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## UNDERSTANDING BLOOD CANCERS AND TREATMENT OPTIONS

Visit [www.LLS.org/CaregiverWorkbook](http://www.LLS.org/CaregiverWorkbook) to access all chapters and worksheets.

**Blood, Marrow and the Lymphatic System.** Blood is the main transport system in the body. It is the liquid that flows through a person's arteries and veins. It carries oxygen and nutrients to the lungs and tissue. It carries away waste products by taking them to the kidneys and liver, which clean the blood.

**Blood Cells.** Blood contains the following components:

- **Red blood cells.** Red blood cells contain a protein called "hemoglobin" which carries oxygen to all the cells in the body and helps remove carbon dioxide from the body.
- **Platelets.** Platelets help stop bleeding at the site of an injury.
- **White blood cells.** White blood cells help fight infection and disease. There are several types of white blood cells including neutrophils, monocytes, eosinophils, basophils and lymphocytes.
- **Plasma.** The liquid part of blood, called "plasma," is largely water but also includes chemicals such as proteins, hormones, vitamins, minerals, electrolytes and antibodies.

The healthcare team will closely monitor your loved one's blood cell counts during and after treatment. See **Blood Cell Counts** on page 17 to learn more.

**Bone Marrow.** Bone marrow is the spongy tissue inside bones. Stem cells in the bone marrow develop into blood cells. The process of blood cell formation is called "hematopoiesis." Healthy individuals have enough stem cells to keep producing new blood cells continuously. Blood passes through the marrow and picks up fully developed and functional red blood cells, white blood cells and platelets to circulate through the body.



Visit [www.LLS.org/3D](http://www.LLS.org/3D) to view an interactive 3D image of blood cell development.

**The Lymphatic System.** The lymphatic system is part of the immune system, which helps protect against disease and infection. It includes

- Lymph nodes (small, oval-shaped organs located throughout the body that help trap and kill disease and infection)
- Lymphatic vessels
- The spleen (the organ that filters blood)
- Bone marrow
- The thymus gland (the organ that produces lymphocytes until young adulthood).

Lymph (clear fluid) and lymphocytes (type of white blood cells) travel through the lymph vessels into the lymph nodes where the lymphocytes destroy infection and disease that invade the body. There are three main types of lymphocytes. They are

- B lymphocytes (B cells)
- T lymphocytes (T cells)
- Natural killer (NK) cells.

Lymphocytes are also found in other parts of the body including the skin, spleen, tonsils and adenoids, intestinal lining and the thymus.

**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 of these blood cancers also contains different subtypes. Blood cancers affect people of all ages, races and genders. Blood cancers can be acute (severe and sudden onset) or chronic (disease progresses slowly).

**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 the ways in which 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 is distinguished from other types of lymphoma by the presence of Reed-Sternberg cells. These are large, cancerous cells, named for the scientists who first identified them. With proper treatment, HL can be cured in most patients.

Non-Hodgkin lymphoma (NHL) comprises 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 (about 80 to 85 percent) have a B-cell subtype of lymphoma. The others (about 15 to 20 percent) have a T-cell subtype or natural killer (NK)-cell subtype of lymphoma. Some patients with fast-growing NHL can be cured. For patients with slow-growing NHL, treatment may keep the disease in check for many years. It is important to know the patient’s exact NHL subtype because different subtypes of NHL require different treatment.

Some of the subtypes of NHL include

- Diffuse large B-cell lymphoma (DLBCL)
- Follicular lymphoma
- Burkitt lymphoma
- Cutaneous T-cell lymphoma (CTCL)
- Mantle cell lymphoma (MCL).

**Myeloma.** Myeloma begins in the bone marrow. It is a cancer of plasma cells (known as “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.

**“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](http://www.LLS.org/TheBloodline))

- 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, which progresses slowly; however, the patient has no signs and/or symptoms, even though he or she has the disease.
- Symptomatic myeloma, which 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 blood cells, red blood cells and platelets. Types of MPNs include

- Myelofibrosis
- Polycythemia vera
- Essential thrombocythemia.



For more information about blood cancers, speak one-on-one with an LLS Information Specialist who can provide you with accurate, up-to-date disease, treatment and support information. Visit [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists) or call **(800) 955-4572**.



You can also visit [www.LLS.org/DiseaseInformation](http://www.LLS.org/DiseaseInformation) or [www.LLS.org/webcast](http://www.LLS.org/webcast) to find more disease-specific information.

For more information about these diseases, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view, print or order free LLS disease booklets.

For more information about lab and imaging tests, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view, print or order the free LLS booklet ***Understanding Lab and Imaging Tests***.

**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 your loved one and all his or her other healthcare providers to know the specific diagnosis, such as “diffuse large B cell lymphoma (DLBCL),” not just the more generalized term “non-Hodgkin lymphoma.” Take your loved one’s medical records to all of his or her appointments with new healthcare providers and to any emergency room visits.

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### 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 treatment options 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
- Targeted therapy
- Radiation therapy
- Immunotherapy
- Stem cell transplantation
- Clinical trials
- Blood transfusion
- Palliative care
- 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. Drug therapies can be given in a few different ways. See **Methods To Administer Drugs** on page 12.



Once the treatment plan is decided, note the details in **Your Loved One's Treatment Plan** on page 20.

**Generic and Biosimilar Drugs.** Your loved one's treatment plan may include the use of a generic or biosimilar drugs. Both generic and biosimilar drugs are versions of brand-named drugs (the reference products) approved by the United States Food and Drug Administration (FDA). Both may offer a more affordable treatment option for patients. Generic drugs have the same active ingredients as the reference product. Biosimilars have active ingredients that are highly similar to the reference product, without any clinically meaningful differences.

**How Generics Are Made.** Generic drugs are chemical copies of the reference drug. They work the same way as brand-name medicines. The FDA approves generic drugs based on matching chemical structure.

**How Biosimilars Are Made.** Biologic products (also known as "biologics") are the reference products for biosimilar drugs. Biologics are produced through biotechnology and use living systems, such as a microorganism or a plant cell. Monoclonal antibodies and vaccines are some examples of biological products. Because the makeup of biologics are very complex, it is challenging to create imitations of the drug. Generic drug development is simple, like following a recipe with standard ingredients. Biosimilars are more challenging because they are made up of living cells, which are very sensitive to their environments and cannot be recreated by a chemical formula. Manufacturers have to create their own, unique process to create an identical outcome to an existing treatment.

Biosimilars

- Are imitations of biologics (the FDA-approved reference product)
- Are highly similar to their reference products—this means that the product is analyzed using technology that compares the characteristics of the reference product and the biosimilar.
- Have no meaningful differences from the biologics—this means that the manufacturer of the biosimilar has shown that there are no differences between the reference product and the biosimilar in terms of safety, purity and potency (safety and effectiveness). This is shown by putting the biosimilar through human clinical trials.

Visit [www.LLS.org/biosimilars](http://www.LLS.org/biosimilars) to learn more about generic and biosimilar drugs.

## 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. See **Palliative Care** on page 15.

## TIP:

Pack a tote bag with items to make waiting rooms and treatment days more bearable. Bring a book, tablet, 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!

**Helping Your Loved One Choose a Treatment Plan.** 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 to confirm the treatment plan.
- 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, treatment decisions are up to the patient. In an open discussion, you can share your perspective with the patient. Be respectful and supportive of the patient’s decisions, 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.



LLS offers free materials and services designed to simplify this search for information and support. Visit [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists) or call **(800) 955-4572**.



Visit [www.LLS.org/treatment](http://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 either 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?
- Whom should I call if the patient begins to experience a side effect?
- What side effects, symptoms or signs prompt a call to the healthcare team?
- What side effects, symptoms or signs require a trip to the emergency room?
- Is there any risk to me, as the caregiver, from this treatment?

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.



Read **Palliative Care** on *page 15* for more information about palliative care.



For more information about side effects, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) (filter by “Treatment”) to view, print or order the free LLS resources from our **Side-Effect Management** series.

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**Watch and Wait.** The watch-and-wait approach involves closely monitoring a patient's condition without starting any treatment until disease characteristics, signs and/or symptoms either 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. This approach is usually recommended for patients who are in the 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 for the blood cancer diagnosis during this period. (The patient may be on medications for other medical conditions.) The patient can avoid drug treatment and its potential side effects until they are needed. The watch-and-wait approach is based on study findings that indicate early treatment for some patients, in some situations, isn't beneficial.

Patients 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
- Pain.

**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 signs or symptoms.

Your caregiver responsibilities during this time may be limited to accompanying your loved one to checkups and providing emotional support. During watch and wait, it's very important for your loved one to follow up with the healthcare team as instructed, even if he or she feels fine. Encourage your loved one to maintain the appropriate follow-up schedule. Ask how you may be able to help, for example, scheduling appointments for him or her or sending reminders for upcoming appointments. You can also help him or her to watch for new signs and/or symptoms and make sure that they are reported to the healthcare team right away.

Ask your loved one if he or she is comfortable sharing the diagnosis with others during watch and wait. Some patients are less comfortable sharing their diagnosis if they will not be receiving treatment in the immediate future.

**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 stage.

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 can be given in different ways depending on the specific drug. See **Methods to Administer Drugs** on page 12 to learn more. Chemotherapy may also be combined with radiation therapy, targeted therapy, immunotherapy or stem cell transplantation.

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 issues, and problems with concentration and focus. Ask members of the healthcare team what to expect and alert them to any new or worsening symptoms.

**Caregiver Responsibilities During Chemotherapy.** During chemotherapy, 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. Your loved one may also need you to accompany him or her to medical appointments.

Your loved one may receive chemotherapy at a treatment center or follow an oral therapy regimen at home. Turn to **Drug Therapy at a Treatment Center** and **Drug Therapy at Home** on page 14 to learn how you can assist your loved one and questions to ask the healthcare team.

If your loved one has a device in place to administer chemotherapy drugs, you can assist your loved one in caring for the device and checking for signs of infection. Turn to **Caring for a Central Line, PICC Line or Port** on page 13 to learn more.

**Targeted Therapy.** Targeted therapy is another type of drug therapy used to treat cancer. Unlike the drugs used in chemotherapy, the drugs used in targeted therapy specifically attack cancer cells. They “target” the genetic changes or proteins that contribute to the cancer cells’ growth and survival.

Each cell in the body has chromosomes that carry genes. Genes give instructions for making proteins. Proteins help the cell to do its job. Changes to chromosomes or genes cause normal cells to become cancer cells. Cancer cells do not function properly and continue to grow and divide.

Not all blood cancer cells are the same so a targeted therapy that may be appropriate for one patient may not be appropriate for another patient. The specific genetic or molecular markers that the drug targets need to be present in the cancer cells for the drug to work. The healthcare team will do tests to identify these genetic or molecular markers.

Some examples of tests used to identify the “targets” of targeted therapy include cytogenetic analysis, which examines the chromosomes of the cancer cells, and fluorescence in situ hybridization (FISH), which is used to look at the genes or chromosomes in cells and tissues. Doctors use these tests to find cancerous changes in chromosomes and genes.

Targeted therapies may cause side effects, but they may be different or less severe than the side effects caused by chemotherapy. Usually, the drugs used in targeted therapies do not affect healthy cells as much as standard chemotherapy drugs. The types of side effects vary depending on the specific drug used. Rashes are a common side effect of targeted therapies. The patient may also experience nausea, fatigue, diarrhea, fever, muscle or joint pain, or other side effects. Ask members of the healthcare team what to expect and alert the healthcare team to any new signs or symptoms or side effects.

Targeted therapies may be used along with chemotherapy or other treatments. Targeted therapy drugs can be administered in a variety of ways. See **Methods to Administer Drugs** on page 12 to learn more.

**Caregiver Responsibilities During Targeted Therapy.** Depending on the specific treatment, your loved one may experience side effects that can make it more difficult to carry out daily tasks, such as cleaning, cooking, or grocery shopping. You can help with these tasks and assist with treatment adherence and side-effect management.

Your loved one may receive targeted therapy at a treatment center or follow an oral therapy regimen at home. Turn to **Drug Therapy at a Treatment Center** and **Drug Therapy at Home** on page 14 to learn how you can assist your loved one and questions to ask the healthcare team.

If your loved one has a device used to administer drugs in place you can assist your loved one in caring for the device and checking for signs and/or symptoms of infection. Turn to **Caring for a Central Line, PICC Line or Port** on page 13 to learn more.

**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 United States Food and Drug Administration (FDA) or are under study in clinical trials to determine their effectiveness in treating various types of cancer.

Immunotherapy treatments and the ways in which the treatments are given vary. 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 signs and symptoms or side effects.

**Caregiver Responsibilities During Immunotherapy.** Depending on the specific treatment and side effects, your loved one either may or may not need 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. If your loved one does experience side effects, you can help your loved one to manage them. You can also accompany your loved one to appointments and assist with treatment adherence.

**Radiation.** Radiation therapy is also called “radiotherapy” or “irradiation.” Radiation therapy damages the genetic material called “deoxyribonucleic acid (DNA)” within cells, preventing 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. However, the person who goes with your loved one will not be allowed in the room while the actual radiation treatment takes place.

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 become red and irritated and occasionally it will 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.” See **Chemotherapy** on page 7 and **Radiation** on page 8.

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, before he or she receives conditioning treatment.
- 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 HLAs on the donor cells are identical or similar to that of the patient, the transplant is more likely to be successful.

In some 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. The healthcare team can find matched unrelated donors (MUDs) 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 is referred to as a “haploidentical donor.” 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 haploidentical donor.

**Cord blood.** Stem cells are present in blood from the placenta and umbilical cord of a newborn baby. These stem cells can 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 stem cell transplantation, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view, print or order the free LLS booklet **Blood and Marrow Stem Cell Transplantation**.

**Graft-Versus-Host Disease (GVHD).** Graft-versus-host disease develops after an allogeneic transplantation 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 signs and/or 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. 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.

**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 may 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/or 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 you both find a place to stay that is closer to the center in case serious complications arise after your loved one is discharged from the hospital. Some treatment centers offer special housing for patients undergoing a stem cell transplant. However, cost can be an issue, so discuss options with your treatment team. During this time it is important for the patient to have a caregiver with him or her. If the patient does not have caregiver available post-transplant, the healthcare team may opt not to do a transplant. Regardless of distance, even if the patient is five minutes from the hospital, he or she must have a caregiver.



Read the **Chemotherapy** and **Radiation** sections on *pages 7 and 8* to learn more about each of these treatments.



For more information about GVHD, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view, print or order the free LLS booklet **Graft-Versus-Host Disease**.

Visit [www.joeshouse.org](http://www.joeshouse.org) for a searchable database of discounted lodging facilities near treatment centers, such as hospitality houses and hotels that offer medical rates.

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**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. A clinical trial may be the best treatment choice for some blood cancer patients. 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
- Patients whose disease is in remission (for these patients, the goal is to extend remission).
- Patients who have not been able to achieve remission.

## FACT

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

**How Do Clinical Trials Work?** A cancer clinical trial is a controlled research study conducted by doctors to test a new treatment, new combinations of treatments, or new dosages. A treatment that's proven safe and effective in a cancer clinical trial may be approved by the 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.

**Who Can Participate?** Each clinical trial has a "road map" or protocol that includes information about which patients are eligible 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.

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

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

Clinical trials are carefully designed studies that put the health and safety of the patients first. Placebos are not used in cancer clinical trials unless they are given along with an active drug. No one can be forced to take part in a study. Participation in a clinical trial is always voluntary, and patients can leave the study at any time.

**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
- Patients whose first or subsequent treatment was not effective
- Patients whose disease has come back after a period of remission
- Patients whose current treatment is causing unacceptable side effects
- Patients who desire an alternative to the suggested treatment
- A patient whose disease is in remission and who is interested in possible ways to extend remission.

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

Some of the many things a patient needs to consider before he or she decides to enter a clinical trial, include

- The potential side effects of the treatment
- Required tests and procedures
- The number of doctor visits
- The amount of time the patient may be required to be away from home
- Potential costs involved and which costs 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** or visit **[www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)**. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical-trial process. Visit **[www.LLS.org/CTSC](http://www.LLS.org/CTSC)** for more information.



For more information about clinical trials, visit **[www.LLS.org/ClinicalTrials](http://www.LLS.org/ClinicalTrials)** or visit **[www.LLS.org/booklets](http://www.LLS.org/booklets)** to view, print or order the free LLS booklet ***Understanding Clinical Trials for Blood Cancers***.

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**Methods to Administer Drugs.** The drugs used in chemotherapy, targeted therapy and other drugs can be given in different ways depending on the specific drug. Commonly used methods of administration include

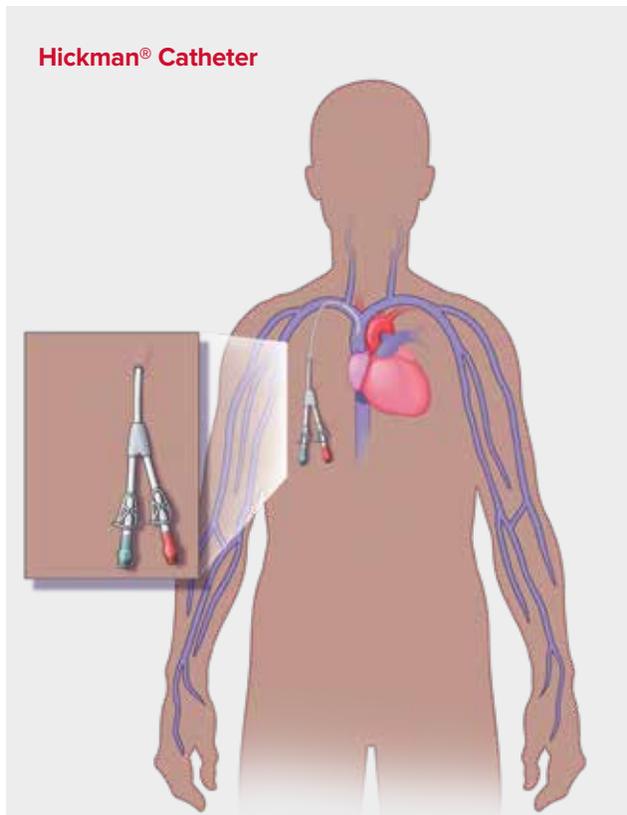
- Intravenous (IV)—into a vein
- Oral (PO)—by mouth as a pill, liquid or capsule
- Intramuscular (IM)—injection into a muscle
- Subcutaneous (SC)—injection under the skin
- Intrathecal—into the cerebrospinal fluid (CSF).

**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 central venous catheter that can stay in place longer than a regular IV catheter.

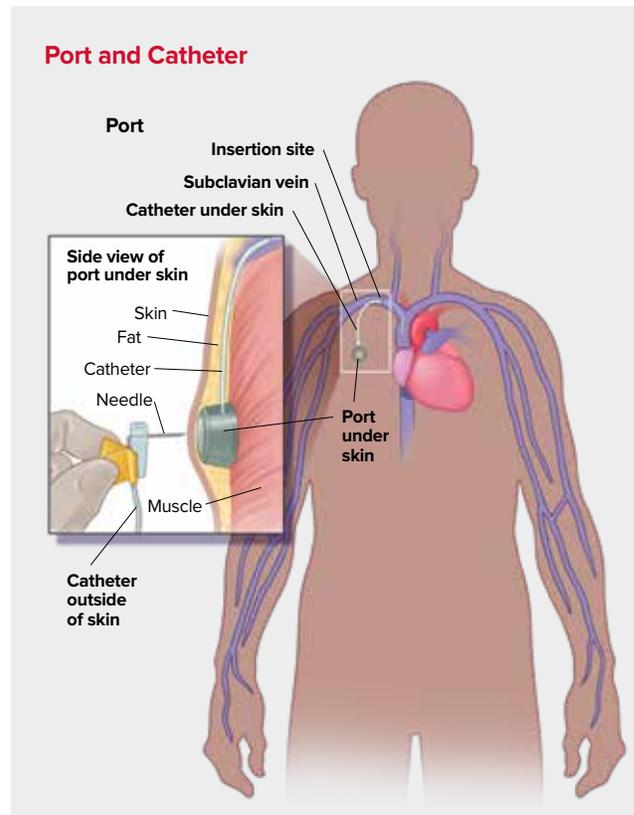
- Central line: A thin tube that is put under the skin and threaded into a large vein in the chest or neck. A central line is placed by a doctor. The central line stays firmly in place. It can remain in place for weeks or months. A central line also allows for safe and painless blood draws for lab work. Central lines are also called “central venous catheters (CVCs).” See the image of a **Hickman® catheter** on *page 13*.
- Port: This is a small device attached to a central line. The port is surgically placed, typically under the skin of the chest. After the site heals, no dressings are necessary and no special home care is needed. To access the vein, the nurse inserts a needle through the skin into the port. A numbing cream can be put on the skin before the port is used. See image of a port on *page 13*.
- Percutaneously (under the skin) inserted central venous catheter (PICC line): This type of central line is typically inserted through the skin and into a vein in the arm. The doctor or nurse 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. Once the PICC line is placed, blood for lab work can be safely and painless withdrawn from a capped, self-sealing valve at the end of the catheter.

These devices can be used to administer chemotherapy drugs, other drugs, 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.**

© Fran Milner 2018

**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 the development of blood clots (thromboses). Hospital or clinic staff will show you and your loved one how to clean and care for the device. Signs and symptoms of infection include

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

Let the healthcare team know immediately if you notice these signs and/or symptoms. Although blood clots often have no symptoms, some signs and/or symptoms of a blood clot can include pain, redness, and discoloration of the skin. An ache in the shoulder or jaw could also be a symptom 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 when you administer drugs, fluids or nutrition at home. This may include

- Learning how to connect and disconnect the lines
- Programing 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.

If your loved one’s care involves the use of a device, a member of the healthcare team will teach you how to use and care for the device. 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, and/or nutrition.

**Drug Therapy at a Treatment Center.** If the drug therapy is administered by an IV infusion either at the hospital or at a 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 therapy at a clinic or treatment center, ask the healthcare team the following questions:**

- Is there anything the patient needs to do to prepare for infusions?
- What signs and/or symptoms require medical attention, and what should I do if I notice these signs and/or symptoms?
- Whom can I call after hours or in an emergency situation?
- Are there any foods, vitamins, medications, or supplements that the patient needs to avoid because they can interact with the drug after infusions?
- Are there any precautions I need to take when helping the patient once he or she comes home after an infusion?

**Drug Therapy at Home.** Treating cancer at home has many advantages. Your loved one can be comfortable at home and avoid additional trips to the treatment center. However, when treating cancer at home, there’s a shift in responsibility from the healthcare provider to the patient (and caregiver). “Treatment adherence” means taking medication as prescribed. Treatment adherence is very important. The medication may not work effectively if the patient does not take it as prescribed by the doctor. You can assist your loved one with taking the medication as prescribed.

In some cases, your loved one may need to receive medications by an IV infusion at home. See **Additional Care and Use of Devices** above to learn more.

## Questions to Ask Members of the Healthcare Team

Before the patient begins treatment 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 the patient needs to avoid because they can interact with the drug?
- 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 member of the healthcare team after hours?

**Palliative Care.** Palliative care, or supportive 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 signs and 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
- 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 age, prognosis or stage of treatment. Palliative care may also be useful for patients who are newly diagnosed.**

### TIP:

Palliative care is appropriate for anyone who has a serious illness, regardless of age, stage of the disease or 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 signs and/or symptoms caused by cancer or the side effects of treatment, ask the healthcare team for a referral to a palliative care specialist. To help your loved one manage gastrointestinal side effects or weight loss or weight gain issues, you can ask for a referral to a registered dietitian.

**Pain Management.** A cancer diagnosis does not mean that your loved one will have pain. However, a number of cancer patients do have pain at some point. Your loved one may experience pain related to the cancer, its treatment (eg, bone or nerve pain as a side effect of certain medications) or other coexisting diseases (eg, arthritis). Pain may be short lived (acute) or continue longer after a disease or injury (chronic or persistent). The type and severity of pain depends on the type of cancer, treatment, and the patient's overall health. Pain left untreated can suppress the immune system, delay healing and may lead to depression. Your loved one should not try to manage pain with over-the-counter medications without discussing them with the healthcare team first. Some medications should not be combined with certain cancer treatments. The healthcare team can help determine the best plan to manage your loved one's pain.

**Treatments for Pain Management.** The healthcare team should assess your loved ones' pain and ensure it's managed throughout treatment and recovery. Pain management often includes a combination of medications and nondrug options to provide relief. Treatments for pain management may include

- Medication: nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, opioid analgesics, antidepressant and anticonvulsant drugs; nerve blocks, corticosteroids, anesthetics; specialized injections, infusions, topical creams and skin patches
- Other medical interventions: medical devices, surgical procedures or treatments to address the source of the pain (eg, radiation therapy to relieve pain caused by enlarged liver, lymph nodes or spleen)
- Psychosocial interventions: stress management, counseling, coping mechanisms
- Rehabilitation techniques: exercise therapy, application of heat or cold, myofascial therapy
- Complementary and alternative medicine (CAM): acupuncture, hypnosis, yoga, aromatherapy, therapeutic massage, supplements.

Consult with the healthcare team before your loved one tries any CAM therapies or takes new medications or supplements. Some therapies may interfere with cancer treatment.

Be persistent in working with the healthcare team to set up a pain management plan that reduces suffering and improves function. If the pain is not being managed effectively, ask for a referral to a pain specialist.

**Supporting Your Loved One.** As a caregiver, encourage your loved one to seek treatment for pain early to avoid suffering and additional health problems later. Early treatment of pain is more effective than waiting until it is more severe. Your loved one may be reluctant to seek pain care for the following reasons:

- Fear that seeking pain relief will distract from treating the cancer
- A false belief that relief isn't possible
- Fear that pain may be a sign of disease progression
- Worry about becoming addicted to pain meds
- Wanting to appear strong and brave
- Worrying about the side effects of pain medication.

These concerns should not keep your loved one from seeking relief. Pain can be managed. No pain should go untreated or ignored. Unrelieved pain may cause needless suffering and suppress the immune system.

**Addiction Risk.** People who have a personal or family history of substance abuse or a history of mental illness have an increased risk of developing an addiction to opioid medications. If this applies to your loved one, encourage him or her to discuss concerns and options with the healthcare team. Taking medications as prescribed by the doctor greatly reduces the risk of addiction. Discuss other ways to decrease the risk of addiction with the healthcare team. Strategies may include only taking medication for a short period of time, changing medication and using other pain management techniques.

**Keeping Track of Pain.** Keeping a record of your loved one's pain on a daily or weekly basis can help the healthcare team understand the nature and extent of the pain and how to manage it. You can help your loved one track and record his or her pain.



Use **Worksheet 10: Pain Log** to keep a record of your loved one's pain.



For more information about pain, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view, print or order the free LLS fact sheet **Pain Management**.

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**Blood Cell Counts.** The healthcare team will order frequent blood tests to monitor your loved one's blood cell counts, both during and after treatment. Blood cancers and treatment for blood cancers affect blood cell counts in a number of different ways. Patients with low blood cell counts can develop

- Anemia (a low number of red blood cells)
  - Red blood cells contain hemoglobin which carry oxygen around the body. Patients with severe anemia can be pale, weak, tired and become short of breath.
- Thrombocytopenia (low numbers of platelets)
  - Patients with thrombocytopenia are at risk for excessive bruising and bleeding. Bleeding can occur from a wound or it can be internal. Ask the healthcare team what precautions your loved one should take.
- Neutropenia (a low number of neutrophils, a type of white blood cell)
  - Patients with neutropenia are at an increased risk of infection.
  - Pancytopenia (a low number of all three blood components).

**Treating Low Blood Cell Counts.** Severely low blood cell counts can lead to serious complications that can cause delays in treatment. Common treatments include

- Blood transfusions to replace blood cells (See **Blood Transfusions** on page 19.)
- Medications called “growth factors” to stimulate the bone marrow to produce more blood cells.



For more information about blood cell counts, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) (filter by “Treatment”) to view, print or order the free LLS fact sheet **Side Effect Management: Managing Low Blood Cell Counts**.

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**Monitoring Blood Cell Counts and Lab Values.** Be sure to talk with the healthcare team about your loved one's blood cell counts, especially if the levels change. Ask for an explanation and if there is anything to do to help blood cell counts return to a healthy range. Find out if your loved one needs to take any special precautions to avoid complications. Ask members of the healthcare team for printed copies of all lab reports to keep with your loved one's medical records.

If the hospital or treatment center provides a web-based “patient portal” to access medical records, ask the healthcare team how to access and navigate the patient portal to view lab reports.

## LAB REPORT TERMINOLOGY

These definitions of lab terms will help you understand the information on the lab report. Ask the patient's healthcare team to explain how changes in these readings affect the patient's health.

<b>Absolute Neutrophil Count (ANC)</b>	The number of neutrophils (a type of white blood cell that fights infection). It is calculated by multiplying the total number of white blood cells by the percentage of neutrophils.
<b>Complete Blood Count (CBC)</b>	The number and types of cells circulating in the blood. A CBC is measured using laboratory tests that require a blood sample.
<b>Differential</b>	A breakdown of the different types of white blood cells (WBCs) that make up the total WBC count. The different types of WBCs include neutrophils, band neutrophils, lymphocytes, monocytes, eosinophils, and basophils.
<b>Hematocrit (HCT)</b>	The amount (percentage) of blood that is occupied by red blood cells.
<b>Hemoglobin (HGB)</b>	A protein in red blood cells (RBCs) that carries oxygen to cells and tissues throughout the body. The HGB test is used to check for low (anemia) or high (polycythemia) counts of hemoglobin.
<b>Mean Corpuscular Hemoglobin (MCH)</b>	Calculation of the average amount of hemoglobin in a single RBC; the amount is determined by the hemoglobin divided by the RBC count.
<b>Mean Corpuscular Hemoglobin Concentration (MCHC)</b>	Calculation of the average concentration of hemoglobin per unit volume in a single RBC; the concentration is calculated by multiplying hemoglobin by 100 and then dividing by hematocrit.
<b>Mean Corpuscular Volume (MCV)</b>	Calculation of the average volume of the red blood cells (RBCs); the value is determined by the hematocrit divided by the RBC count.
<b>Mean Platelet Volume (MPV)</b>	The average volume of platelets in the blood.
<b>Platelets (PLTs)</b>	Small cells that stick to the site of a blood vessel injury where they clump up and seal off the injured blood vessel to stop bleeding. This measures the number of platelets in a sample of blood.
<b>Red Blood Cell Distribution Width (RDW)</b>	The numerical expression of the degree of variation in the volume of the population of RBCs. Typically, as new normal-sized cells are produced, the RDW increases.
<b>Red Blood Cells (RBCs)</b>	Red blood cells contain a protein called "hemoglobin" which carries oxygen to the cells and tissues of the body. The RBC count is the amount of red blood cells in the blood.
<b>White Blood Cells (WBCs)</b>	White blood cells (or leukocytes) help the body to fight infections. There are several different types of white blood cells; each type has a different function. The WBC count is the total of all the white blood cells in the blood.

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

**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 that he or she is experiencing any of the following signs or symptoms, however slight, alert the nursing staff promptly to prevent avoidable serious complications. Look for

- 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 signs and/or 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 the heart and liver. The patient may need medication to remove excess iron from the body.

- Cytomegalovirus (CMV) transmission
  - Cytomegalovirus is 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](http://www.LLS.org/booklets) to view, print or order the free LLS booklet **Blood Transfusion**.

**Caregiver Responsibilities During Blood Transfusions.** As a caregiver, you can accompany your loved one to the blood transfusion appointments. Transfusions 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.

**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 following notes pages. 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?
- Does a caregiver need to be with the patient while the treatment is administered?
- What are the side effects and long-term effects of this treatment?
- Can the patient be referred to a palliative care specialist to get help with managing side effects?
- What signs and/or symptoms indicate I should call the healthcare team? Whom can I contact after working hours if I have questions or concerns?
- What signs and/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?



