

# Blood and Marrow Stem Cell Transplantation Guide



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## A six-word narrative about living with blood cancer from patients in our LLS Community

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Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.



Discover what thousands already have at  
[www.LLS.org/Community](http://www.LLS.org/Community)

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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Drugs may have been approved since this book was printed.

Check [www.LLS.org/DrugUpdates](http://www.LLS.org/DrugUpdates) or call (800) 955-4572.

## INTRODUCTION

Thank you for picking up this book about stem cell transplantation. Stem cell transplantation is a type of treatment for some patients with blood cancers. This easy-to-understand guide will provide you with basic information about stem cell transplantation. If you are interested in finding out more information about stem cell transplantation, you can order the free LLS booklet *Blood and Marrow Stem Cell Transplantation*. Go online to [www.LLS.org/booklets](http://www.LLS.org/booklets) to order a copy or download a PDF. You can also call an LLS Information Specialist at (800) 955-4572 for a copy and ask other questions.

Over 17,500 stem cell transplantations are performed each year in the United States. As transplantation procedures and follow-up care have improved, stem cell transplantation has become safer, and patient survival continues to improve. Stem cell transplantation might help patients live longer and may even offer the possibility of a cure for certain blood cancers in some patients.

This guide has sections with information about stem cell transplantation and questions to ask your healthcare team. Some words in the guide may be new to you. See *Health Terms* beginning on *page 34*, or call our Information Specialists at (800) 955-4582.

## PART 1 Understanding Stem Cell Transplantation

For thousands of people with blood cancers, stem cell transplantation (SCT) is a potentially life-saving treatment. Most patients who undergo SCT have blood cancers such as leukemia, lymphoma, myeloma, myelodysplastic syndromes or myeloproliferative neoplasms.

### About Bone Marrow, Blood and Blood Cells

The definitions in this section about normal blood and bone marrow may help you understand SCT in the rest of this guide.

**Bone marrow** is the spongy center located inside the bones, where blood cells are made.

**Blood cells** begin as stem cells in the bone marrow. Stem cells grow and mature into different types of cells: red blood cells, white blood cells and platelets.

**Red blood cells** carry oxygen throughout the body. When the number of red blood cells is below normal, a condition called **anemia** may develop. Patients with anemia may feel weak, tired or short of breath.

**White blood cells** fight infection in the body. There are two major types of white blood cells:

- Lymphocytes, which are infection-fighting cells:
  - B cells
  - T cells
  - NK cells
- Germ-eating cells:
  - Neutrophils
  - Monocytes

**Platelets** help stop bleeding by clumping together (called **clotting**) at the site of an injury.

**Plasma** is the liquid part of the blood. Although mostly water, plasma also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.

# What Is a Stem Cell Transplantation?

Blood stem cells are produced in the marrow of the bones and can become any kind of blood cell the body needs. Stem cells are constantly dividing and maturing into different types of blood cells, replacing older and worn-out blood cells in the body. They produce billions of new blood cells every day. If the stem cells cannot make enough new blood cells, many serious health problems can occur. These problems may include infections, anemia or bleeding.

Healthy stem cells are needed to live. When cancer or cancer treatments destroy the stem cells, stem cell transplantation (SCT) may be the best treatment option. Stem cell transplantation is a procedure in which a patient receives healthy stem cells to replace damaged stem cells.

There are two types of SCT:

- **Autologous** transplantation uses the patient's own stem cells. These cells are collected from the patient and stored for transplantation.
- **Allogeneic** transplantation uses stem cells from a donor. A donor may be a family member or someone who is not related to the patient.

Before SCT, the patient receives high doses of chemotherapy, and sometimes radiation therapy, to prepare the body for transplantation. This is called **conditioning treatment**.

The conditioning treatment can be very hard on a patient's body and can lead to severe side effects and complications. Therefore, it is important for patients to discuss all the risks and benefits of SCT with their doctors. The doctor should also discuss other possible treatment options including taking part in a clinical trial.

# Ask Your Doctor

Talk with the doctor and ask questions about your treatment options including SCT. This will help you become actively involved in making decisions about your medical care.

When you meet with your doctor

- Ask questions. See *page 40* of this guide for a list of questions. Find other “What to Ask” question guides at [www.LLS.org/WhatToAsk](http://www.LLS.org/WhatToAsk). Examples of some questions include:
  - What are my treatment choices?
  - Are there any clinical trials that I can join?
  - When do you think treatment should begin?
  - Is a stem cell transplantation a treatment option?
- Take notes. It may be helpful to write down the answers to your questions and review them later.
- Audio record information from the doctor and then listen to the recording later. Ask the doctor and staff if recording is permitted (smart phones have a “record” function; ask someone how to use it).
- Bring a caregiver, friend or family member who can listen to the doctor along with you, take notes and offer support.
- Make sure you understand what the doctor is saying. If you do not understand, ask the doctor to explain it again.

If you need more information or are not sure about your treatment choices, consider getting another opinion (a “second opinion”) from a different, qualified doctor. If you feel uncomfortable about how to tell your doctor that you want a second opinion, call our Information Specialists at (800) 955-4572 to discuss a way that makes you comfortable.

### Transplant Eligibility

Before receiving an SCT, patients must have a checkup to make sure that they are healthy enough for the procedure.

In order to find out if a patient is a good candidate for SCT, the patient's doctor will consider

- The patient's general health
- Results of the physical checkup and medical tests
- The type and stage of cancer or disease
- Previous medical treatments
- The likelihood that the disease will respond to the transplant
- The ability to use the patient's own stem cells, or the availability of a suitable donor

Some patients may not be eligible for standard SCT due to advanced age or other major health problems such as heart, lung or kidney disease. For some of these patients, a reduced intensity allogeneic SCT may be a treatment option (see *page 14*).

### Medical Tests

Stem cell transplantation (SCT) is a demanding medical procedure. Doctors will order medical tests to make sure that patients are healthy enough for this treatment. Some of these tests may include:

**Chest x-ray.** A chest x-ray provides information about the size of the heart and lungs, and it may also detect the presence of infection or lung disease.

**Pulmonary function test.** A breathing test is used to measure how well the lungs are working.

**Electrocardiogram (EKG).** A test that evaluates the heart's rhythm.

**Echocardiogram (ECHO).** A test that shows the size, shape, and position of the heart. The test also shows the parts inside the heart (such as the valves), and the motion of the heart while it is beating.



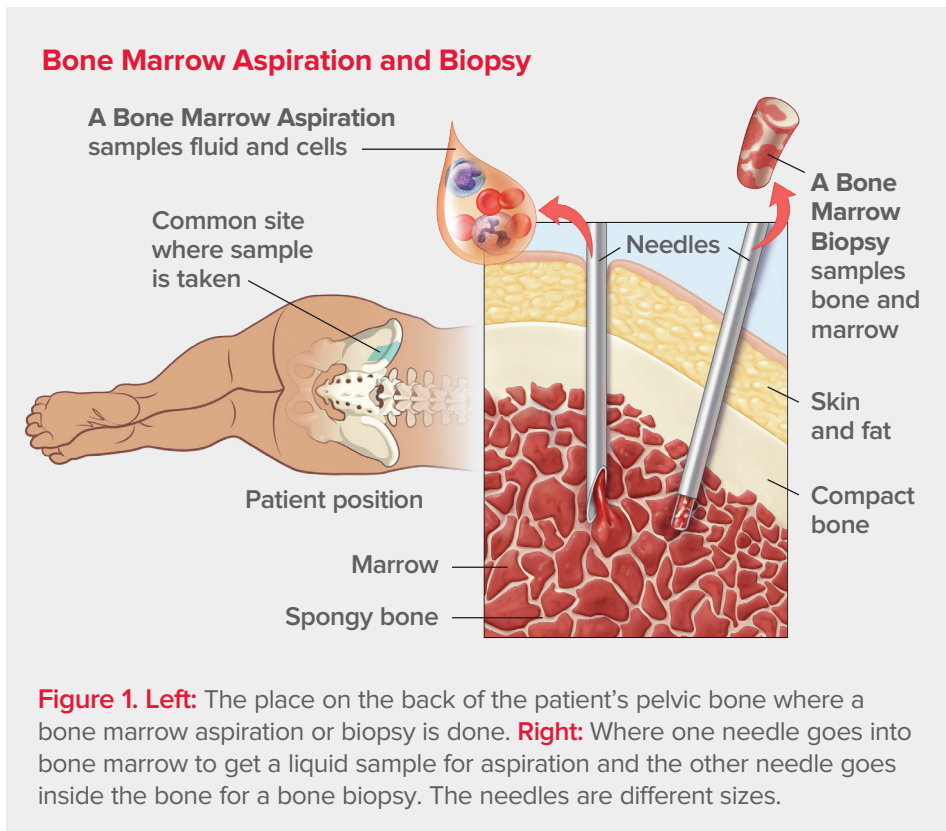
**Blood tests.** Blood tests are used to evaluate kidney and liver function, thyroid function, blood counts and hemoglobin levels. These tests show past exposure to certain infectious diseases, such as human immunodeficiency virus (HIV) and cytomegalovirus (CMV). Blood tests also screen for viral and bacterial infections.

**Computed tomography (CT or CAT) scans.** Computed tomography scans are x-rays that provide detailed images of the body including soft tissue and bone.

**Urine tests.** These tests are used to measure kidney function.

**Bone marrow aspiration and biopsy.** Bone marrow aspiration and bone marrow biopsy are two tests that may be done in the doctor's office or in a hospital. These tests are often done at the same time. See **Figure 1**, below.

- A bone marrow aspiration removes a sample of fluid with cells from the bone marrow.
- A bone marrow biopsy is done with a slightly larger needle and removes a small amount of bone filled with marrow cells.



**Figure 1. Left:** The place on the back of the patient's pelvic bone where a bone marrow aspiration or biopsy is done. **Right:** Where one needle goes into bone marrow to get a liquid sample for aspiration and the other needle goes inside the bone for a bone biopsy. The needles are different sizes.

Some patients are awake for this procedure. Medication may be used to numb the body area where the procedure will take place. This is usually the area near the patient's hip bone. Some patients are given a drug and sedated (asleep) for the procedure.

Blood and bone marrow tests may be done both during and after treatment. The tests are repeated to see if treatment is working.

**Lumbar puncture.** This is a procedure that is used to check for abnormal cells in the fluid that surrounds the brain and spinal cord called the **cerebrospinal fluid**. A thin needle is inserted into the lower part of the spinal column and a small amount of cerebrospinal fluid is collected. A lumbar puncture is done only for certain types of leukemia and lymphoma.

**Dental examination.** A dental checkup is needed to ensure that any dental problems, such as cavities, loose fillings or gum disease, are resolved before the transplantation.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publication *Understanding Lab and Imaging Tests* at [www.LLS.org/booklets](http://www.LLS.org/booklets), to learn more about lab tests and what to expect, or contact an Information Specialist for a copy.

## The Role of a Caregiver

Patients who undergo SCT will need an adult caregiver to provide support and care throughout the process. Sometimes a caregiver is one person, but often several people help at different times. A caregiver can be a spouse, partner, sibling, parent, adult child or a close friend. A caregiver should be with the patient at all times after the patient is discharged from the hospital in case unexpected complications arise and help is needed. Members of the patient's healthcare team will teach the caregiver(s) the necessary skills to care for the patient.

Once the patient returns home, the caregiver will help to

- Ensure that the patient takes the correct dose of medication at the right time

- Monitor the patient for new symptoms and immediately report them to the patient's medical team
- Prepare meals and clean the house
- Provide transportation to frequent medical appointments
- Assist the patient with daily activities including caring for pets, if necessary
- Assist with financial issues and ensure that household bills are paid on time
- Provide emotional support

## Cost of Transplantation

Stem cell transplantation (SCT) is a very expensive procedure, and patients should discuss financial issues with their treatment team. Transplant centers have staff members who can help patients get answers to financial questions concerning health insurance and financial assistance.

Most insurance plans cover some of the costs of SCT for certain cancers or diseases. Before undergoing SCT, patients should contact their medical insurance providers and determine which costs their insurance provider will cover.

Patients in need of financial assistance should talk with their transplant teams about organizations that offer financial assistance to patients who qualify. Patients and caregivers can also call an LLS Information Specialist at (800) 955-4572 for additional resources.

In addition to medical bills, both patients and caregivers may need to plan for taking time away from work. Patients and their caregivers may be eligible to take unpaid, job-protected leave with continuation of group health insurance coverage under the Family and Medical Leave Act. Patients and caregivers should contact their workplace human resources department to see if they are eligible under this law.

## Fertility

High doses of chemotherapy and radiation can affect cells in both male and female reproductive systems. Patients who may want to have children in the future should discuss options to preserve fertility before having an SCT. If possible, patients may also want to discuss these options with a doctor who specializes in fertility and reproduction. Many cancer centers have reproductive specialists who will suggest specific options for each patient.

**For more information, see the free LLS booklet, *Fertility Facts* available at [LLS.org/booklets](http://LLS.org/booklets).**

### PART 3 Types of Stem Cell Transplantation

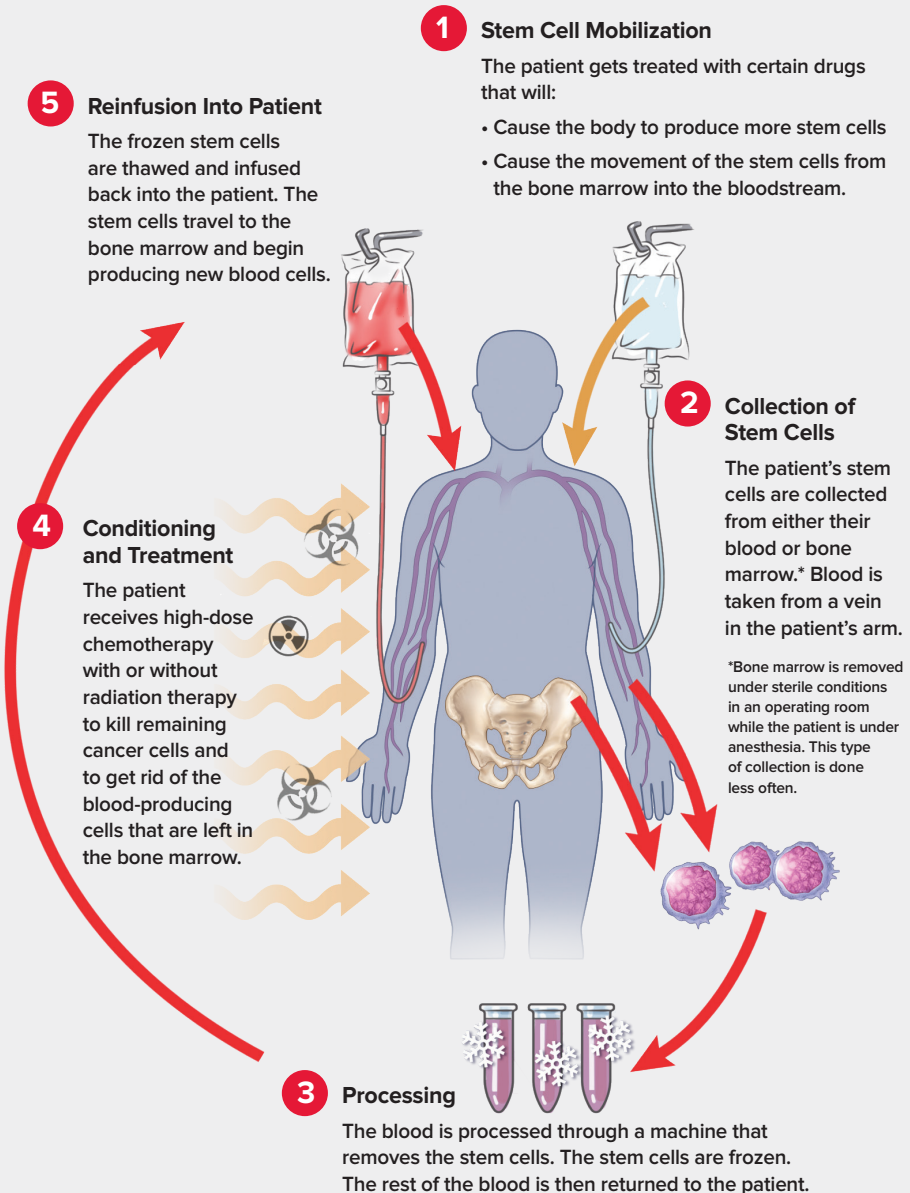
Depending on a patient's disease and health, the doctor may recommend either an autologous or an allogeneic stem cell transplantation (SCT).

## Autologous Stem Cell Transplantation

This procedure uses the patient's own stem cells for transplantation. See **Figure 2** on *page 11*. The stem cells are collected from the patient in advance and are frozen. After the patient undergoes a conditioning treatment of high doses of chemotherapy, either with or without radiation therapy, the stem cells are then returned to the patient's body, where they move through the bloodstream to the bone marrow.

This type of transplant is often used to treat blood cancers such as Hodgkin lymphoma, non-Hodgkin lymphoma and myeloma.

# Autologous Stem Cell Transplantation



**Figure 2.** This illustration shows the autologous stem cell transplantation process. Once the stem cells are collected from the donor (patient), the cells are mixed with a cryoprotective agent so that they can be frozen (for many years) and then later thawed without injury to the cells. Once the patient has completed the conditioning treatment, the frozen stem cell collection is thawed and infused into the patient so that blood cell production can be restored.

# Allogeneic Stem Cell Transplantation

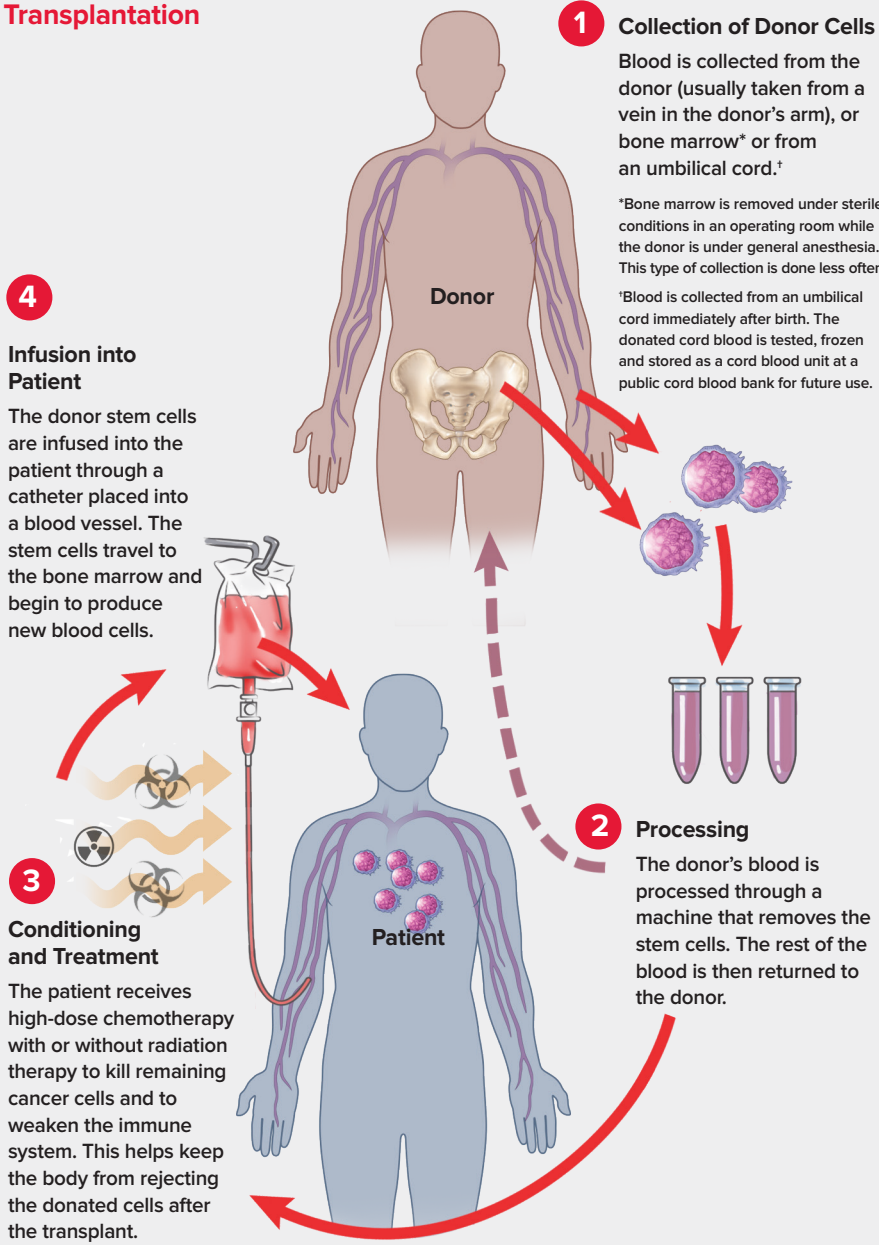
This type of stem cell transplantation (SCT) involves the use of stem cells from someone other than the patient. See **Figure 3** on *page 13*. The donated stem cells can come from either a person related or not related to the donor.

Before an allogeneic SCT, the patient receives conditioning treatment of chemotherapy and sometimes also radiation therapy. This conditioning treatment is given to destroy any remaining cancer cells in the body. But it also weakens the patient's immune system, which helps keep the body from rejecting the donated cells after transplantation. Conditioning treatment allows the donor cells to move through the bloodstream to the bone marrow, where the donor cells begin to grow and produce new blood cells, including red blood cells, white blood cells and platelets.

For some types of blood cancers, an allogeneic SCT may work directly to destroy cancer cells. This is called the **graft-versus-tumor (GVT)** effect. The GVT effect happens when white blood cells from the donor (the "graft") identify any remaining cancer cells (the "tumor") in the patient as foreign and attack them. For some patients, GVT is crucial for the effectiveness of their treatment. It can help prevent their cancer from relapsing. This benefit can only occur in allogeneic SCT. It does not occur in an autologous SCT.

Allogeneic SCT is often used to treat blood cancers such as leukemia, myelodysplastic syndromes and myeloproliferative neoplasms.

# Allogeneic Stem Cell Transplantation



**Figure 3.** This illustration shows the allogeneic stem cell transplantation process. Once the stem cells are collected from the donor, the cells are mixed with a cryoprotective agent so that they can be frozen (for many years), and later, once a patient is identified and the cells are needed, the cells can be thawed without injury and shipped to the patient.

## **Reduced-Intensity Allogeneic Stem Cell Transplantation.**

Reduced-intensity allogeneic SCT (sometimes called mini-transplant or nonmyeloablative transplant) also uses stem cells from a donor, but the conditioning treatment contains lower, less toxic doses of chemotherapy and radiation. This type of SCT may be an option for certain patients who are older or who are otherwise not healthy enough or strong enough to undergo standard allogeneic SCT.

The success of reduced-intensity SCT depends on the graft-versus-tumor (GVT) effect of the donor stem cells, rather than on high-dose treatments to kill the cancer cells. The goal is to have the donor stem cells take up residence in the recipient's marrow and produce white blood cells that will attack the patient's remaining cancerous blood cells.

Research shows that reduced-intensity allogeneic SCT may be effective in treating certain patients with chronic myeloid leukemia (CML), acute myeloid leukemia (AML), non-Hodgkin lymphoma (NHL), chronic lymphocytic leukemia (CLL) or myelodysplastic syndromes (MDSs).

**Tissue Typing for Allogeneic Transplantation.** Once it is determined that allogeneic SCT is a treatment option for a patient, the patient's doctor will begin to search for a suitable donor. For most patients, a close match is important because it improves the chances for a successful transplant by:

- Helping the donor stem cells engraft (grow and make new blood cells in the patient's body)
- Reducing the risks of complications

**HLA Matching.** People have different sets of proteins or markers called **human leukocyte antigens** (HLAs) on the surface of most cells. They make up a person's tissue type, which varies from person to person. For HLA matching:

- The patient and potential donors have their blood drawn
- The blood is tested in a lab to determine each person's HLA type
- The patient's HLA type is compared to the HLA type of potential donors

There are many HLA markers, but HLA typing is usually based on either 8, 10 or 12 HLA markers. In many transplant centers, doctors require at least 6 or 7 of the 8 markers to match, in order to perform an SCT.

Sometimes it is difficult to find an HLA match. Individuals inherit half of their HLA markers from their mothers and half from their fathers, so most often the ideal donor is a patient's sibling who has inherited the same HLA



markers. On average, a person has one chance in four of having the same HLA type as his or her sibling, but many patients do not have a sibling with the same tissue type. For those patients who do not have a matched family donor, an unrelated donor may be found through a volunteer donor registry.

**Haploidentical Transplantation.** To increase the number of potential donors, some transplant centers have begun to perform half-match (haploidentical) transplants for patients who cannot find a closely matched HLA donor. In many cases a healthy, first-degree relative (a parent, sibling or child) can be a half-match donor and donate stem cells. Because a child receives half of his or her HLA markers from a parent, a biological child and his or her parent will always be a half match, while there is only a 50 percent chance of a sibling being a half match. As a result, most individuals will have a suitable related haploidentical donor.

## PART 4 Stem Cell Collection

There are three possible places from which to collect blood stem cells. They are:

- Peripheral blood, the blood circulating throughout the body
- Bone marrow, where most stem cells are found
- Umbilical cord blood of newborn babies

Stem cells from any of these sources can be used in stem cell transplantation (SCT). The doctor chooses the best source for each patient.

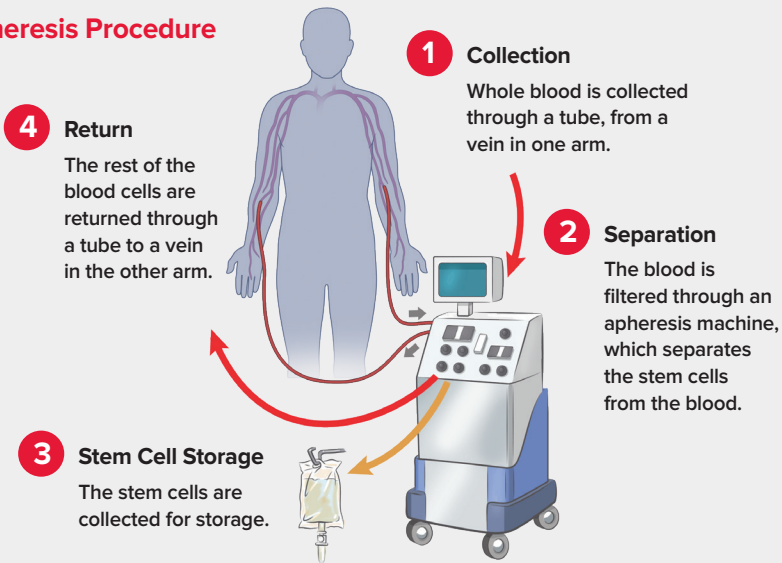
### Peripheral Blood

The stem cells used in a peripheral blood SCT are collected from the bloodstream. It is the most common source of stem cells for both autologous and allogeneic SCTs. Collecting stem cells from the bloodstream is a nonsurgical procedure that collects blood through a vein in the arm. It involves little pain, no anesthesia and no hospital stay.

**Stem Cell Mobilization.** To obtain enough stem cells from the peripheral blood for transplantation, the patient/donor is given drugs that stimulate the release (called **mobilization**) of stem cells from the bone marrow into the blood.

**Apheresis.** Once the stem cells are mobilized, they are collected from the blood of the patient/donor using a process called **apheresis**. See **Figure 4** below. The blood is removed from one of the donor's large veins, usually through a needle inserted into the arm as shown in the illustration. The blood is then circulated through an apheresis machine, which separates the blood into four components: plasma and red blood cells, white blood cells and platelets. The rest of the blood is returned to the patient's/donor's body.

### Apheresis Procedure



**Figure 4.** This illustration shows the apheresis process. This process is for a patient or a donor. This procedure may need to be repeated to obtain enough cells for the transplant. One or two collections may be enough to get the right amount of cells from the donors for allogeneic transplantation. For some patients getting an autologous transplant, three or more apheresis procedures may be needed.

## Bone Marrow

In certain situations, especially in allogeneic SCT, the doctor may prefer stem cells collected from the donor's bone marrow. Bone marrow donation is a surgical procedure that is done in an operating room, using either regional or general anesthesia. The doctor inserts a special hollow needle through the skin into one or more areas of the hip bone and withdraws bone marrow from the top edge of the hip bone of the donor. Several pints of marrow are removed. See **Figure 1** on *page 7*.

## Umbilical Cord Blood

The blood in the umbilical cord and placenta of newborn babies contains stem cells. This blood is collected after the baby is born. The cord blood is placed in a sterile bag and then transported to a cord blood bank for testing, freezing and long-term storage.

### PART 5 Conditioning Treatment

**Conditioning** is the term used for the treatments that prepare patients for stem cell transplantation (SCT). Conditioning is usually a combination of two or more chemotherapy medications. Sometimes, it also includes radiation therapy.

The conditioning treatment

- Provides aggressive treatment to destroy any remaining cancer cells
- Weakens the patient's immune system to keep the body from rejecting the donated cells (in patients who receive stem cells from a donor)

Some patients have a day or two of rest between their conditioning treatment and their stem cell infusion. The rest period gives the chemotherapy time to leave the patient's body.

## PART 6 Stem Cell Infusion

On the day of the stem cell transplant (SCT), the patient receives the stem cells in a procedure that is very similar to receiving blood or medicine through an intravenous (IV) catheter. A catheter is a thin, flexible plastic tube that is inserted into the body to allow, for example, the flow of fluids, delivery of medications, or drawing of blood. Infusing the stem cells usually takes several hours. Patients are checked frequently for signs of fever, chills, hives, a drop in blood pressure or shortness of breath. Often, patients experience no side effects from the infusion.

## PART 7 Immediate Post-Transplant Period

After the stem cells are infused, they will travel in the bloodstream to the bone marrow. These stem cells begin to divide and make new blood cells in the bone marrow, a process called engraftment. Engraftment usually happens within the first 30 days after transplantation, but sometimes it can take longer. The doctor will check the patient's blood counts every day to see if the patient's bone marrow has begun producing new blood cells. As engraftment occurs, the numbers of white blood cells, red blood cells and platelets begin to increase in the patient.

## Side Effects of the Conditioning Treatment

The term **side effect** describes the way that treatment affects healthy cells, and often defines the negative or undesirable effects from a treatment. Patients should talk with their doctors about side effects before they begin treatment.

**Here are some questions that you may want to ask your healthcare team.** See *page 40* for a full list of questions in this Guidebook.

1. What are the common side effects of treatment?
2. What side effects should I report to my healthcare team right away?
3. How long will the side effects last?
4. How can potential side effects be prevented or managed?

Patients react to treatments in different ways. For some patients, side effects may be mild. For others, side effects may be uncomfortable and difficult. Some side effects are serious and may last a long time. The following is a list of the major side effects of conditioning treatment that may occur.

**Low Blood Cell Counts.** After conditioning treatment and before engraftment occurs, blood counts drop to their lowest levels. During this time patients are at risk of (1) infections due a low white blood cell count, (2) anemia due to a low red blood cell count, and (3) bleeding due to a low platelet count.

**Infections.** White blood cells are part of the immune system and they fight infections. During the post-transplant period, patients are very vulnerable to infections because they have very low white blood cell counts. The patient's healthcare team will try to prevent and treat any infections that develop. Many precautions are taken to reduce the patient's risk of infection. For example:

- Patients receive antibiotics, antiviral and antifungal agents to prevent infections.
- Handwashing is very effective in reducing the spread of germs that cause infections. All visitors entering a patient's room should wash their hands.
- No visitors are allowed if they are sick. Patients should avoid close contact with anyone who has a cold, flu, chicken pox, measles or any other illness that can spread to the patient. Patients should also avoid contact with people who have had recent immunizations with live viruses.
- Plants and flowers should not be kept in the patient's room because they are potential sources of harmful microorganisms.
- Patients should receive a diet comprising food that contains low numbers of potentially harmful micro-organisms. Some common foods that should be avoided include raw and undercooked meat and fish, non-pasteurized dairy products, raw eggs, raw honey, and unwashed raw vegetables and fruit.

Patients should continue to follow the recommendations mentioned above even after they are discharged from the hospital, because it takes time for the immune system to recover. They should speak to members of their treatment team for specific recommendations about an appropriate diet or ask for a referral to a dietitian.

**Anemia.** Patients with low red blood cell counts may experience weakness, fatigue, and shortness of breath. Transfusions of red blood cells can ease symptoms until the bone marrow begins to produce sufficient numbers of red blood cells.

**Thrombocytopenia.** Thrombocytopenia is a condition in which there is a lower-than-normal number of platelets in the blood. After transplantation, platelet counts are low. The low number of platelets may result in easy bruising and excessive bleeding. Patients receive platelet transfusions if their platelet counts are too low.

**Other Side Effects.** In addition to low blood counts, the conditioning treatment can cause other short-term side effects. These include

- Upset stomach and vomiting
- Mouth sores
- Diarrhea
- Constipation
- Blood in the urine
- Extreme tiredness
- Fever
- Skin rashes
- Achy feeling
- Hair loss
- Lung, heart or nerve problems

There may be other side effects that are not listed here that patients should watch for when having a specific treatment. Talk to the doctor about the possible side effects of treatment.

It is important for patients to notify their doctor or nurse of any side effects. Treatment to prevent or manage nausea, vomiting, diarrhea and other side effects can help patients feel more comfortable.

### **WANT MORE INFORMATION?**



You can view, print or order the free LLS booklet *Understanding Side Effects of Drug Therapy* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

# Graft-Versus-Host Disease

Graft-versus-host disease (GVHD) is a common but potentially serious complication of standard allogeneic and reduced-intensity allogeneic SCT. Remember that the cells from the donor are called the “graft” and the recipient of these cells is the patient, called the “host.” Sometimes, the cells from the donor (graft) sense that healthy cells of the patient (host) are foreign, and attack and damage the patient’s normal cells. GVHD can be mild, moderate or severe. In some cases, it can be life-threatening.

A close HLA match between the donor and patient helps to lower the risk of GVHD. There are also medications that help prevent GVHD. Even with a close HLA match and medication, some people still get GVHD.

**Types of Graft-Versus-Host Disease.** There are two main categories of GVHD: acute GVHD and chronic GVHD. Each type affects different organs and tissues and has different signs and symptoms. Patients may develop one type, both types, or neither type.

**Acute GVHD.** Acute GVHD usually develops within the first 100 days after transplantation, but it can occur later. Acute GVHD can affect the skin, the gastrointestinal tract or the liver.

## Symptoms of Acute GVHD

Skin	Gastrointestinal Tract	Liver
<ul style="list-style-type: none"><li>○ Rash that can be very faint or severe</li></ul>	<ul style="list-style-type: none"><li>○ Nausea</li></ul>	<ul style="list-style-type: none"><li>○ Jaundice (yellowing of the skin or eyes)</li></ul>
<ul style="list-style-type: none"><li>○ Blisters</li></ul>	<ul style="list-style-type: none"><li>○ Vomiting</li></ul>	<ul style="list-style-type: none"><li>○ Dark urine</li></ul>
<ul style="list-style-type: none"><li>○ Flaking skin</li></ul>	<ul style="list-style-type: none"><li>○ Stomach cramps</li><li>○ Diarrhea</li><li>○ Loss of appetite</li></ul>	<ul style="list-style-type: none"><li>○ Pain in the upper part of the stomach</li></ul>

Many patients who develop acute GVHD are successfully treated with drugs (corticosteroids) that suppress the immune system.

**Chronic GVHD.** This is a syndrome that may involve a single organ or several organs. It often develops from 3 to 6 months after transplantation, but signs or symptoms can appear earlier or later. It is one of the leading causes of medical problems and death after allogeneic SCT.

Patients with mild symptoms of chronic GVHD, especially if the symptoms are in a limited area, can often be treated with close observation or with local (topical) therapies. For example, mild cases of chronic skin GVHD may be treated with skin ointments, and cases of chronic ocular (eye) GVHD may be treated with eye drops.

Patients with more severe symptoms or chronic GVHD that involves many organs typically require systemic treatment (treatment that travels through the bloodstream and reaches cells throughout the entire body).

Not every patient experiences all of the symptoms of GVHD, but many allogeneic transplant recipients experience some of them. Patients must be aware of the warning signs of GVHD and should call their doctors immediately if they have any symptoms. Early detection and treatment may help limit the severity of the disease.

**For more information, see the free LLS fact sheet, *Graft-Versus-Host Disease*.**



## Symptoms of Chronic GVHD

<b>Mouth</b> <ul style="list-style-type: none"><li>○ A very dry mouth</li><li>○ Sensitivity to hot, cold, spicy foods</li><li>○ Painful mouth sores</li><li>○ Difficulty eating</li><li>○ Gum disease and tooth decay</li></ul>	<b>Lungs</b> <ul style="list-style-type: none"><li>○ Shortness of breath</li><li>○ Difficulty breathing</li><li>○ A cough that does not go away</li><li>○ Wheezing</li></ul>
<b>Skin</b> <ul style="list-style-type: none"><li>○ Rash</li><li>○ Dry, tight, itchy skin</li><li>○ Change in skin color</li></ul>	<b>Liver</b> <ul style="list-style-type: none"><li>○ Swelling in the stomach</li><li>○ Yellowing of the skin and/or eyes (jaundice)</li></ul>
<b>Nails</b> <ul style="list-style-type: none"><li>○ Change in nail texture</li><li>○ Hard, brittle nails</li><li>○ Nail loss</li></ul>	<b>Muscle and Joints</b> <ul style="list-style-type: none"><li>○ Muscle weakness and cramps</li><li>○ Joint stiffness</li></ul>
<b>Scalp and Body Hair</b> <ul style="list-style-type: none"><li>○ Loss of hair on the head</li><li>○ Early graying of the hair</li><li>○ Loss of body hair</li></ul>	<b>Female Genitalia</b> <ul style="list-style-type: none"><li>○ Vaginal dryness, itching and pain</li><li>○ Ulcers and scarring on the vagina</li><li>○ Narrowing of the vagina</li><li>○ Difficult and/or painful sex</li></ul>
<b>Gastrointestinal Tract</b> <ul style="list-style-type: none"><li>○ Loss of appetite</li><li>○ Unexplained weight loss</li><li>○ Nausea</li><li>○ Vomiting</li><li>○ Diarrhea</li><li>○ Stomach pain</li></ul>	<b>Male Genitalia</b> <ul style="list-style-type: none"><li>○ Narrowing and/or scarring of the urethra (the tube through which urine leaves the body)</li><li>○ Itching or scarring on the penis and scrotum</li><li>○ Irritation of the penis</li></ul>

## Graft Failure

Graft failure occurs when the transplanted stem cells from the donor (the graft) do not move into the bone marrow and make new blood cells. Graft failure is extremely rare in autologous SCT. In allogeneic SCT, graft failure is more common when the patient and donor are not well matched. The most common treatment for graft failure is a second stem cell transplantation (SCT), either using stem cells from the same donor or from a different donor.

## Post-Transplant Lymphoproliferative Disorders

Post-transplant lymphoproliferative disorders (PTLDs) comprise a group of rare disorders that cause out-of-control growth of lymphocytes after allogeneic SCT. These growths of B lymphocytes can range from benign (noncancerous) tumors to potentially fatal cancerous lymphomas. PTLDs generally occur within the first few months after transplantation. Treatment for a PTLD depends on its subtype, but at this time, there is no standard treatment for PTLDs. Talk to your doctor about treatment in a clinical trial.

**For more information, see the free LLS fact sheet, *Post-Transplant Lymphoproliferative Disorders (PTLDs)*.**

## **PART 8 Early Recovery (From discharge up to about one year)**

A patient is ready for discharge from the hospital when:

- Engraftment has occurred and the patient is producing sufficient numbers of healthy white blood cells, red blood cells and platelets
- There are no signs of infection
- The patient can tolerate medications
- The patient is able to eat and drink and get sufficient fluids and nourishment
- There are no severe treatment complications
- The patient is medically stable and physically able to function outside the hospital

Although the patient's blood counts may be returning to the normal range, the immune system is still very immature. The patient or the patient's caregiver should call the doctor or nurse immediately if there are any symptoms of infection, including

- Fever or chills
- Coughing, sneezing, runny nose, sore throat or shortness of breath
- Nausea, vomiting or diarrhea
- Blood in the urine or pain during urination
- Rash or cold sores

After stem cell transplantation (SCT), follow-up appointments with the doctor are very important and at first, doctor visits may be frequent; allogeneic transplant patients may need follow-up visits as often as several times per week. At these visits, the doctor will order blood tests to check blood counts, electrolyte levels, and liver and kidney function. At some visits, bone marrow aspirations and biopsies will be done to check blood cell growth in the bone marrow. If the patient is doing well, the number of follow-up visits may be reduced by the doctor.

In general, there is a shorter recovery period after autologous SCT than after allogeneic SCT. In an autologous SCT, it often takes the immune system 3 to 12 months to recover. For an allogeneic SCT, it often takes at least 6 to 12 months for the patient's body to recover to near-normal

blood cell levels. For most people, the first few months to one year after transplantation remain a time of recovery. As patients regain more strength, they may begin slowly resuming daily activities.

The recovery time a stem cell transplant recipient needs before he or she feels “normal” or returns to work or school is different for each person. For some patients, recovery after SCT can be very difficult. It depends on a patient’s side effects and complications.

**Nutrition.** In the recovery phase after SCT, it is important to eat a well-balanced diet. After a patient undergoes chemotherapy and radiation treatment, his or her cells need to recover and repair themselves. Protein from food provides energy for the body and the building blocks for that repair. If a patient does not get the necessary number of calories and enough protein, the body may take the energy it needs from the muscles, causing further weakness and fatigue.

Consultation with a dietitian is important if a patient’s food and drink intake is lacking, inappropriate, or even harmful. Reach out to LLS Information Specialists, at (800) 955-4572, to schedule a free consultation with a registered dietitian.

**For more information, see the free LLS fact sheet *Food and Nutrition Facts*.**

**Exercise.** After SCT, many patients find it takes time to regain their strength. It may be helpful to follow a regular exercise plan. Physical activities, such as walking, riding a stationary bicycle, yoga, tai chi, swimming or water exercises, and strength training may alleviate fatigue and increase energy levels. Patients should consult with their doctors before starting an exercise program.

**Sexual Health.** After SCT, patients often have difficulty engaging in sexual activity. Many of these difficulties are due to the physical effects of chemotherapy and radiation treatments. Common concerns include fatigue, loss of sexual desire, vaginal dryness in women or getting and maintaining an erection in men.

Patients are encouraged to find someone on their transplant team with whom they feel comfortable discussing their concerns. There are medical and psychological interventions that are available to help patients.

**For more information, see the free LLS fact sheet, *Sexuality and Intimacy Facts*.**

## PART 9 Survivorship (One year after transplant and beyond)

Long-term follow-up care is important after both autologous and allogeneic SCT. Even after cancer treatment has ended, patients need to continue to schedule appointments with their cancer team in addition to having routine check-ups and health screenings. Long-term follow-up appointments and tests typically continue for many years.

### Long-Term and Late Effects

**Long-term effects** are side effects of treatment that may last for months or years after treatment ends. GVHD and fatigue are examples of long-term side effects in SCT patients. In children, learning skills may be affected.

**Late effects** are side effects of treatment that may not show up until years after treatment ends. Heart disease is an example of a possible late side effect.

Not everyone who is treated with SCT develops long-term or late effects. It depends on the patient's age, overall health and specific treatment. Patients should talk with their doctors about any long-term or late effects that they think may be related to their treatment. Parents who think their child's learning skills may have been affected by treatment should also consult with their doctor.

**Here are some questions you may want to ask your healthcare team.**

See *page 40* for a full list of questions in this Guidebook.

1. How will I be monitored for long-term and late effects of treatment?
2. What types of long-term and late effects should be brought to the healthcare team's attention?

#### WANT MORE INFORMATION?



You can view, print or order the free LLS booklets *Long-Term and Late Effects of Treatment for Childhood Leukemia or Lymphoma Facts*; *Learning and Living with Cancer: Advocating for your Child's Educational Needs*; and *Long-Term and Late Effects of Treatment in Adults Facts* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copies.

## Follow-Up Care

Follow-up medical care is important for every patient who undergoes stem cell transplantation (SCT). Follow-up care helps doctors monitor patients for late effects and disease recurrence.

SCT patients should see their hematologist-oncologist (blood cancer specialist) and a primary care doctor for follow-up care. Patients should talk to their doctor about how often to have follow-up visits. You can ask your doctor what tests will be needed and find out how often you should have these tests. It is important to get and keep a record of your cancer treatment, including the drugs you received and when you took them, so that your doctor can follow up on specific long-term effects that may be associated with your treatment.

Follow-up care includes physical exams and blood tests. Sometimes bone marrow tests are also needed. The doctor may advise longer periods of time between follow-up visits if a patient

- Continues to be free of signs and symptoms of cancer
- Does not need medical care for any long-term or late effects

To find a survivorship clinic and other resources for child and adult survivors, contact our Information Specialists at (800) 955-4572.

## Immunizations

After SCT, patients lose the protection they received as children when they were given vaccines. All transplant patients need to receive childhood vaccines again, once their immune systems have recovered. Autologous transplant recipients typically receive inactivated vaccines starting 6 months after transplantation and live vaccines 24 months after transplantation. For patients who have undergone allogeneic SCT, many doctors wait until 12 months after transplantation to start vaccinating patients or until patients have completed immunosuppressive therapy (drugs that are used to prevent rejection of the graft [donor tissue] in an allogeneic transplant). After that, they should follow their transplant doctor's recommended schedule.

**Here are some questions you may want to ask your healthcare team.**

See *page 40* for a full list of questions in this Guidebook.

1. Who should I work with to ensure life-long follow-up care?

2. Will I continue to see this healthcare team?
3. What information will be provided to my primary doctor about past treatment and what treatments may be needed in the future?

## Take Care of Yourself

- Keep all appointments with your doctor.
- Discuss how you feel with the doctor at each visit. Ask any questions that you have about side effects.
- SCT patients may have more infections. Follow the doctor's advice for preventing infections.
- Eat healthy foods each day. It is okay to eat 4 or 5 smaller meals instead of 3 bigger ones.
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. Patients who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screenings. See your primary care doctor to handle your other healthcare needs.
- Seek medical advice if you feel sad or depressed and your mood does not improve over time. For example, if you feel sad or depressed every day for a two-week period, seek help. Depression is an illness that can be treated. Treatment for depression has benefits for people living with cancer.

## PART 10 Clinical Trials

There are new treatments under study in clinical trials that seek to improve the remission and cure rates for patients with blood cancers. Every new drug or treatment regimen goes through a series of studies called clinical trials, before it can become part of standard therapy. Clinical trials are carefully designed and reviewed by researchers to ensure as much safety and scientific accuracy as possible. There are clinical trials for patients who need an SCT. Participation in a carefully conducted clinical trial may be the best available therapy for some blood cancer patients.

**Here are some questions you may want to ask your healthcare team about clinical trials.** See *page 40* for a full list of questions in this Guidebook.

1. Is a clinical trial a treatment option?
2. Where is the clinical trial taking place?
3. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs, such as testing?
4. Who pays for the travel costs to get to the clinical trial location?

Ask your doctor if treatment in a clinical trial may be right for you.

For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can provide more information about clinical trials and conduct individualized clinical-trial searches for patients, family members and healthcare professionals. When appropriate, Information Specialists refer patients for personalized clinical-trial navigation by trained nurses, which is available through our Clinical Trial Support Center. Visit [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

### WANT MORE INFORMATION?



You can view, print or order the free LLS publications *Understanding Clinical Trials for Blood Cancers* and *Knowing All Your Treatment Options* at [www.LLS.org/booklets](http://www.LLS.org/booklets), or contact our Information Specialists for a copy.

**Feedback.** To make suggestions about the content of this booklet, go to [www.LLS.org/PublicationFeedback](http://www.LLS.org/PublicationFeedback).



## Resources and Information

LLS offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

### For Help and Information

**Consult with an Information Specialist.** Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date information about disease, treatment and support. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)
- Live chat: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)
- Visit: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

**Clinical Trials (Research Studies).** New treatments for patients are underway. Patients can learn about clinical trials and how to access them. For more information, please call (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches. When appropriate, personalized clinical-trial navigation by trained nurses is also available. Visit the LLS Clinical Trial Support Center at [www.LLS.org/CTSC](http://www.LLS.org/CTSC) for more information.

**Free Information Booklets.** LLS offers free education and support publications that can either be read online or ordered. Please visit [www.LLS.org/booklets](http://www.LLS.org/booklets) for more information.

**Telephone/Web Education Programs.** LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit [www.LLS.org/programs](http://www.LLS.org/programs) for more information.

**Financial Assistance.** LLS offers financial assistance to individuals with blood cancer. Visit [www.LLS.org/finances](http://www.LLS.org/finances) for more information.

**Co-Pay Assistance Program.** LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please

- Call: (877) 557-2672
- Visit: [www.LLS.org/copay](http://www.LLS.org/copay)

**One-on One Nutrition Consultations.** Access free one-on-one nutrition consultations by a registered dietitian with experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit [www.LLS.org/nutrition](http://www.LLS.org/nutrition) for more information.

**Podcast.** Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Visit [www.LLS.org/TheBloodline](http://www.LLS.org/TheBloodline) for more information and to subscribe.

**Suggested Reading.** LLS provides a list of selected books recommended for patients, caregivers, children and teens. Visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) to find out more.

## Community Resources and Networking

**LLS Community.** The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Visit [www.LLS.org/community](http://www.LLS.org/community) to join.

**Weekly Online Chats.** Moderated online chats can provide support and help cancer patients reach out and share information. Please visit [www.LLS.org/chat](http://www.LLS.org/chat) for more information.

**LLS Chapters.** LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups and other great resources. For more information about these programs or to contact your chapter, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/ChapterFind](http://www.LLS.org/ChapterFind)

**Other Helpful Organizations.** LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit [www.LLS.org/ResourceDirectory](http://www.LLS.org/ResourceDirectory) to obtain our directory.

**Advocacy.** The LLS Office of Public Policy (OPP) enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: [www.LLS.org/advocacy](http://www.LLS.org/advocacy)

### **Additional Help for Specific Populations**

**Información en Español (LLS information in Spanish).** Please visit [www.LLS.org/espanol](http://www.LLS.org/espanol) for more information.

**Language Services.** Let your doctor know if you need a language interpreter or other helper, such as a sign language interpreter. Often, these services are free.

**Children's Concerns.** Parents of a child who is getting a transplant may want to talk to members of their child's healthcare team about how to find enough time for everything, pay for treatment, and best help their children. For more information, see the free LLS booklet *Coping With Childhood Leukemia and Lymphoma*.

**The Trish Greene Back to School Program for Children With Cancer.** This program helps doctors, nurses, parents and school personnel work together for a smooth return to school for children with cancer. For more information, contact your LLS chapter or call (800) 955-4572.

**World Trade Center Survivors.** People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: [www.cdc.gov/wtc/faq.html](http://www.cdc.gov/wtc/faq.html)

**People Suffering from Depression.** Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time, for example, if you feel depressed every day for a two-week period. For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at [www.nimh.nih.gov](http://www.nimh.nih.gov) and enter “depression” in the search box

## Health Terms

**Allogeneic Stem Cell Transplantation.** A treatment that uses donor stem cells to restore a patient’s bone marrow and blood cells. First, the patient is given conditioning therapy (high-dose chemotherapy or high-dose chemotherapy with total body radiation) to treat the blood cancer and to “turn off” the patient’s immune system so that the donor stem cells will not be rejected. See also Reduced-Intensity Allogeneic Transplantation.

**Anemia.** A decrease in the number of red blood cells. This results in diminished ability of the blood to carry oxygen. If severe, anemia can cause a pale complexion, weakness, fatigue and shortness of breath on exertion.

**Apheresis.** The process of removing certain components of a donor’s blood and separating out various parts of blood including white blood cells, red blood cells and platelets.

**Autologous Stem Cell Transplantation.** A procedure in which stem cells are removed from a cancer patient, stored, and then given back to the patient after the patient undergoes intensive chemotherapy, with or without radiation therapy.

**Bone Marrow.** The spongy tissue in the hollow central cavity of the bones that is the site of blood cell formation.

**Chemotherapy.** The use of chemicals (drugs or medications) to stop the growth of cancer cells by killing the cancer cells or by stopping them from dividing.

**Conditioning Treatment.** A process that usually includes chemotherapy either with or without radiation therapy and that is used prior to autologous or allogeneic stem cell transplantation to prepare a patient's body for the procedure.

**Engraftment.** The process in which transplanted donor stem cells travel to the patient's bone marrow where they, like all stem cells, produce blood cells of all types.

**Graft-Versus-Host Disease (GVHD).** A potentially serious complication of allogeneic stem cell transplantation, caused when the white blood cells from a donor (the graft) attack the healthy tissue of the transplant patient (the host).

**Graft-Versus-Tumor Effect.** A positive immune response in which transplanted donor's white blood cells (the graft) recognize and attack the patient's cancer cells (the tumor). This response can occur only in allogeneic stem cell transplantation.

**Haploidentical Stem Cell Transplantation.** A type of allogeneic stem cell transplantation that uses healthy, blood-forming cells from a half-matched donor to replace the unhealthy ones. The donor is typically a family member.

**HLA(s).** The abbreviation for human leukocyte-associated antigen(s). These are proteins on the surface of most tissue cells that give an individual his or her unique tissue type. Human leukocyte-associated antigens play an important part in the body's immune response to foreign substances. Human leukocyte-associated antigen factors are inherited from one's mother and father, and the greatest chance of having the same HLA type is between siblings. On average, one in four siblings is expected to share the same HLA type.

**Host.** The person (patient) who receives the donated stem cells in a transplant.

**Peripheral Blood.** Blood that circulates throughout the body.

**Platelet.** A type of blood cell that helps stop bleeding. Platelets gather at the site of an injury and cause the blood to clot.

**Radiation Therapy.** The use of high-energy radiation (from x-rays, gamma rays, neutrons, protons, and other sources) that kills cancer cells.

**Red Blood Cell.** A blood cell that carries the red-colored protein hemoglobin, which binds oxygen and delivers it to the tissues of the body.

**Reduced-Intensity Allogeneic Stem Cell Transplantation.** A form of allogeneic transplantation in which patients receive lower doses of chemotherapy drugs and/or radiation in preparation for the transplant. Immunosuppressive drugs are used to prevent rejection of the graft (donor tissue). The engraftment of donor immune cells may allow these cells to attack the disease (graft-versus-tumor effect). This term is sometimes called **nonmyeloablative stem cell transplantation**.

**Stem Cell.** A primitive cell in the bone marrow that is essential to the formation of white blood cells, red blood cells and platelets. Stem cells are largely found in the bone marrow, but some leave the bone marrow and circulate in the blood. They are also found in the umbilical cord and placenta of newborn babies.

**Survivorship.** In cancer, survivorship focuses on the life of a person with cancer.

**Systemic Treatment.** Treatment that travels through the blood to cells all over the body. Systemic treatment goes throughout the whole body, whereas topical treatment is put on a specific surface area.

**Umbilical Cord Blood.** Blood from the umbilical cord of a newborn baby. This blood contains a high concentration of stem cells.

**White Blood Cell.** Any of the five major types of infection-fighting cells in the blood, which include neutrophils, eosinophils, basophils, monocytes and lymphocytes.

## My Healthcare Team Contact List

Use this list to remember names and contact information for members of your healthcare team.

CAREGIVER NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PRIMARY CARE DOCTOR NAME:

Address: \_\_\_\_\_

Phone Number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

PHARMACY NAME:

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Additional information: \_\_\_\_\_

**Information Specialists:**

**Phone: 1-800-955-4572**

**Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)**

**Website: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)**

**HEMATOLOGIST-ONCOLOGIST NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Website/Portal: \_\_\_\_\_

Additional information: \_\_\_\_\_

**NURSE/NURSE PRACTITIONER NAME:**

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**SOCIAL WORKER NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**INSURANCE CASE MANAGER/  
CARE COORDINATOR NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Website or email address: \_\_\_\_\_

Additional information: \_\_\_\_\_



**PHYSICIAN ASSISTANT NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email Address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**NURSE NAVIGATOR NAME:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**OTHER:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

**OTHER:**

Address: \_\_\_\_\_

Phone number/Fax number: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional information: \_\_\_\_\_

## Question Guide

Asking questions will help you take an active role in managing your care. If you do not understand any part of the information that your doctor tells you, ask the doctor to explain it in another way. This will help you to become actively involved in making decisions about your medical care. The following are questions that you may want to ask your doctor.

(Note: The use of “I (we)” and “me (us)” in lists of questions is used for situations in which the patient may not be old enough or able to make his or her own decision. A parent, relative, or caregiver may be assisting or making the decision.)

DOCTOR'S NAME: \_\_\_\_\_

Date of appointment or phone call: \_\_\_\_\_

1. What is the goal of this treatment?
  - To produce a long-term remission?
  - To cure my disease?
2. What are the possible benefits and risks of this treatment?
3. What are the possible side effects of this treatment?
4. Will this treatment affect the ability to have children in the future? If yes, what are the options for preserving fertility?
5. How long will treatment last?
6. Is it possible to work or go to school during treatment?
7. How will I/we know if the treatment is effective?
8. What is the prognosis (the likely outcome) of this disease?

## **Questions to ask about stem cell transplantation (SCT) when meeting with an SCT doctor**

1. When should a stem cell transplant be done?
2. What are the risk or benefits of trying other treatments first?
3. How long will the hospital stay be during the transplant?
4. When will I/we be able to return home?
5. What kind of care will be needed after returning home?

## **Questions to ask if an allogeneic SCT is recommended**

1. Is a reduced-intensity stem cell transplant an option?
2. Which family members will you test as possible donors?
3. Is a haploidentical (half-matched) stem cell transplant an option?
4. What happens if there is no match in the family?

## **Questions to ask if an autologous stem cell transplantation is recommended**

1. When will be the best time to collect my stem cells?
2. When will be the best time for the transplantation of stem cells?

## **Questions to ask about social/financial concerns**

1. Are there any side effects that will affect appearance or ability to do a job/go to school?
2. What kind of financial and social support services are available to me/us and our family?
3. How can I (we) find out if insurance will cover the costs of the treatment or the study treatment?
4. Who is the best person to speak to about bills and insurance coverage?
5. If I (we) do not have insurance coverage, how can the healthcare team help get the treatment needed? Is there someone I can speak to for assistance?

6. If I (we) get in a study treatment (clinical trial), will I (we) be responsible for paying treatment-related costs, such as tests, travel or for clinical trial drugs?
7. How can I (we) find out if the insurance covers the cost of the clinical trial treatment and treatment-related costs such as testing?

**Questions to ask about follow-up care and long-term and late effects**

1. Who should I (we) work with to ensure life-long follow-up?
2. Will I (we) continue to see this healthcare team?
3. How can I be monitored for long-term and late effects of treatment?
4. What types of long-term and late effects should be brought to the healthcare team's attention?
5. If there are side effects later, how can the healthcare team be reached?
6. What information can be provided to the primary doctor about past treatment and what may be needed in the future?

# NOTES

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Get support.

Reach out to our

## **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individual clinical-trial searches

Contact us at

**800-955-4572** or  
**www.LLS.org/  
informationspecialists**

(Language interpreters can be requested)





For more information, please  
contact our Information Specialists  
**800.955.4572** (Language interpreters  
available upon request).

**BEATING  
CANCER  
IS IN  
OUR BLOOD.**

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**National Office** 3 International Drive, Suite 200 Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at [www.LLS.org](http://www.LLS.org).