer drugs, fluids, or nutrition at home. This may include

- Learning how to connect and disconnect the lines
- Programming a "pump" to deliver medications or fluids as prescribed
- Flushing the lines
- Checking for air bubbles or other issues
- Storing and disposing of medical items properly
- Maintaining a sterile environment to prevent infection.

You will be well-trained by a member of the healthcare team and learn how to complete all needed tasks. In this type of situation, you and your loved one will likely receive scheduled at-home visits from a nurse who will draw blood for the lab tests and oversee the care of the line as well as the administration of drugs, fluids, or nutrition.

Targeted and Other Drug Therapies. In addition to chemotherapy, other types of drug therapies are also used to treat blood cancers and the side effects of blood cancers.

Similar to chemotherapy, other drug therapies can be administered in a variety of ways including through an intravenous infusion; by an intramuscular (IM), intravenous (IV) or subcutaneous (SC) injection; or orally in either pill or liquid form. Unlike chemotherapy, some drug therapies can specifically target cancer cells. Others use the patient's own immune system to fight the cancer. Drug therapies may also cause side effects. .

Caregiver Responsibilities During Chemotherapy or Drug Therapy. During chemotherapy or other drug therapies, there are many things you can do to help your loved one. Side effects may make it more difficult for your loved one to carry out many daily tasks, such as cleaning, cooking, or grocery shopping. You can take on these tasks and assist with treatment adherence and side-effect management.

Chemotherapy or Drug Therapy at a Treatment Center. If the chemotherapy or drug therapy is administered by an IV infusion at the hospital or treatment center, you can keep your loved one company during these appointments. Infusions can last for several hours; some even require hospitalization.

Questions to Ask Members of the Healthcare Team

Before the patient begins chemotherapy or drug therapy at a clinic or treatment center, ask the healthcare team the following questions:

- Can I receive a copy of all instructions in writing?
- Whom can I call with general questions?
- Whom can I call after hours or in an emergency situation?
- What signs or symptoms require medical attention, and what should I do if I notice these signs or symptoms?
- Is there anything the patient needs to do to prepare for infusions?
- Are there any foods, vitamins, medications, or supplements that can interact with the drug that the patient needs to avoid after infusions?
- Are there any precautions I need to take when assisting the patient at home after an infusion?

Chemotherapy or Drug Therapy at Home. If your loved one will be doing an oral therapy regimen at home, you can assist your loved one with taking the medication as prescribed.

Questions to Ask Members of the Healthcare Team

Before the patient begins oral therapy at home, ask the healthcare team the following questions:

- What if the patient misses a dose?
- What if the patient vomits immediately after taking the medication?
- Are there any foods, vitamins, supplements, or medications that can interact with the drug that the patient needs to avoid?
- Is it safe for the patient to drink alcohol while he or she is taking this drug?
- When should the patient take the medication and how often?
- How should the medication be stored and handled?
- Is it safe for me to handle the medication?
- Does the patient need to take this drug with food?
- When and how should I contact the healthcare team with questions?
- How do I contact a healthcare professional after hours?

Immunotherapy. Immunotherapy, also called “biological therapy,” utilizes the patient’s own immune system to fight cancer. The body’s immune system helps protect against disease and infection. In most circumstances, the body’s natural immune system seems unable to identify cancer as a foreign invader. Immunotherapy is based on the concept that immune cells or antibodies that can recognize and kill cancer cells can be produced in the laboratory and then given to patients to treat cancer. Several types of immunotherapy are either approved for use by the Food and Drug Administration (FDA) or are under study in clinical trials to determine their effectiveness in treating various types of cancer. Descriptions of different types of immunotherapies begin on the next page.

Chimeric Antigen Receptor (CAR) T-Cell Therapy. The patient's T cells are removed through "apheresis," a procedure during which blood is withdrawn from the body and one or more blood component (such as plasma, platelets or white blood cells) are removed. The remaining blood is then returned to the body. The cells are modified in a laboratory so that they can be reprogrammed to target tumor cells through a gene-modification technique. After the patient has undergone a course of chemotherapy these modified T cells are returned to the patient.

Cytokine Treatment. Other treatments used to stimulate the immune system in a general way and used in combination with monoclonal antibodies, vaccines or chemotherapy are substances called "cytokines." These are hormones produced by the body that help the immune system function. Man-made cytokines are used as an adjunct (additional) therapy to boost the immune system.



For more information about immunotherapy, visit www.LLS.org/booklets to view, print or order *Chimeric Antigen Receptor (CAR) T-Cell Therapy Facts*, a free LLS booklet.

Donor Lymphocyte Infusion. During this procedure, doctors transfer lymphocytes (a type of white blood cell) from the original stem cell donor's blood to the patient. The goal of the lymphocyte infusion is to attack or suppress leukemia cells by inducing an intense immune reaction against the patient's cancer cells. This reaction is called a "graft-versus-tumor (GVT) effect."

Monoclonal Antibody Treatment. Monoclonal antibody therapy makes use of laboratory-made immunoglobulins (proteins that help the body fight infection) that are used to

- Target and attack cancer cells
- Deliver toxins (anticancer drugs or radiation) directly to cancer cells with less harm to healthy cells.

These immunoglobulins are designed to mimic the natural antibodies produced during an immune response.

Monoclonal antibody therapies are generally given to individuals in an outpatient setting, usually over a period of several weeks. The drug is infused, via a needle, into a vein in the arm. (Some monoclonal antibody therapies are given as a subcutaneous injection instead of an IV infusion.) The doctor may prescribe drugs before each infusion to reduce certain side effects. Scheduled blood tests between treatments and after treatment will help to identify related side effects.

Radioimmunotherapy. Radioimmunotherapy is mainly used to treat lymphoma. It combines a radioactive substance with a monoclonal antibody that's infused into the body. The monoclonal antibody targets, and sometimes reacts with, proteins on cancer cells (antigens). The radioactive molecule destroys the cancer cells.

In most cases, patients are treated in an outpatient facility. Therapy is administered over the course of 1 to 2 weeks. Before the patient receives the treating dose of radioimmunotherapy, he or she will be given a preparatory intravenous (IV) infusion of the antibody. On treatment day, the patient receives the antibodies via infusion, but this time, within four hours following the infusion, the patient will receive the dose of the radiation. It takes about 10 minutes to administer the injection.

FACT

The patient must take certain precautions to protect other people from radiation exposure during radioimmunotherapy treatment. A member of the healthcare team will explain the precautions. Ask for printed list of the precautions, if needed. As the caregiver, you are likely to be the person in closest contact with the patient, so it is helpful for you to learn these precautions, too.

After treatment, the patient will need routine blood tests for a few months to make sure that blood counts are returning to normal ranges. Most patients have a mild to moderate decrease in blood cell production for a short time.

Radioimmunotherapy works gradually, so it may take several months for cancer cells to die and tumors to shrink. The healthcare team monitors the treatment's effects with physical examinations and imaging tests, such as computed tomography (CT) scans and positron emission tomography (PET) scans. Overall, radioimmunotherapy is usually well tolerated.

Therapeutic Cancer Vaccines. Vaccines designed to treat cancer don't prevent the disease in the same way that conventional vaccine therapy prevents conditions such as measles or polio. The therapeutic cancer vaccines are designed to treat an already-present cancer and reduce its potential to grow.

The goal of vaccine therapy is to make the immune system attack any cancer cells. Most cancer vaccine studies involve administering chemotherapy, radiation or other standard cancer therapy to reduce the amount of disease in the body before giving the vaccine.



For more information about immunotherapy, visit www.LLS.org/booklets to view, print or order *Immunotherapy Facts*, a free LLS booklet.

Caregiver Responsibilities During Immunotherapy. Immunotherapy treatments and the ways in which the treatments are given vary and so do side effects. Common side effects of immunotherapy include skin reactions (rashes) and flulike symptoms, such as fatigue, body aches, nausea, and fever. However, other side effects are possible. Ask members of the healthcare team what to expect and alert the healthcare team to any new symptoms or side effects. As the caregiver, you can help your loved one to manage any side effects that do occur.

Depending on the specific treatment and side effects, your loved one may not need a lot of assistance with everyday tasks. Even so, cancer treatment can be mentally and physically draining, so he or she may need emotional support or help with shopping, cooking, or cleaning. You can also accompany your loved one to immunotherapy treatments, and take him or her for blood work and scans.

Radiation. Radiation therapy is also called “radiotherapy” or “irradiation.” Radiation therapy damages the genetic material called deoxyribonucleic acid (DNA) within cells, which prevents them from growing and reproducing. Although the radiotherapy is directed at cancer cells, it can also damage healthy cells, but current methods minimize the damage done to nearby tissues. The type of radiation used for radiotherapy (ionizing radiation) is the same as that used for diagnostic x-rays. The doses of radiation used for radiotherapy, however, are higher than the doses used for x-rays and imaging procedures.

When radiotherapy is used for blood cancer treatment, it's usually part of a treatment plan that includes drug therapy. Radiotherapy is sometimes given to prepare a patient for a stem cell transplant. Radiotherapy can also be used to relieve pain or discomfort caused by an enlarged liver, lymph node(s) or spleen.

External Beam Radiation. External beam radiation is the type of radiotherapy used most often to treat blood cancers. A focused radiation beam is delivered from outside the body by a machine called a “linear accelerator,” or “linac” for short. A member of the healthcare team may mark the patient's skin with small dots of semipermanent ink to ensure that the radiation is aimed at the same part of the body during each treatment session.

Caregiver Responsibilities During Radiation. Treatments are typically done every weekday for a period of 2 to 10 weeks. The appointments are usually quick. The patient will likely spend 20 to 30 minutes in the treatment area, even though actual radiation exposure lasts only a few minutes.

You can help by going with your loved one to these daily treatments or by coordinating schedules with family members and friends who are available to accompany your loved one if he or she doesn't want to go alone.

Typically, radiation causes fewer side effects than chemotherapy; however, fatigue is a common problem for patients undergoing radiotherapy. Your loved one may need some assistance with daily tasks in order to rest.

You may also need to help your loved one with skin care. Radiation can cause the skin to be red and irritated and occasionally blister (similar in some ways to a sunburn). Your loved one should bathe the area with warm water, protect the area from the sun, and wear loose clothing. Do not use skincare products on the area without first checking with a member of the healthcare team.

If your loved one receives external beam radiation, you and other people in contact with your loved one will not be exposed to any radiation.

Stem Cell Transplantation. Stem cell transplantation, sometimes referred to as “bone marrow transplantation,” is a procedure that replaces unhealthy blood-forming cells with healthy cells.

First, the patient receives a regimen of high-dose chemotherapy and/or radiation therapy which kills the patient's stem cells to increase the chance of eliminating the blood cancer in the marrow. This is called “pretreatment” or “conditioning treatment.”

After the conditioning treatment, the patient receives the stem cell transplant. Stem cells are transfused into the patient's blood. The transfusion is done through a catheter and can last several hours. The transplanted stem cells go from the patient's bloodstream to his or her marrow. The new cells grow and provide a supply of red blood cells, white blood cells (including immune cells) and platelets.

Types of Stem Cell Transplantation. There are four types of stem cell transplantation. The three most common are

- Autologous transplantation: The stem cells come from the patient's own body.
- Allogeneic transplantation: The stem cells come from a healthy person (the donor).
- Reduced-intensity stem cell transplantation: As in an allogeneic transplant, the stem cells come from a healthy person (the donor), but the conditioning chemotherapy is less intensive.

A fourth type of stem cell transplantation, syngeneic transplantation, is an option for patients who have an identical twin with whom the patient has identical genetic makeup and tissue type.

Finding a Donor. For an allogeneic stem cell transplant, the patient will need a bone marrow donor. To determine if a potential donor is a match for a patient, a lab technician examines samples of tissue cells from each person to compare the proteins on the outer part of the cells. These are called “human leukocyte antigens (HLAs).” If the HLA on the donor cells are identical or similar, the transplant is more likely to be successful.

In many cases, the donor is a brother or a sister (if one is available) if he or she is a match for the patient. Otherwise, an unrelated person with stem cells that match the patient's tissue type can be used. These matched unrelated donors (MUDs) can be found through stem cell donor banks or registries.

Other Sources of Donor Stem Cells

Haploidentical donor. A potential stem cell donor who has a 50 percent human leukocyte antigen–match (HLA-match) with a patient. Sometimes it is not possible to find a donor who is a close HLA match with the patient. Siblings have a 50 percent chance of being haploidentical. If the discrepancy in tissue type is not too great and the benefits of treatment outweigh the risk, a transplant may still be a possible option for a person with a haloidentical donor.

Cord blood. Stem cells are present in blood from the placenta and umbilical cord of a newborn baby. These stem cells have the capability to repopulate the marrow of a compatible recipient and produce blood cells. Frozen cord blood is a source of donor stem cells for transplantation to HLA-matched recipients. Most cord-blood transplants are given by either matched or nearly matched unrelated donors.



For more information about transplantation, visit www.LLS.org/booklets to view, print or order *Blood and Marrow Stem Cell Transplantation*, a free LLS booklet.

Graft-Versus-Host Disease (GVHD). Graft-versus-host disease develops when the donor’s immune cells mistakenly attack the patient’s normal cells. This reaction can be mild, moderate or severe—even life threatening. Its symptoms can include

- Rashes
- Blistering
- Nausea, vomiting, abdominal cramps, diarrhea and loss of appetite
- Jaundice (yellowing of the skin), which indicates liver damage
- Excessive dryness of the mouth and throat, leading to ulcers
- Dryness of the eyes, lungs, vagina and other surfaces.

Graft-versus-host disease can be either acute or chronic. Its severity depends on the differences in tissue type between patient and donor. The older the patient, the more frequent and serious the reaction may be.

One to two days before the stem cell infusion, the healthcare team will give the patient a regimen of drugs to help prevent GVHD. These regimens suppress the immune system. The patient may need to continue to take these drugs for many months after transplantation.

Graft-Versus-Host Disease Treatment. Several drugs have been developed to prevent or lessen GVHD. These drugs, in addition to early detection and advances in understanding the disease, have resulted in a significant reduction in serious or fatal outcomes from GVHD. However, GVHD doesn’t always respond to these treatments. It can still have a fatal outcome. Many deaths related to GVHD occur because of infections that develop in patients who have suppressed immune systems.



For more information about GVHD, visit www.LLS.org/booklets to view, print or order *Graft-Versus-Host Disease*, a free LLS booklet.

Visit www.joeshouse.org for a searchable database of discounted lodging facilities near treatment centers, such as hospitality houses and hotels that offer medical rates.

Caregiver Responsibilities During a Stem Cell Transplant. During the pretreatment (conditioning) chemotherapy and/or radiation treatment, the caregiver can assist the patient with daily tasks, help the patient manage side effects, and accompany the patient to treatment.

After the stem cell transplant, the patient will spend 30 or more days in the hospital. Once the patient leaves the hospital, the caregiver can help the patient reduce the risk of infection by cleaning the home, practicing good food safety, caring for pets, encouraging proper self-care and hygiene, and helping the patient to avoid crowds and people who are sick. The caregiver can also be on the lookout for signs and symptoms of GVHD and alert the healthcare team to any changes to the patient's well-being.

If your loved one lives more than 15 to 20 minutes from the treatment center, the healthcare team may require that the patient find a place to stay that is closer to the center in case serious complications arise. Some treatment centers offer special housing for patients undergoing a stem cell transplant. However, cost can be an issue. Discuss options with your treatment team.

Blood Transfusions. Using cells donated by healthy volunteers, transfusions can help replace red blood cells, platelets and other blood components. Some blood cancer patients need periodic blood transfusions to improve blood counts.

Patients with low blood counts can develop

- Anemia (low numbers of red blood cells)
- Thrombocytopenia (low numbers of platelets)
- Leukopenia (low numbers of white blood cells, either granulocytes or lymphocytes, or both).

Blood Components. When a patient receives a transfusion, he or she won't be getting whole blood. Instead, the patient will receive components of blood that has been filtered. Components that the patient can receive separately by transfusion are

- Red blood cells
- Platelets
- Granulocytes (white blood cells)
- Plasma and cryoprecipitate
- Gamma globulin
- Albumin.

Blood Transfusion Safety. Many patients, caregivers and doctors are concerned about blood supply safety. The good news is that the risk of transmitting viral diseases, such as human immunodeficiency virus (HIV) and hepatitis by blood transfusion has dropped dramatically because of a multilayered approach to safety. Today, 12 different tests are performed on each unit of donated blood to check for infectious diseases.

Complications of Blood Transfusions. Most patients who receive a transfusion don't suffer any adverse reactions. However, it's still possible for reactions to occur with any blood component. A reaction can occur both at the time of the transfusion or weeks or months later. The doctor may prescribe medication before the transfusion to reduce the risk of side effects.

During the infusion if either you or the patient notice any of the following symptoms, however slight, alert the nursing staff promptly to prevent avoidable serious complications:

- Fever
- Rash or hives
- Chills
- Nausea

- Pain at the transfusion site
- Back pain
- Shortness of breath
- A drop in blood pressure
- Dark or red urine.

Reactions that aren't immediate include

- Alloimmunization
 - This occurs if the body produces antibodies against certain antigens in transfused blood. Alloimmunization may not cause immediate symptoms, but the healthcare team will need to take special precautions if the patient receives more transfusions.
- Iron overload
 - If the patient receives ongoing red blood cell transfusions, he or she is at risk for developing iron overload. If it is not treated, iron overload can damage your heart and liver. The patient may need medication to remove excess iron from the body.
- Cytomegalovirus (CMV) transmission
 - A virus that can cause serious problems, eg, pneumonia, for immunosuppressed patients
- Viral infection transmission
- Bacterial infection transmission
- Graft-versus-host disease (GVHD).

Most of these reactions are either rare or manageable, thanks to new procedures and precautions for blood transfusions.



For more information about blood transfusion, visit www.LLS.org/booklets to view, print or order *Blood Transfusion*, a free LLS booklet.

Caregiver Responsibilities During Blood Transfusions. As a caregiver, you can accompany your loved one to the blood transfusion appointments which can last for several hours. Keep an eye on the your loved one and report any side effects that occur, either during or after the transfusion, to the healthcare team immediately.

Palliative Care. Palliative care is specialized medical care that focuses on providing relief from the side effects and emotional stress of a serious illness, such as cancer. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by an interdisciplinary team of palliative care specialists including doctors, nurses, and social workers. Other professional team members may be included and each member will be working with you, family members and your loved one as well as with the other members of the healthcare team to provide an extra layer of support.

The type of care the team will suggest depends on the symptoms that interfere with the patient's quality of life and goals for treatment. For example, if joint pain causes mobility issues, the patient may benefit from physical therapy.

Examples of palliative care include

- Nutrition
- Physical or occupational therapy

TIP:

Palliative care is appropriate for anyone who has a serious illness, regardless of age, stage of the disease or prognosis.

- Pain management
- Medications to ease side effects
- Therapy or counseling
- Help with practical issues, such as managing finances or relationships
- Other medical treatments.

Your loved one will work with the palliative care team to develop a plan that addresses his or her needs.

More About Palliative Care. The palliative care team communicates with every member of the healthcare team to improve overall care coordination.

- Palliative care is best delivered early in the course of the disease so the patient can gain control of symptoms before they worsen or cause disruptions to the treatment plan.
- Palliative care can be provided in a hospital or at an outpatient clinic and, sometimes, at home.
- Most insurance plans, including Medicare and Medicaid, cover palliative care.

You may hear people use the terms “hospice” and “palliative care” interchangeably, but they are not interchangeable. Hospice care is end-of-life care. Palliative care can be used by any person who has a serious illness, regardless of prognosis.

As cancer treatments improve, the number of cancer survivors continues to grow; however, curative treatments can still cause unpleasant side effects. Palliative care offers many ways to help the patient feel better physically, emotionally, and spiritually during cancer treatment and into survivorship.

Caregiver Responsibilities. If your loved one is suffering from pain or other symptoms caused by cancer or the side effects of treatment, ask the healthcare team for a referral to palliative care.

Clinical Trials. Taking part in a clinical trial is a treatment option that many blood cancer patients will consider at some point in their journey. There are trials for

- Patients who are receiving their first treatment
- Patients whose first treatment was not effective
- Patients whose cancer has returned following a period of remission.

In some trials, the goal is to extend remission (once that has been achieved).

How Do Clinical Trials Work? A cancer clinical trial is a controlled research study conducted by doctors that may improve the care and treatment of people who have cancer. A treatment that’s proven safe and effective in a cancer clinical trial may be approved by the US Food and Drug Administration (FDA) for use as a standard treatment. Virtually all of today’s standard treatments for cancer are based on the outcomes of previous clinical trials.

The purpose of blood cancer clinical trials is to improve treatment options by

- Increasing survival
- Decreasing the side-effects of treatment.

Clinical trials are designed to test a new treatment, new combinations or new dosages.

Who Can Participate? Each clinical trial has a “road map” or protocol that includes information about which patients will be allowed to enroll in the trial and which will be excluded from participation. These inclusion and exclusion criteria are very specific and usually cannot be changed.

FACT

Advances in treatment for blood cancers depend on patients’ participation in clinical trials.

Eligibility for any given clinical trial depends on many factors, such as

- Diagnosis
- Stage of the disease
- Current physical condition
- Other medical problems
- Prior treatments and responses to those treatments
- Presence or absence of certain genetic mutations
- Age.

What Should You Do if Your Loved One is Interested in a Clinical Trial? Ask the healthcare team if a clinical trial could be considered at this particular point in the patient’s treatment. Clinical trials may be considered in many situations including, but not limited to

- Newly diagnosed patients considering a first treatment
- First or subsequent treatment was not effective
- Disease has come back after a period of remission
- Current treatment is causing unacceptable side effects
- An alternative to the suggested treatment is desired.

The patient does not have to wait until the disease is in an advanced state to participate in a clinical trial.

There are also many things a patient needs to consider before he or she decides to enter a clinical trial, including

- The potential side effects of the treatment
- Required tests and procedures
- The number of doctor visits
- The amount of time he or she may be required to be away from home.

In addition, it is important to understand which charges are covered by the clinical-trial sponsor, which are covered by the patient and which are covered by the insurance company.



Talk to an LLS Information Specialist to learn more. Call **(800) 955-4572**. If appropriate, an Information Specialist can connect you with a Clinical Trial Specialist at the Clinical Trial Support Center. Clinical Trial Specialists can personally assist you and the patient throughout the entire clinical-trial process. Clinical Trial Specialists are registered nurses with extensive knowledge and training in blood cancers and understanding of clinical trials.

Your Loved One’s Treatment Plan. Once the treatment plan is in place, write down the details of your loved one’s treatment plan in the space below and on the notes page on *page 18*. Keep in mind that the treatment plan may change depending on how your loved one responds to treatment.

Questions to Ask Members of the Healthcare Team

- What does the treatment plan include?
- How will the treatment be administered?
Will the patient be treated in the hospital or at an outpatient treatment center?
- How long will the treatment last?
- What are the side effects and long-term effects of this treatment?
- Can the patient be referred to palliative care for help managing side effects?
- What signs or symptoms indicate I should call the healthcare team? And, whom can I contact after working hours if I have questions or concerns?
- What signs or symptoms indicate that a trip to the emergency room is necessary?
- Will the patient need to follow a special diet or avoid any specific foods, medications or supplements while receiving this treatment?
- Are there any other precautions that need to be taken by either the patient or myself while the patient is receiving this treatment?
- What kind of testing will be done to monitor the disease and treatment? How often will the testing be needed?
- How will we know if the treatment is effective? What options are available if the treatment is not effective?

