Stem Cell Transplantation and Cellular Therapy Guide

THE UNIVERSITY OF TEXAS
MD Anderson ~~Cancer~~ Center
Making Cancer History®

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PATIENT EDUCATION

Introduction to Stem Cell Transplantation

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Overview

Stem Cell Transplant Care Team

MD Anderson Cancer Center uses a team approach to treat patients. Experts from many clinical areas will work together to care for you. Read this handout to learn more about your care team in the Stem Cell Transplantation and Cellular Therapy (SCTCT) Center.

Doctors

A doctor will oversee your treatment. You will meet with your doctor in the SCTCT Center at your appointments. This is where you will also have your follow-up care after the stem cell transplant.

Fellows are doctors in training. Fellows work closely with the SCTCT doctors. You may meet a fellow during your appointments.

Inpatient Care

A SCTCT doctor other than your clinic doctor may provide care for you while you are in the hospital. Our doctors rotate their schedule to cover the inpatient unit. They work as a team and will update each other about your care.

Advanced Practice Providers

Advanced Practice Nurses and Physician Assistants

Advanced practice providers (APPs) are licensed members of the care team. They can be an **advanced practice registered nurse (APRN)** or **physician assistant (PA)**. APPs work closely with all members of the care team to manage your care, perform medical exams and certain procedures, diagnose illnesses, manage treatment plans, and write prescriptions. An advanced practice nurse (APN) will see you during your hospital stay and after your stem cell transplant. A physician assistant (PA) will see you before and after the stem cell transplant in the clinic. The PA will perform outpatient procedures as needed, such as a bone marrow biopsy and lumbar puncture.

Advanced practice providers will:
- Ask you about your medical history.
- Do physical exams.
- Teach you about transplant-related health concerns.
- Write and update prescriptions.
- Help manage your care.
- Work closely with the SCTCT doctors and care team.
- Perform biopsies.

Nurses

Clinic Nurses

Your doctor works with a clinic nurse in the SCTCT Center to manage your outpatient care. The clinic nurse will see you during your pre-transplant work-up and follow-up visits.
At each visit, your clinic nurse will:

- Ask how you feel.
- Ask about any pain you may have.
- Record the medicines you take.
- Assess your risk for falls.

Talk with your clinic nurse if you have any problems or concerns.

Inpatient Nurses

Inpatient nurses have special training to care for SCTCT patients in the hospital. Your nurse will ask you about your health history and any special needs. This information helps the nursing team plan your care during your hospital stay. Your inpatient nurse will:

- Do physical exams.
- Give needed treatments.
- Teach you about your care.
- Watch your condition closely.
- Give you medicines.
- Contact your doctor when needed.

Talk with your inpatient nurse if you have any concerns while you are in the hospital.

Research Nurses/Study Coordinators

A research nurse/study coordinator may screen you to see if you are able to join a clinical trial, based on the study criteria. The principle investigator (PI) is the person in charge of the clinical trial.

If you choose to join a clinical trial, the research nurse/study coordinator will monitor and report your progress to the PI and your SCTCT doctor. The research nurse also reports any side effects and makes sure the study is done correctly and safely.

SCTCT Coordinators

There are 2 groups of stem cell transplant coordinators: autologous and allogeneic related transplant coordinators and unrelated (MUD/cord blood) transplant coordinators.

In some cases, patients may be their own stem cell donors, which is called an **autologous** transplant. Other patients may receive stem cells from a person that is related or unrelated to them. This is called an **allogeneic** transplant.

SCTCT Related Coordinators

An SCTCT related coordinator is a registered nurse. You will work with a related coordinator if you are having an autologous transplant or if you are having an allogeneic transplant from a donor who is related to you.

Before your transplant, the SCTCT related coordinator will:

- Be your contact person for your pre-transplant assessment.
- Work with your doctor to plan tests and procedures before your hospital admission.
- Schedule donor work-up appointments if your transplant is from a related donor.
- Work closely with the care team.

SCTCT Unrelated Coordinators

You will work with an SCTCT unrelated coordinator if you are having an allogeneic transplant from a donor who is not related to you or from a cord blood donor.

Before your transplant, the SCTCT unrelated coordinator will:

- Search for unrelated donors through the National Marrow Donor Program and worldwide registries.
- Coordinate the list and work closely with your doctor to select the best donor.
- Schedule all tests before your hospital admission.
- Serve as the contact person for your donor, if appropriate.
- Work closely with the care team.

Receptionists and Patient Service Coordinators

Receptionists

When you arrive to SCTCT Center, the receptionist will greet you. This person helps:

- Answer your phone calls.
- Confirm your arrival at appointments.
- Collect co-payments, if needed.
- Sign you up for MyChart.
- Confirm your local contact information.

Patient Service Coordinators/Schedulers

The SCTCT patient service coordinator (PSC) schedules your tests and appointments. The PSC helps answer phones and performs general office duties. At each clinic visit, ask for your updated appointment schedule (patient appointment letter). Contact the PSC to confirm, reschedule or cancel your appointments.

Patient Access Center (Financial Services)

Patient Access Specialists

The patient access specialist (PAS) is a financial counselor. This person works closely with your insurance company to confirm approval of payment for tests, procedures, medicines and the stem cell transplant procedure. The PAS is available to meet with you to answer any financial questions you have about the transplant process.

Patient Access Coordinator Nurses

The patient access coordinator (PAC) nurse is the contact for your health insurance company. This person handles all health information related to tests, procedures, medicines and the stem cell transplant.

Patient Business Services

The Patient Business Services staff answer questions about medical bills and charges. You may contact the staff through MyChart or by calling 713-792-2991. The office is in the Main Building.

Other Team Members

Pharmacists

The SCTCT pharmacists have their Doctor of Pharmacy degree. They are referred to as a clinical pharmacy specialist or Pharm D. Your pharmacist will:

- Work with the care team to monitor your drug treatment.
- Take part in your care when you are in the hospital and when you are in any of the outpatient areas, such as the Ambulatory Treatment Center, Fast-Track Clinic and Apheresis Clinic.
- Help with chemotherapy dosing/orders and review your prescribed medicines for possible allergies and drug reactions.
- Work with you to find the best medicines to reduce treatment side effects, such as upset stomach, vomiting, diarrhea, pain or infections.
- Talk with you about your medicines and answer your questions.

❗ Tell your pharmacist about the medicines you take. This includes any over-the-counter medicines, herbal or natural supplements, teas and vitamin supplements. Many of these could have serious side effects when taken with transplant medicines. The outpatient pharmacies are in the Main Building.

Dietitians

A registered dietitian nutritionist (RDN) will assess your nutrition needs and create a nutrition care plan for you to follow during your treatment and recovery. The RDN will meet with you during your hospital stay to check for any problems you may have with eating or drinking. The RDN will work with you and suggest ideas that may help when needed.

You may also meet with a RDN while you are an outpatient, if needed. Ask your clinic nurse to schedule an appointment for you.

Social Work Counselors

Social work counselors are licensed professional counselors. Your social work counselor is available to help you or your caregiver cope with the stress and challenges of your diagnoses and care, as well as concerns such as housing and transportation. Social work counselors offer many services to help support patients and caregivers. They can also help find resources for you. For a complete list of services, ask your care team for a copy of the **Resources and Services** guide or you may call Social Work at 713-792-6195, Monday through Friday, 8 a.m. to 5 p.m.

Patient Advocates

Patient advocates help patients and family members who may have problems or concerns with MD Anderson. An assigned patient advocate is available to help you, if needed. Patient Advocacy is in the Main Building, Monday through Friday, 8 a.m. to 5 p.m. Call 713-792-7776 for more information. After hours and on weekends, call 713-792-7090.

Case Managers

Case managers are licensed professionals. Your case manager is the contact for your health insurance company while you are an inpatient. The case manager also coordinates services for you after you are discharged from the hospital.

Chaplains

Chaplains are available 24 hours a day and serve all faith traditions. They help patients and family members with spiritual support and pastoral care. Ask your nurse if you would like to speak with a chaplain, or you may call Spiritual Care and Education at 713-792-7184.

Psychiatry Services

Clinical nurse specialists from Psychiatry Services help support patients while they are in the hospital for a transplant. A psychiatrist may meet with you to do a pre-transplant assessment before the care team admits you to the hospital. This provider can also help you and your family cope with concerns that may arise. Ask your doctor or the clinical nurse specialist for a referral.

Physical and Occupational Therapists

Rehabilitation Services offers physical and occupational therapy to patients in the inpatient and outpatient setting. Therapists can work with you to help you regain physical strength and abilities that may be affected during and after your transplant. Your doctor may refer you for therapy, or you can ask for a referral.

SCTCT Management/Leadership Team

The SCTCT management/leadership team is available to answer questions, hear suggestions or address any concerns you may have during your transplant journey. Tell the receptionist if you would like to speak with a member of the leadership team.

Stem Cell Transplant Overview

This handout provides basic information about the types of stem cell transplants that are done at MD Anderson and what to expect before, during and after treatment.

About Bone Marrow

It is helpful to know about blood cells and bone marrow in order to understand stem cell transplants. The bone marrow is a spongy tissue found inside the large bones of the body, such as the hip bones and the breastbone. Bone marrow makes blood-forming cells, also known as blood stem cells.

The bone marrow constantly makes these stem cells. Stem cells are immature cells that make up the blood and immune system. Each stem cell grows into a certain type of blood or immune system cell as it matures. A stem cell is also called a **hematopoietic progenitor cell**, which means parent of blood cells or a hematopoietic stem cell.

The stem cells mature into red blood cells, white blood cells and platelets. See Figure 1.

- **Red blood cells** carry oxygen to all of the other cells and organs of the body.
- **White blood cells** protect the body against infection.
- **Platelets** help the blood clot and prevent bleeding.

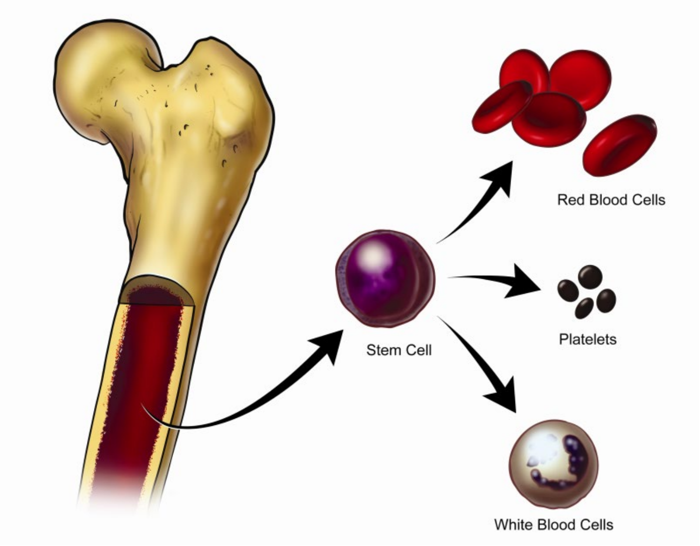

Figure 1
Stem Cell Differentiation
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Each type of blood cell lives in the body a certain amount of time. For this reason, it is important for the bone marrow to always make new stem cells.

Stem cells move throughout the body. Besides the bone marrow, stem cells are also found in the blood and in a newborn baby's umbilical cord blood.

Damage to the Bone Marrow

Chemotherapy, other treatments, radiation and bone marrow diseases may damage and wipe out bone marrow. When this happens, the bone marrow cannot make blood cells properly. This may result in a person not having enough of the right cells or too many immature or abnormal cells. Both conditions are serious and life threatening. Examples include:

- Anemia – not enough red blood cells to carry oxygen

- Neutropenia – not enough white blood cells to fight infection
- Thrombocytopenia – not enough platelet cells to help with normal blood clotting
- Leukemia – too many immature white blood cells that grow rapidly and crowd out normal cells in the bone marrow
- Lymphoma – too many immune system lymphoid cells that grow and crowd out normal cells
- Multiple myeloma – too many plasma cells that crowd out and destroy normal cells

About Stem Cell Transplants

Stem cell transplants treat a range of different cancers and conditions, including:

- Acute and chronic leukemias
- Myelodysplastic syndrome
- Myelofibrosis
- Hodgkin and non-Hodgkin lymphomas
- Multiple myeloma
- Germ cell tumors and certain brain tumors
- Other blood diseases, such as aplastic anemia and bone marrow failure syndromes

Stem Cell Collection

Stem cells are collected from 3 sources:

- Blood using a procedure called **apheresis**
- Bone marrow
- Newborn baby's umbilical cord blood

Your stem cell transplant doctor will talk with you about which source of stem cells is best for you.

Apheresis Collection

Apheresis collection requires the stem cell donor to receive a special injection of white blood cell growth factor for several days before the collection procedure. The injection increases the number of stem cells in the blood.

During apheresis, an IV line moves blood out of the body and filters it through the apheresis machine. Another IV line returns the blood back into the body. The apheresis machine collects the stem cells by choosing cells of a certain size as they move through the machine.

This procedure takes about 4 hours. In order to collect the exact number of cells for the transplant, more than one procedure may be needed. The care team will let the donor know if further collection dates are needed.

Bone Marrow Collection or Harvest

Bone marrow is collected by the doctor while the donor is asleep under general anesthesia. A special needle is placed through the skin and into the back of the hip bone. The needle makes small punctures in the hipbone to remove the bone marrow. The bone marrow is placed in the collection bag and processed before it is infused into the patient. The collection takes about 1 to 1½ hours.

Cord Blood Cell Collection

A mother may donate stem cells from her newborn baby's umbilical cord. This type of collection is done in the delivery room after a mother gives birth to the baby. These cells are frozen and stored in a cord blood bank facility until needed by a patient. The assigned stem cell transplant coordinator will search the cord blood banks for a suitable match, if needed.

Stem Cell Use

MD Anderson does not use or do research with embryonic stem cells, which are stem cells that come from an early embryo. Stem cells used for transplant come from volunteer donors and women who have donated umbilical cord blood after giving birth.

Stem Cell Transplant Process

Having a stem cell transplant allows doctors to treat diseases with high doses of chemotherapy possibly combined with radiation. In general, the stem cell transplant process follows these steps:

1. A healthy person donates stem cells.
2. The patient has chemotherapy possibly combined with radiation to wipe out the cancer and blood forming cells. This treatment also weakens the immune system so that the body is less likely to reject the donor's stem cells.
3. The patient receives an infusion of the donor's healthy stem cells. Using an IV, the cells are infused into the bloodstream, similar to a blood transfusion. The infusion can take from 30 minutes to several hours.
4. When a transplant is successful, the bone marrow goes into the cavities of the large bones. Over time, the stem cells grow in the bone marrow, which makes the right amount of healthy, normal blood cells.

Types of Transplants

Autologous

When a patient is their own donor, this is called an **autologous** transplant. The stem cells are collected, frozen and stored in the lab. The patient then receives high doses of chemotherapy to treat the cancer. After the treatment, the patient receives an infusion of the stem cells to speed recovery of the blood counts. This allows a patient to receive a higher and possibly more effective dose of chemotherapy than they could otherwise tolerate.

Allogeneic

When a patient receives a transplant from a donor, this is called an **allogeneic** transplant. A special test called **human leukocyte antigen or HLA** typing is done to determine if a patient and donor match.

There are 6 types of allogeneic transplants:

- **Related donor transplant** - This type of transplant is done if a family member, such as a brother or sister who is a HLA match. Siblings have a 25% chance of matching patients.
- **Matched unrelated donor or MUD transplant** - The patient receives a transplant using stem cells from an unrelated donor. The search looks at HLA typing from volunteer donor registries to find a possible donor.

- **Haploidentical transplant** - Many patients who need a stem cell transplant cannot find a donor that matches their HLA type. When a matched donor is not available, a half-matched (haploidentical) donor can now safely be used with stem cell transplant. Possible donor matches come from first-degree relatives (siblings, children, or parents).
- **Syngeneic transplant** - The patient receives a transplant from an identical twin. Since the patient and donor's genes are identical, there is much less risk of graft versus host disease, referred to as GVHD, or rejection. GVHD is a reaction of donated bone marrow or peripheral stem cells against the recipient's tissue. Patients usually tolerate this type of transplant very well.
- **Umbilical cord blood transplant** - The patient receives a transplant using stem cells from a newborn baby's umbilical cord blood found in public cord blood banks. This may be an option for patients who do not have a donor.

Caregiver Role

A caregiver provides vital physical and emotional support and helps keep you safe. They also help you with your recovery. This includes getting you to and from the hospital for appointments or for an emergency. A caregiver makes sure you eat, drink, sleep and takes medicines as instructed.

Your caregiver must stay with you during your recovery and for the first 30 to 100 days after your transplant. Your care team will provide your caregiver with a copy of the **Stem Cell Transplantation and Cellular Therapy: Caregiver Guide**. It has more information about the caregiver role and available resources.

Before Treatment

Tests

Before your treatment, you will have a series of tests to assess your physical health in order to make sure you are ready for a stem cell transplant. These tests may include blood and urine tests, dental exams, chest x-rays, electrocardiograms, echocardiograms, CT and PET scans, bone marrow aspirations, and pulmonary function tests. Your transplant team will decide which tests are needed and will coordinate these tests before your transplant.

Consent Forms and Chemotherapy Teaching

You will meet with members of your stem cell transplant care team, including your doctor. The care team will review your chemotherapy and stem cell transplant plan and discuss the benefits, risks, and side effects. Your care team will talk with you about any concerns or questions you may have. You will also review and sign treatment consent forms. Then, your care team will schedule your chemotherapy and stem cell transplant appointments.

Medicines

It is important that you keep a current list of all the medicines you take and share it with the care team, as it helps them take better care of you. This includes prescribed and over-the-counter medicines, vitamins, minerals, and herbs. Be sure to tell your care team any time you stop taking a medicine or start taking a new one.

During your clinic visit, your care team will review your list of medicines with you to make sure it is correct. Keep a list with you when you meet with your care team, have tests, or if you go to the MD Anderson Acute Cancer Care Center. Talk with your care team if you have any questions about your medicines.

Possible Side Effects of Chemotherapy

Before you start conditioning, your transplant team will discuss possible side effects of chemotherapy with you. Side effects can vary, but may include:

- **Anemia -** This occurs when your blood does not carry as much oxygen as normal to the tissues of your body. The signs of anemia can include fatigue, shortness of breath, headache, and weakness. If needed, you may receive a blood transfusion to treat anemia.
- **Diarrhea** - If you have diarrhea that does not stop, contact the SCT Fast Track Clinic. Keep in mind that diarrhea can lead to dehydration by loss of fluids.
- **Fatigue** - This is common during conditioning. It is important to stay active during treatment and try to plan 2 or 3 short walks throughout the day for 10 to 15 minutes per walk.
- **Hair loss** - Most patients lose their hair during chemotherapy. Deciding how to manage hair loss and whether to wear a wig is entirely your decision. Many times, patients choose to cut their hair short before starting treatment in order to reduce any shock of hair loss during chemotherapy.
- **Infertility** - Chemotherapy may cause infertility. Talk with your care team about fertility planning before you start the conditioning phase.
- **Mouth sores** - The inside of your mouth can become irritated during conditioning as the chemotherapy can kill the cells that make up the lining of your mouth. This can make eating and swallowing uncomfortable. Read the section below on **Hygiene, Skin and Mouth Care** for information on how to take care of your mouth during treatment.
- **Nausea** - This is common during the conditioning phase and how bad it can get depends on the type of chemotherapy you receive. Your care team will give you medicines to help with nausea.
- **Neutropenia** - Neutrophils are a type of white blood cell found in your blood. Their role is to kill bacteria, fungi, and viruses that enter your body. If your neutrophil count drops too much, your risk of infection increases.
- **Skin changes -** Your skin may get more dry, flaky and more sensitive to sun burns. Avoid direct sunlight, use SPF 50 sunscreen, and wear protective clothing when outdoors, including a hat and sunglasses. Use mild soaps made for sensitive skin when you bathe.
- **Thrombocytopenia** - Platelets are the cells that help your body form clots in the blood to stop bleeding. If your platelet count is low, your risk of bleeding increases. If your platelet count drops too much, you may receive a platelet transfusion.

Risk of Bleeding

Take these precautions to help avoid bleeding:

- **Do not** use razors with blades. Use an electric razor instead.
- **Do not** use nail clippers, knives, and scissors.
- **Do not** strain during bowel movements. If needed, ask your care team for a stool softener to help with constipation.
- **Do not** get tattoos, piercings, manicures, or pedicures.

- **Do not** get dental work until you first talk with your transplant care team.

Below are some general guidelines on what to do if you are bleeding:

- Apply pressure with a sterile gauze or clean towel or cloth. Elevate the wound area while you apply pressure. If the bleeding does not stop after 10 minutes, go to the MD Anderson Acute Cancer Care Center **right away**.
- If you have a nosebleed, apply pressure to the bridge of your nose and put a bag of ice on your nose until the bleeding stops. If a nosebleed continues for more than 30 minutes, go to the MD Anderson Acute Cancer Care Center **right away**.

Risk of Infection

Conditioning kills the stem cells that produce the white blood cells of your immune system. White blood cells fight infections. Without these immune cells, your risk of infection increases. If you develop a fever, this is a key sign that you may have an infection and your transplant team will do tests to determine if it is an infection. If needed, you will receive antibiotics through your CVC, which is effective in treating most infections.

You will need to do what you can to avoid infection throughout your treatment, such as:

- Stay away from people who may be sick or may have been exposed to someone who is sick.
- **Do not** shake hands or come into close physical contact with others. Use hand sanitizer when needed.
- Wear a mask when you go outside of your home.
- Wash your hands often.
- Eat foods that have been properly prepared, stored, and cooked.
  - Refer to the stem cell transplant nutrition handout for more information.

Plans for Home and Work or School Life

If you have young children, you may not feel well enough to continue normal childcare duties during your treatment. If you have concerns, talk with your social worker.

Plan to be away from work/school for about 3 to 6 months. Be sure to arrange for a leave of absence or disability during this time. How soon you can return to work or school depends on how you feel. You may feel well enough to return in less time or it could take more time.

Before you start treatment, make sure all pets in your home are up to date with their vaccines. During your treatment, avoid close contact with pets. Avoid cleaning litter trays and contact with feces. This can increase your risk of infection.

Fertility

Talk with your stem cell transplant team before you start treatment if you have concerns about fertility or want to have children after your treatment. Your care team can refer you to a fertility specialist for counseling to discuss your options, such as sperm banking, and egg and embryo freezing.

Local Housing

Before your hospital admission, you will have outpatient tests, consults, and procedures. You will also need to have local housing plans in place. After you are discharged, you will come to the MD Anderson Stem Cell Transplant Clinic 3 to 4 times a week. For 1 to 3 months depending on type of transplant, you must stay within 30 minutes of MD Anderson.

During Treatment

Managing Your Home

Throughout treatment, keep your home clean to help reduce the risk of infection. Your caregiver will need to do most of the household chores while you are undergoing conditioning, transplant, and engraftment.

- Stay out of damp areas where mold may grow, such as a basement.
- **Do not** use a humidifier. Mold can grow easily in it.
- Your caregiver should take care of any dusting, vacuuming, and cleaning the bathroom. This will help reduce your exposure to bacteria.
- Only use clean eating utensils. It is fine to use normal dishwashing detergent and a dishwasher
- **Do not** touch the soil of houseplants or the water in flower vases. Have your caregiver take care of any plants.
- Avoid contact with animals and make sure your pets are up to date on all vaccines.

Hygiene, Skin and Mouth Care

It is important to maintain proper hygiene throughout your treatment. This helps lower your risk of infection. If your skin becomes dry and flaky during treatment, try the following to help reduce skin irritation:

- Use mild body soaps, such as unscented Dove®, Dove® for sensitive skin, Cetaphil® or CeraVe®, Aveeno®, or Basis®.
- Use mild, fragrance-free laundry detergent. It may help reduce skin irritation.

During treatment, you will need to change how you care for your teeth to help prevent bleeding and infection in your mouth. You may also develop mouth sores after treatment. To help prevent further mouth irritation, use gentle mouth care products and do the following:

- Use a soft bristle toothbrush.
- Use alcohol-free mouthwash.
- Use lip balm as needed.
- **Do not** floss your teeth.
- If you have dentures, clean them every day with denture cleaner.
- Contact your transplant care team if you develop pain from mouth sores.
- **Do not** have a dental procedure until you first talk with your transplant team.

You may also have a dry mouth during and for several months after treatment. This happens when your salivary glands do not work as well as they did before transplant. Avoid using a mouthwash with alcohol in it, which can cause further dryness. Using lozenges or hard candy can increase your saliva production. Talk with your dentist for help with managing dry mouth.

Home Supplies

Here is a list of supplies you will need to have at home.

Infection Prevention

- Thermometer to check your temperature at least 2 times a day
- Masks
- Gloves
- Antibacterial soap for every sink in the house
- Hand sanitizer for every room in the house
- Disinfectant wipes

Hygiene and Oral Care

- Alcohol-free mouthwash, soft-bristle toothbrush and toothpaste
- A mirror to check your mouth and skin daily
- Mild body soaps, such as unscented Dove, Dove for sensitive skin, Cetaphil or CeraVe, Aveeno, or Basis, are suggested
- Mild laundry detergent. Fragrance-free detergent may cause less skin irritation.
- Paper towels or hand towels. Use a clean hand towel daily.
- Shower patch supplies for your CVC

Sun and Skin Protection

- Sunscreen SPF 50 or higher with broad-spectrum ultraviolet (UVA/UVB) protection
- Wide-brimmed hat
- Sunglasses with ultraviolet (UV) protection
- Ultraviolet protection or UVP products, such as clothing or hats with UVP. Consider a less costly option, like Rit SunGuard™ where you wash your clothes with it to add UVP to your clothes. Protection lasts up to 20 washes. This product can be purchased online.
- Moisturizers, creams, ointments or emollients, such as Aquaphor, CeraVe or Aveeno
- Closed toe shoes
- Mosquito repellent. Try a clip-on fan or spray.

Cooking, Food, and Drinks

- Food thermometer, and a refrigerator thermometer if your refrigerator does not have one
- Healthy, high protein foods and snacks
- Water and other non-caffeine drinks
- Sponges to clean food preparation surfaces. Clean the sponge in the dishwasher every day.

Daily Self Care

- Take your temperature at least 2 times a day, in the morning and evening and when you feel bad or have chills.
- Drink 64 ounces or 2 liters of liquids a day.
- Eat smaller, meals or snacks more often throughout the day.
- Stay active. Plan short walks, 2 to 3 times a day for about 10 to 15 minutes at a time.

- Wear a mask and wash your hands often. Also wash your hands before removing your mask.
- Brush your teeth with a soft toothbrush 3 or 4 times a day.
- Rinse your mouth with baking soda solution – ½ teaspoon baking soda mixed in 8 ounces water, every 3 to 4 hours while awake.
- Stay away from crowds.

Things to Avoid

- Refer to the patient education handout **Food and Safety During and After Stem Cell Transplant** for more information about foods to avoid and food/cooking precautions.
- Alcohol
- Raw seafood, including sushi and oysters
- Foods or liquids that are acidic, such as orange juice, if your mouth is sore
- Direct sunlight and extreme hot or cold temperatures
- Activities that could cause injury or bleeding
- **Do not** floss your teeth when your absolute neutrophil count, referred to as ANC, is less than 1,500 and your platelet count is less than 20,000

Post Transplant

Vaccines

About 6 months after your transplant and once your white blood cell count recovers, you will be ready to start getting vaccines that you received in the past as a child. Your doctor will determine which vaccines you will need and when you are ready to receive them.

Hair

It usually takes 3 or more months for hair to start growing back after treatment. The texture of the hair may be different than before your transplant. It is not very common, but it is also possible to have hair loss in the years following a transplant.

Sun Exposure

Your skin will still be more sensitive to sunburns after your transplant. Be careful about the amount of time you spend in direct sunlight. Use sunblock with SPF 50 and reapply it often, and wear ultraviolet protective UVP clothing, a hat, and sunglasses when outside.

Exercise

During the first few months after your transplant, try to stay active. As you gain more strength, you can start to exercise more and slowly increase your workouts over time. You can swim in a pool as long as it is well kept, treated with chlorine, and is not crowded. **Do not swim** if you still have a central venous catheter in place. Talk to your doctor before you do any strenuous exercises, such as contact sports or activities that increase your risk of injury.

Sexual Health and Activity

Talk to your doctor about when you can safely have sexual activity after your transplant. In general:

- If your platelet count is below 50,000 and ANC is below 2,000, avoid activities involving vaginal or anal penetration. You should also avoid oral sex.

- Talk to your doctor before having sex if either you or your partner has or may have a sexually transmitted infection.

Females

- You may have no or fewer menstrual periods following your transplant.
- You may have vaginal dryness. Talk with your doctor if you have vaginal discomfort.

Males

You may have erectile dysfunction following your transplant. Talk with your doctor if you have this.

Returning to Work or School

Deciding when to return to work or school will vary and depends on how quickly you recover. In general, you should wait 3 to 6 months after your transplant before you go back to work or school and should only return when you feel well enough to do so. If possible, you may want to think about going back on a limited or part-time schedule and increase your workload as you feel able. Talk with your doctor about when it is safe for you to return to work or school.

Alcohol and Tobacco

Never smoke cigarettes, cigars, other tobacco products, or marijuana. This can lead to further illnesses and a lung infection after your transplant. If you smoke, tell your doctor. MD Anderson offers smoking cessation programs to help you quit.

Alcohol damages your liver and can harm your bone marrow as it recovers. Talk with your doctor about when it is safe to drink alcohol.

Eye Exams

Your vision may change after your transplant. If it does, you may need to change your prescription. If you have any vision changes, see an eye doctor. You should also contact an eye doctor if you have any double, cloudy or blurry vision, or changes in vision at night or how you see colors. Be sure to tell the eye doctor you had a stem cell transplant.

Caregiver's Role in Stem Cell Transplant

This handout describes how the caregiver takes part in the patient's care while they are in the Stem Cell Transplant and Cellular Therapy Program. Read this handout and talk with the care team if you have questions or concerns.

A stem cell transplant caregiver provides vital physical and emotional support to the patient and helps keep them safe. They also help patients with their recovery. This includes getting the patient to and from the hospital for appointments or for an emergency. A caregiver makes sure the patient eats, drinks, sleeps and takes medicines as instructed.

There are specific times during stem cell transplant where a caregiver is required. Many care team members will teach you about your role during inpatient and outpatient care.

Time Off and FMLA

If you work, you will need to take time off. Some caregivers use vacation time, while others take time away using FMLA (Family Medical Leave Act). You may contact the patient's care team if you need a letter or form completed for your employer.

Contact Information and Care Schedule

The care team must have your name and phone numbers to reach you at all times. If there is more than one caregiver, the care team will also need their information. The care team will also need a schedule of which caregiver is caring for the patient and when.

Caregiver Duties

The caregiver role varies throughout the transplant phase. It can include the role of driver, cook, cleaner, bather and dresser, entertainer, advocate and friend. Caregivers must also:

- Perform central venous catheter (CVC) care for the patient. You must learn how to care for the patient's CVC before they are discharged from the hospital. Classes are offered every weekday.
- Watch the transplant discharge video with the patient before they are discharged from the hospital.
- Help the patient get to follow-up visits at the Ambulatory Treatment Center (ATC) or Fast-Track Clinic as scheduled after hospital discharge.
- Shop for and prepare healthy meals and snacks and encourage the patient to eat plenty of food daily.
- Help the patient follow a certain diet and understand safe food handling practices.
- Help the patient take their medicines on time.
- Help the patient contact the social worker, chaplain and community resources if needed.

When to Call the Care Team

In some cases, patients may not be aware of problems that develop. **It is important that you contact the care team about any changes in the patient's symptoms, such as:**

- Fever or chills
- Vomiting
- Diarrhea
- Problems with eating or drinking
- Depression or changes in mental status

The patient's outcome and safety could be at risk if these symptoms are not reported to the care team **right away**.

Daily Activities

You may be asked to keep a daily log of the patient's activities to give to the care team. Encourage the patient to do as much of their care as possible and to stay safe. The patient should try to resume normal activities as soon as they feel able to do so. Talk with the care team about physical or occupational therapy if there are concerns about the patient's safety. This may also be helpful if they need help with exercise or cannot do daily activities because of fatigue.

Communication

It is important to keep family and friends updated on the patient's condition. This may not be easy to do. Much of the information and terms may be hard for others to understand. Having to repeat the same information can take a great deal of time. Some find it helpful to share updates with family and friends through a newsletter, email, church bulletin or other ways. You or the patient may want to choose someone to oversee sharing updates. The care team can help this person explain information in simple terms.

Take Care of Yourself

Fatigue, weakness and problems with eating can also be a challenge for the caregiver. Talk with the care team if you have concerns about your role or taking care of yourself.

Caregiver duties are like a full-time job. Do not be afraid to ask for help or let others know what you or the patient needs. Family members and friends are often willing to help with some of the tasks, such as preparing meals, helping with childcare, running errands, and doing house and yard work. Being a blood donor is another way family and friends can help as well.

It is important that you are in good physical and emotional health in order to carry out the many required caregiver duties and tasks. Talk with your own doctor about the best way to manage your own care if you have a medical condition that needs routine follow-up or care. There are hospitals and clinics in the Houston area that you can contact directly if medical needs arise.

Take time to exercise, manage stress, and eat well. Doing these things for yourself can also help encourage the patient. Remember, the patient cannot make progress and succeed in their treatment without you.

Autologous

Autologous Bone Marrow or Stem Cell Transplant

This handout is for patients who may receive their own stem cells after treatment with high-dose chemotherapy

General Information

Blood forming stem cells, also known as **hematopoietic cells**, are the seed cells that make your blood cells in the body. These cells live in the bone marrow and in normal conditions, only small amounts are in your blood. Some types of cancers, such as multiple myeloma, certain types of lymphoma, germ cell tumors and others, respond better when high doses of chemotherapy are given. When chemotherapy is given at high doses, it may affect the marrow and its stem cells, resulting in prolonged periods of low blood counts.

Patients with these cancer types may benefit from using their own stem cells to allow doctors to safely give higher doses of chemotherapy. This procedure is called an **autologous transplant**. In general, stem cells are collected during a time of complete or near complete remission (no evidence of disease), and then given back (infused) after high-dose chemotherapy.

The information below explains the pre-transplant phase, stem cell collection, the inpatient phase, and outpatient recovery phase.

Pre-Transplant Phase

The pre-transplant phase involves a few important steps. The care team will:
- Confirm financial approval.
- Make sure the disease stage will respond to treatment.

For some patients, the pre-transplant phase is quite short, and for others the process can take months. This depends on any problems or delays with disease control, or with finances. Your stem cell transplant coordinator will guide you through this process.

Central Venous Catheter (CVC)

Throughout your treatment, you will use a central venous catheter (CVC), which is inserted into a large vein located in your chest. The CVC has 2 or 3 small tubes that remain outside your body. The CVC is used when you receive chemotherapy, stem cells, fluids, medicines, blood transfusions. It is also used to draw blood instead of using a needle each time.

Your CVC may be placed a few days before treatment starts. Your transplant team will schedule the placement procedure with you. Once in place, you will keep it throughout your treatment. Your transplant team will decide when it is no longer needed and when it can be removed.

You must keep the CVC clean and dry, but it should not stop you from your normal physical activities. Talk with your transplant care team before you participate in any contact sport or strenuous exercise while your CVC is in place. You should always keep the CVC secure with medical tape as directed.

Before your transplant, you will receive instructions about your CVC and how to clean and care for it properly. It is important that you and or your caregiver attend the CVC Care class to learn how to manage and care for your CVC. You will receive several patient education handouts in the class, including **Central Venous Catheter (CVC): Dressing Change**.

CVC Care Classes
Vascular Access and Procedures Center
Main Building, Floor 8 near Elevator C, Room 8.2192
Monday through Friday, 8 a.m.
Return demonstrations daily after class until 12 p.m.
Weekends and Holidays – No classes
Class takes 1 to 1½ hours to complete.
713-792-2316, select option 3

Peripheral Blood Stem Cells

Stem cell collection is a procedure that involves separating and collecting stem cells from the blood or bone marrow and storing them for transplant. **Apheresis** is a process that collects peripheral blood stem cells (PBSC) from the bloodstream.

Peripheral Blood Stem Cell Collection (PBSC) Using Apheresis

Apheresis is the most common method used at MD Anderson for stem cell collection. It is usually done on an outpatient basis in 3 phases: **mobilization, monitoring and collection**.

Mobilization Phase

During the mobilization process, stem cells are prepared for collection. The donor (patient) receives growth factor injections, such as G-CSF (Zarxio®) or G-CSF with Mozobil®, under the skin. This medicine helps the body to make stem cells and increases the numbers of stem cells in the blood.

Growth factor injections may cause bone pain because the bone marrow is making more stem cells. The pain goes away once the injections stop. **Do not** take pain relievers, such as Advil®, Aleve® or aspirin unless your doctor says it is okay to do so.

Chemotherapy Mobilization

Some patients who donate stem cells to use for themselves may receive chemotherapy before mobilization. Your doctor will explain why chemotherapy is needed and if it can be given as an outpatient or inpatient. After chemotherapy, you will receive the growth factor injection to help increase the number of stem cells in the blood. If you received chemotherapy, you will need to be watched closely as an outpatient in our Fast Track Clinic before collection.

Monitoring Phase

You will receive appointments for the growth factor injections. After several days, you will have your blood drawn to assess your response. During the lab visit, the clinic staff takes a blood sample and tests it to see how many stem cells have moved from the bone marrow out into the bloodstream. The test takes a few hours to run. The results show if you are ready to start the collection. If there are not enough stem cells, you will return to the lab each day for tests. Once the tests show that there are enough stem cells in the bloodstream, the clinic team will schedule an apheresis appointment to collect the stem cells.

Collection Phase

A cell separator machine separates and collects the stem cells. This process is known as **apheresis**. Patients will have a central venous catheter (CVC) inserted for this procedure. See Figure. This procedure normally takes about 4 hours. Cells are collected every day until enough of them are collected for stem cell transplant. Your doctor will decide how many cells are needed for collection. It may take longer depending on how quickly the stem cells are removed from the blood. After the procedure, the apheresis nurse will give you an instruction sheet about self-care.

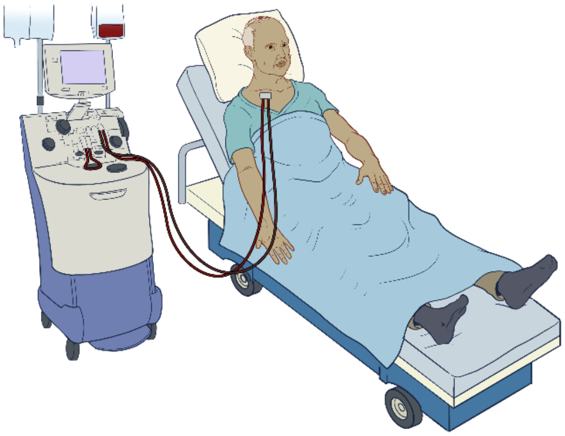

Figure. Stem Cell Collection Using a Central Line
©MD Anderson Cancer Center

Your doctor may need to prescribe another medicine called plerixafor (Mozobil) if there are not enough cells being collected. This medicine helps release the stem cells into the peripheral blood. It is given as an injection at 8 p.m., the night before your morning stem cell collection.

Admission for Stem Cell Transplant

Pre-Admission Testing

You will need a series of tests before you are admitted for the stem cell transplant. The tests assess your condition and health. Some may be tests you have already had, but they need to be done within 30 days of your transplant. The test results help your care team make sure that it is the best time for you to have a transplant. The results also tell the team if you have any health conditions that may need more assessment.

Common tests include:

- Echocardiogram. This test checks blood flow through the heart.
- Electrocardiogram. This test checks the electrical activity throughout the heart.
- Pulmonary function test. This test checks the health and strength of the lungs.
- CAT/PET scan. This test checks location and activity of some cancers.
- Bone marrow aspiration. This test checks for cancer in the bone marrow.
- Blood and urine tests. This test checks blood counts and levels.
- Dental exam. This exam checks for dental concerns or problems, like gum or tooth infection. The dental exam can be done with your dentist before your transplant appointment.

Your stem cell transplant coordinator and treatment team will talk with you about the tests needed and will help coordinate your tests before the transplant. Once admitted to the hospital, you will be an inpatient for 2 to 3 weeks.

Outpatient Transplants

If your kidney, lung, and heart function is adequate, you may be eligible to receive your stem cell transplant on an outpatient basis. The decision to do the transplant as an inpatient or outpatient will be made by your doctor several days before the date of the transplant. As an outpatient transplant patient, you are seen every day in the Fast Track Clinic until you have recovered from the transplant. Talk with your doctor if you are interested in this option. For outpatient, local housing needs to be secured and you need to have a caregiver who can bring you daily to the clinic.

Conditioning Phase

During conditioning, you will get high-dose chemotherapy to kill the cancer cells. Conditioning also kills bone marrow and stem cells, which is why you receive a stem cell transplant following chemotherapy. Your transplant doctor will decide the type, dose, and how often you receive chemotherapy with or without radiation. This usually depends on the type of cancer you have and what previous treatments you have already had. Your transplant care team will coordinate with you to schedule your conditioning.

Stem Cell Infusion

You will be ready to receive your transplant once the chemotherapy and radiation is done. During the transplant, the stem cells are infused through a central venous catheter (CVC). The stem cells go into your blood and travel to the bone marrow. These stem cells produce new blood cells in the bone marrow. The day of the transplant is called **Day 0**. The infusion lasts from 30 minutes to several hours.

Initial Recovery Period

After the stem cells are infused:

- You will stay in the hospital for about 2 to 3 weeks while your blood counts recover.
- Your treatment team will monitor your blood counts daily and help manage any side effects.
- Several IV medicines and fluids may be given.
- You will be discharged from the hospital once you have engrafted, meaning that your white blood cells have recovered, and you are eating and drinking well.
- Each patient will be assessed on an individual basis. For example, you may need to stay in the hospital longer if you have a fever or other conditions that require medical care.

Engraftment

After the transplant, the infused stem cells will go into your blood and travel to the bone marrow. These stem cells produce new blood cells (red, white and platelets) in the bone marrow. This process is called **engraftment**. It can take days to weeks after the transplant before the stem cells start making new blood cells.

In general, your white blood cell counts will start to recover faster than your red blood cell and platelet counts. During this time, you will:

- Be at continued increased risk for developing an infection.
- Have regular blood tests. Blood tests are done to check the progress of the engraftment. As blood counts increase over time, this means the engraftment is successful.
- Receive transfusions to maintain your electrolyte levels, red blood cells, and platelets, if needed.
- Continue to do what you need to do to avoid infections.
- Continue managing your side effects and watch for new side effects. You may also have problems sleeping, develop a rash, and have bone pain.
- Continue to stay active and take a few short walks throughout the day.
- Obtain a medical alert necklace or bracelet in case of an emergency. This informs medical emergency responders and staff that you have had a transplant. This is important because any blood products you may receive need to be **irradiated** (treated with radiation). Be sure to inscribe the jewelry with the words **"Stem cell transplant patient, irradiated blood products only**."

Follow-Up and Recovery

Even after your engraftment, it is likely that you will not feel completely back to normal. You may have a low appetite, feel tired (fatigue), and have less strength, especially for the first few months after treatment. It will take time to start feeling more like you did before your illness. You will likely start feeling much better around the third month through the first year after transplant

After your discharge:

- You must have a caregiver 24 hours a day, 7 days a week upon discharge.
- The care team will monitor your recovery in the Fast Track Clinic for 2 to 3 weeks. Follow-up visits are usually every day or 2 times a week depending on your health and needs.
- You will have lab tests done at every visit to check your blood counts, electrolytes, and kidney function. Test results may take a few hours.
- The care team will weigh you, take your vital signs, ask about any side effects you may have, and answer your questions or concerns.
- Your transplant care team will determine any care you need for the day based on your lab test results.
- The care team will transition you to your stem cell transplant clinic doctor when you no longer need to be monitored by the Fast Track Clinic. Your doctor will talk with you and decide when you can move your care to your cancer or primary care doctor in your home area.
- Your CVC will be removed.

Talk with your care team if you have any questions.

Autologous Stem Cell Transplant With Chemo Mobilization

Estimated Timeline

Week 1 to 2
- Outpatient testing
- Doctor visit
- CVC insertion
- Admitted to inpatient 1 to 4 days or outpatient chemo mobilization

Week 3 to 5
- Outpatient filgrastim growth factor
- Fast Track follow ups and stem cell collection in Apheresis

Week 6 to 8
Day -7 to Day +14
- Consent for transplant
- Inpatient high dose chemo and transplant
- Caregiver optional while you are hospitalized

Week 9 to 11
Day +14 to Day +30±
- Outpatient follow up in Fast Track
- Caregiver and local housing required

Important Information
- You must have housing and a caregiver secured before you start the stem cell transplant timeline.
- The stem cell transplant timeline may change based on your needs.

Revised 01/2025, Patient Education

Autologous Stem Cell Transplant With Filgrastim (G-CSF) Mobilization

Estimated Timeline

Week 1
- Outpatient testing
- Doctor visit
- CVC insertion

Weekend
- Outpatient filgrastim growth factor begins

Week 2
- Outpatient stem cell collection in Apheresis

Week 3 to 5 (6)
Day -7 to Day +14
- Consent for transplant
- Inpatient chemo and transplant
- Caregiver optional while you are hospitalized

Week 6 to 8
Day +14 to Day +30$^{\pm}$
- Outpatient follow up in Fast Track
- Caregiver required 24 hours a day, everyday
- Local housing required

Important Information

- You must have housing and a caregiver secured before you start the stem cell transplant timeline.
- The stem cell transplant timeline may change based on your needs.

Outpatient Autologous Stem Cell Transplant With Filgrastim (G-CSF) Mobilization

Estimated Timeline

Week 1
- Outpatient testing
- Doctor visit
- CVC insertion

Weekend
- Outpatient filgrastim growth factor begins

Week 2
- Outpatient stem cell collection in Apheresis

Week 3 to 6
Day -5 to Day +25
- Consent for transplant
- Chemo in Stem Cell Transplant clinic
- Transplant in Apheresis
- Fast Track follow ups
- Caregiver and local housing required

Important Information

- You must have housing and a caregiver secured before you start the stem cell transplant timeline.
- The stem cell transplant timeline may change based on your needs.

Allogeneic

THE UNIVERSITY OF TEXAS
MD Anderson ~~Cancer~~ Center

PATIENT EDUCATION

Allogeneic Stem Cell Transplant

This section is for patients who may receive donor stem cells from peripheral blood or bone marrow.

General Information

Stem cells are collected from three sources:
- Blood
- Bone marrow (spongy tissue found inside the large bones of the body)
- Newborn baby’s umbilical cord after birth

During an allogeneic transplant, stem cells are collected from a donor and infused into a patient. A special blood test called human leukocyte antigen (HLA) typing checks to make sure the patient and donor are a match. This test requires 2 separate collections done as a blood draw or cheek (buccal) swabs. The donor may be:
- An identical twin (a syngeneic transplant)
- A relative
- Someone who is not a relative (matched unrelated donor, or MUD transplant)
- A newborn baby (umbilical cord blood transplant)

Before the transplant, you will receive high doses of chemotherapy and/or radiation to destroy the cancer cells. This also causes damage to cells in other parts of the body, including the bone marrow and immune system. The immune system is the body’s defense against disease and infection. This process also causes damage to healthy blood cells.

With certain types of cancer, the care team can give slightly less or smaller doses of chemotherapy before stem cells are given. The stem cell transplant allows your body to create new, healthy blood cells from the donor stem cells.

The type of chemotherapy given varies between patients. Your stem cell transplant doctor will decide which type you will receive. There are 3 common types of conditioning:

- **Myeloablative transplant** – This type of transplant uses high doses of chemotherapy, with or without radiation. The chemotherapy and radiation are given to kill the cancer, but it will also kill the stem cells in your bone marrow. The cells you receive from your donor will replace the ones killed by the chemotherapy and radiation. This treatment is intense and your stem cell transplant team will decide if it is right for you.
- **Non-myeloablative transplant** – This type of transplant uses low-dose chemotherapy, with or without radiation, to prepare you for the transplant. The stem cells from your donor briefly co-exist with your own cells and work together to fight cancer cells. Side effects are usually less severe.

- **Reduced-intensity transplant –** This type of transplant also uses low-dose chemotherapy, with or without radiation. The concept behind this type of transplant is that high-dose therapy may not be needed for you to accept the stem cells from your donor. This type of transplant has fewer risks and can be done as an outpatient since it does not involve high-dose therapy.

Outpatient Allogeneic Stem Cell Transplant

Some patients have good results and may benefit from receiving their allogeneic stem cell transplant as an outpatient. When patients are in the hospital, there is a greater chance of being inactive. This can lead to loss of muscle strength and mass, and deconditioning. Also, patients often do not rest well at night while in the hospital and many do not want to stay in the hospital for weeks. These things can have a negative effect on a patient's well-being and recovery.

Your doctor carefully reviews your case and decides whether they feel you can manage your transplant as an outpatient and comply with the treatment plan. If so, you are followed closely from the start of your chemotherapy and through your first 100 days after the stem cell transplant**.**

Allogeneic Transplant and Graft-Versus-Disease Effect

Allogeneic transplant is the choice for patients with leukemia or certain types of lymphoma because the disease may be present in the person's own stem cells, so getting their own cells (autologous transplant) is not an option. Graft versus disease effect (GVL/GVD) is a major benefit of an allogeneic transplant. It occurs when the donor's cells destroy your cancer cells because it sees them as foreign and different.

Enhanced Recovery Stem Cell Transplant (ER-SCT)

Enhanced recovery for stem cell transplant (ER-SCT) is special care that takes place before chemotherapy and allogeneic stem cell transplant. The goal is to:
- Improve physical and mental health.
- Lessen symptoms and treatment side effects.
- Improve quality of life.

Eligibility

- The care team will routinely screen any patient age 65 and older who is planning to have a stem cell transplant donor (allogeneic) for the ER-SCT program. All patients whose medical team have concerns about any of the conditions and symptoms may request that you participate in the weeks or months leading up to your stem cell transplant.
- Your stem cell transplant doctor and other members of the care team recommend enhanced recovery care to help lessen the impact of side effects related to your stem cell transplant. An advanced practice provider works with you to review details of your health and well-being. You may also have visits with other enhanced recovery care team members.

Before Your Transplant

You will be in the hospital for about 3 to 6 weeks for your stem cell transplant. During this time, your risk for side effects and infection is high because your white blood cell counts are low. You may have weakness, muscle loss, nutrition problems, severe fatigue, and changes in the way you think and do routine tasks. These symptoms can affect your quality of life and increase your risk for serious medical problems.

As a result, your doctor may want you to take part in this program, which includes the following:
- An exercise program called **prehabilitation (prehab)** and assessment by an occupational therapist
- Review of your nutrition status by a clinical dietitian
- Review of your current medicines and the treatment medicines you will take while in the hospital by a clinical pharmacist
- Patients age 65 years and older will meet with the Geriatric Care Team to review your condition and help with support of any chronic conditions, stress, and memory loss.

Types of Allogeneic Transplants

Your doctor will discuss the type of transplant that is best for you.

Matched Related Donor (MRD)

This type of transplant is done if a family member, usually a brother or sister, is determined to be a **complete** HLA match.

Matched Unrelated Donor (MUD) Transplant

If a family member is not a match, your doctor might recommend a search for a matched unrelated donor (MUD). The search looks at HLA typing from donor volunteer registries in the U.S and all over the world to find a possible donor. These lists are updated often.

Haploidentical Transplant

Many patients who need a stem cell transplant cannot find a donor who fully match their HLA type. Advances in technology now allow transplants from donors who are a **half** match. These donors may be used when a matched donor is not found or timing for the transplant does not allow the time needed to find an unrelated donor. Potential donor matches will come from first-degree relatives including siblings, children, or parents.

Umbilical Cord Blood Transplant

Many transplants are being done using stem cells from umbilical cord blood due to an increase in public cord blood banks. If you do not have a donor, you may be a candidate for cord blood transplant. The benefit of using cord blood is that it is likely to be available right away. A drawback is that the number of available stem cells from one umbilical cord donor is a small amount. There may not be enough stem cells to do a transplant.

Syngeneic Transplant

A syngeneic transplant is done when you have an identical twin. Since twins have the same genes, there is less risk of problems. The patient usually tolerates this type of transplant very well.

Pre-Transplant Phase

The pre-transplant phase involves important steps, which include:
- Confirming financial approval
- Making sure the disease stage will respond to treatment
- Finding a HLA-matched donor, which can be a long process

For some patients, the pre-transplant phase is quite short, for others the process can take months. This depends on any problems or delays. There can be problems with disease control, finding a donor match, or with finances. Your transplant coordinator will guide you through this process.

HLA Typing

HLA typing is a special blood test that needs to be done if you are being considered for an allogeneic transplant. The test finds antigens, which are proteins in white blood cells, and compares them to a donor's antigens. Antigens make each person's tissue type unique. Both you and your family members should have HLA typing done to help find a possible HLA-matched donor.

Finding an HLA-Matched Donor

Finding the most highly matched donor available is very important. There is less risk of problems if you and the donor are HLA-matched.

An HLA-matched sibling is the best donor for an allogeneic transplant. This is because parents pass on one half of their HLA typing to their children. A brother or sister has a 25 percent chance of being a match with the patient. There is about a 1 percent chance of being matched with a parent, child or distant relative.

MD Anderson must complete the donor HLA typing. If you have siblings that live in the Houston area, they may come to MD Anderson to be HLA typed. If they live outside of the area, we can mail HLA kits directly to them. A local lab facility (e.g. Labcorp®) can take their blood samples. Instructions on how to return the kit to MD Anderson are included. It takes about 2 to 4 weeks to get the HLA typing results.

Financial approval for the test is needed before testing can occur.

If a Family Member Is a Match

If a family member is a match, the **related stem cell transplant coordinator** will be your main contact. This coordinator reviews your family member's health history to confirm that they are in good health to be your donor. Conditions such as high blood pressure, diabetes or high cholesterol need to be assessed, but seldom keep someone from being a donor.

Your transplant process and the donor's stem cell collection are coordinated by the transplant coordinator. Donors must come to MD Anderson for the stem cell collection procedure. It can take up to 2 weeks to complete the collection process.

Any recent history of cancer or an autoimmune disease, like rheumatoid arthritis or multiple sclerosis, needs further assessment by the treatment team. This may prevent your family member from being a donor.

If more than one sibling is a match, your treatment team will decide which donor is best based on age, gender, health and other criteria.

If You Do Not Have a Family Member Match

If no family member is a match, the **unrelated stem cell transplant coordinator** will start the process of finding an unrelated donor.

Unrelated Donor Search

Possible unrelated donor matches can be assessed quickly using a worldwide donor database of volunteer donors. The database only provides initial information, so HLA testing is needed to identify and confirm a donor match.

The transplant coordinator and your stem cell transplant doctor work together to find the best donor for you. The formal search starts once financial clearance is obtained and you give a verbal consent to proceed.

The donor search can be costly. Your insurance company will review your request and if they do not cover the donor search, a representative with MD Anderson's Business Center will give you a quote for the cost of the search and review it with you.

Once a search begins, the transplant coordinator will help with the following:
- Review the list of possible donors and request the most suitable ones for further testing. This process usually takes 2 to 4 weeks, but can take longer depending on the donor making an appointment for the blood draw.
- Ask the donors to send a blood sample to MD Anderson for HLA typing. Once the sample arrives at MD Anderson, it usually takes 7 to 10 business days to confirm the donor's HLA typing.
- Review the test results and consult with your care team to decide the most appropriate donor for you.

When a Donor Is Found

Once a donor is found, you and your care team will decide the best time for the transplant. This depends on many factors, such as:
- Your disease status
- The date of your last chemo treatment
- Whether you have an infection
- Donor availability

If there is a special event in your life, such as a wedding, birth of a child or holiday, your transplant may be planned around it. Talk with your doctor about events that you would like to plan around.

Stem Cell Collection

Related Patient and Donor Transplant

For donors who are relatives, the **related stem cell transplant coordinator** will schedule the stem cell collection as close to the transplant date as possible. If needed, the team may allow the collection to happen weeks to months before the transplant.

Unrelated Patient and Donor Transplant

For unrelated transplant patients, the **unrelated stem cell transplant coordinator** will file a request with the National Marrow Donor Program to request stem cell donation dates. During this same time, you will start testing and chemotherapy. Your transplant coordinator will discuss details with you so you can prepare for your stay in Houston.

Some patients may want to contact their donor. Guidelines vary with each donor center. Talk with your transplant coordinator about this once you proceed with the transplant.

Peripheral Blood Stem Cells or Bone Marrow Collection

Stem cell collection is a procedure that involves separating and collecting stem cells from the blood or bone marrow and storing them for transplant.
There are 2 main ways to collect stem cells:

- **Apheresis** is a process that collects peripheral blood stem cells (PBSC) from the bloodstream.
- **Bone marrow collection (harvest)** is a process that collects cells directly from the bone marrow.

Peripheral Blood Stem Cell Collection (PBSC) Using Apheresis

Apheresis is the most common method used at MD Anderson for stem cell collection. It is usually done on an outpatient basis in 3 phases: **mobilization, monitoring and collection**.

Mobilization Phase

During the mobilization process, stem cells are prepared for collection. The donor receives growth factor injections, such as G-CSF (Zarxio®) or G-CSF with Mozobil™, under the skin. This medicine helps the body make stem cells and increases the number of stem cells in the blood.

Growth factor injections may cause bone pain because the bone marrow is making more stem cells. The pain goes away once the injections stop.

Monitoring Phase

When donors receive the growth factor prescription, they also get an appointment for a lab visit a few days after starting the shots. During the lab visit, the clinic staff takes a blood sample and tests it to see how many stem cells have moved from the bone marrow out into the bloodstream. The test takes a few hours to run. The results show if the donor is ready to start the donation. If there are not enough stem cells, the donor will come to the lab each day for tests. Once the tests show that there are enough stem cells in the bloodstream, the clinic team will schedule an apheresis appointment to collect the stem cells.

Collection Phase

Related donors usually donate cells through an intravenous catheter (IV) in each arm. The IV in one arm is used to draw the blood out of the body and into the apheresis machine. The machine filters out the stem cells. The IV in the other arm is used to return the blood to the body. See Figure 1.

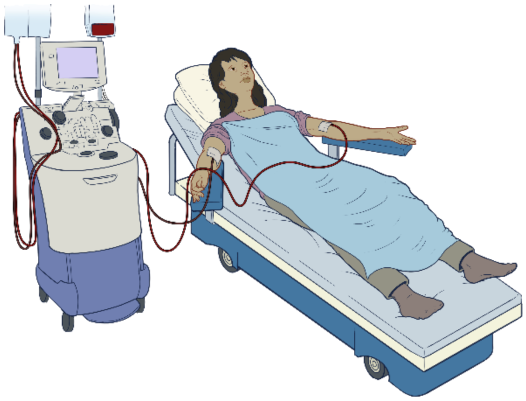

Figure 1
Stem Cell Collection
©MD Anderson Cancer Center

Some donors may need a central venous catheter (CVC) for the procedure. Your care team will discuss this with the donor before the procedure. Patients will have a central venous catheter (CVC) inserted for the transplant procedure.

The donation procedure normally takes about 4 hours. It may take longer depending on how quickly the stem cells are removed from the blood. After the procedure, the apheresis nurse will give the donor an instruction sheet about self-care.

Bone Marrow Collection (Harvest)

Doctors usually do bone marrow collections while the donor is asleep, using sedation. In an operating room, the doctor uses a special needle to remove marrow from the back of the hip bone. The process usually takes about 1 hour to collect all the bone marrow needed for the transplant. The stem cell transplant coordinator and clinic nurse will help prepare the donor for the procedure and answer any questions.

Admission for Stem Cell Transplant

Pre-Admission Testing

You will need a series of tests before being admitted for the stem cell transplant. The tests assess your condition and health. Some may be tests you have already had, but they need to be done again within 30 days of your transplant.

The test results help your care team make sure that it is the best time for you to have a transplant. The results also tell the care team if you have any health conditions that may need more assessment.

Common tests include:

- Echocardiogram. This test checks blood flow through the heart.
- Pulmonary function test. This test checks the health and strength of the lungs.

- CAT/PET scan. This test checks location and activity of some cancers.
- Bone marrow aspiration. This test checks for cancer in the bone marrow.
- Blood and urine tests. This test checks blood counts and levels.
- Dental exam. This exam checks for dental concerns or problems, like gum or tooth infection. The dental exam can be done with your dentist before your transplant appointment.

Your stem cell transplant coordinator and treatment team will talk with you about the tests needed and will help coordinate these tests before the transplant.

Conditioning Phase

Chemotherapy with or without radiation is given during the conditioning phase. This helps to:

- Wipe out the existing bone marrow cells to allow the donor's new, healthy stem cells to grow.
- Destroy any existing tumor cells if there is cancer or a tumor.

Once the conditioning phase starts, you will receive infusions of IV fluids through your central venous catheter to keep you well hydrated throughout the transplant. These infusions may be continuous or last for a few hours based on your treatment plan. Your care team will discuss which chemotherapy and medicines you will receive during the conditioning phase. Each chemotherapy is given on certain days leading up to your transplant day.

If your conditioning will be done in the outpatient setting, you will see the outpatient stem cell transplant team. This team includes an advanced practice registered nurse (APRN), a pharmacy specialist (PharmD) and sometimes a stem cell transplant doctor. Your chemotherapy is scheduled in the outpatient Ambulatory Treatment Center (ATC). Refer to your appointment schedule for all appointment times and locations.

After you complete the conditioning phase, you will be admitted to the hospital for the rest of your treatment until your counts recover. Then, you will have weekly or daily follow-up visits in the outpatient ATC.

Stem Cell Infusion

You will be ready to receive your transplant once the chemotherapy and radiation are completed. During the transplant, the stem cells are infused through a tube called a central venous catheter (CVC). The stem cells go into your blood and travel to the bone marrow. These stem cells produce new blood cells in the bone marrow. The day of the transplant is called **Day 0**. The infusion lasts from 30 minutes to several hours.

Initial Recovery Period

After the stem cells are infused:

- You will stay in the hospital for about 3 to 6 weeks while your blood counts recover.
- Your treatment team will monitor your blood counts daily and help manage any side effects.
- Several IV medicines and fluids may be given.

- You will be discharged from the hospital once you have engrafted, which means that your white blood cells have recovered and you are eating and drinking well.
- Each patient will be assessed on an individual basis. For example, you may need to stay in the hospital longer if you have a fever or other conditions that require medical care.

Engraftment

After the transplant, the infused stem cells will go into your blood and travel to the bone marrow. These stem cells produce new blood cells (red, white and platelets) in the bone marrow. This process is called **engraftment**. It can take days to weeks after the transplant before the stem cells start making new blood cells.

In general, your white blood cell counts will start to recover faster than your red blood cell and platelet counts. During this time, you will:

- Continue to be at increased risk for developing an infection.
- Have regular blood tests. Blood tests are done to check the progress of the engraftment. As blood counts increase over time, this means the engraftment is successful.
- Receive transfusions to maintain your electrolyte levels, red blood cells, and platelets, if needed.
- Continue doing what you need to do to avoid infections.
- Continue managing your side effects and watch for new side effects. You may also have problems sleeping, develop a rash, and have bone pain.
- Continue to stay active and take a few short walks throughout the day.
- Obtain a medical alert necklace or bracelet in case of an emergency. This informs medical emergency responders and staff that you have had a transplant. This is important because any blood products you may receive need to be **irradiated** (treated with radiation). Be sure to inscribe the jewelry with the words **"Stem cell transplant patient: Use irradiated blood products only**."

Follow-Up and Recovery

After your discharge:

- You **must** have a caregiver with you 24 hours a day.
- Wear a mask for outpatient appointments, when you come to MD Anderson and when you are in crowded places.
- Take your temperature with a thermometer by mouth, 2 times a day (morning and before bedtime).
- Wash your hands with soap and water or use hand sanitizer often. Do not wear gloves.
- Screen visitors to make sure they are healthy with no fevers, colds, coughs or sore throat.
- Drink at least 6 to 8 cups (1.5 to 2 liters) of fluids each day, such as water, sports drinks (Gatorade® or PowerAde®), juices, lemonade or nutrition drinks (Boost® or Breeze®). Limit caffeine intake and do not drink alcohol.
- Do activity such as walking and stay out of the bed as much as possible during the day.
- Know your blood counts.
- Raw fruits and vegetables are okay to eat once you have engrafted (when your ANC is greater than 1).

- No sexual activity unless your ANC is greater than 2 and your platelet count is consistently greater than 50,000 without platelet transfusions for 2 weeks. You may kiss, hug and sleep in the same bed with your partner.
- You will come to the Ambulatory Treatment Center (ATC) as needed. This can vary from every day to 3 or 4 times a week for the first 100 days after transplant. How often you need to come for follow-up visits depends on your health and needs.
- Tests to restage the disease may be done around day +30, +60 and +90. This may include a chest x-ray, bone marrow aspiration, PET scan, 24-hour urine test, or CT scan. Your advanced practice provider schedules these tests for you. You will have an appointment with your stem cell transplant doctor to review the test results.
- You will transition to your stem cell transplant doctor’s routine clinic when your counts and electrolytes are stable with only slight changes needed, and you can take your medicines by mouth as needed.
- The goal is for you to go home after the first 100 days. This may vary and depends on your condition. Once you are cleared to leave the Houston area, you will continue to have follow-up visits with your cancer or primary care doctor in your home area. Some patients may need continued monitoring and symptom management. If this is the case, you will need to stay within 30 minutes of MD Anderson until your doctor tells you it is OK.
- You will also need to attend a survivorship visit before leaving the Houston area.

After the first 100 days, you will continue to have regular lab tests done. Results will need to be sent to MD Anderson for review. You will need to come back for tests and exams every 3 to 6 months for the first year and then every 6 to 12 months. This can vary for each patient and depends on your condition. Your doctor will make a follow-up plan for you.

Things to Avoid

- Sick people and crowds, like at church and the gym. Do not go to a zoo or go swimming. It is okay to go to public places, but try to go when it is less crowded.
- Children under 12 years of age and people who have received a live vaccine in the past 6 to 8 weeks.
- Food buffets. Everything must be made to order.
- Gardening, plants, and pets
- Sun exposure. Use sunscreen with SPF 45 or higher for sensitive skin, wear a hat and light, long sleeve shirts even when short period of sun exposure cannot be avoided.

Unexpected Hospital Admission

An unexpected hospital admission is common for outpatient stem cell transplant patients. The most common reasons include:

- Fever or signs of infection
- Severe nausea and vomiting that results in major weight loss or problems with eating, drinking and taking medicines
- Severe diarrhea
- A rash that does not respond to oral medicines and requires IV treatment
- Uncontrolled symptoms such as pain

When to Go to the Acute Cancer Care Center

Go to MD Anderson's Acute Cancer Care Center **right away** if you have:

- A fever of 100.4°F (38°C) or greater
- Nausea, vomiting, or diarrhea that does not stop
- Bleeding that does not stop after 10 minutes of applying light pressure
- Pain that does not go away
- Chest pain
- Shortness of breath when resting

Ambulatory Treatment Center (ATC)

The ATC is located in the Main Building on Floor 10, near Elevator C. When you come for your ATC visits, the care team suggest that your caregiver use this time to leave the hospital and relax or do any errands they may have.

Here is a brief overview of a general ATC visit.

- Wear comfortable clothing that allows the care team easy access your central venous catheter (CVC).
- At each visit, you will have lab tests to assess your blood counts, electrolytes, and kidney function levels. It may take a few hours to get the test results.
- The care team will take your vital signs and weigh you, ask you about any side effects you have, and discuss your questions and concerns. The advanced practice provider will do a quick physical exam, check your mouth and skin, listen to your lungs and heart, and check for any fluid retention.
- Your care team will decide on any care you need for the day once they review your lab test results. Your care may include:
  - Changes to your medicines
  - An infusion of a blood products or fluids
  - Receiving medicines through an IV (intravenous)
  - No changes to treatment

During your visits, you will stay in the ATC until the care team reviews your lab results and gives you any treatments, if needed. Then, your caregiver may pick you up from the ATC and take you back to the place you are staying. Continue to take your temperature 2 times a day and make sure you drink at least 64 ounces (2 liters) of fluids a day.

What to Bring to the ATC

Bring the following items when you come for your ATC visits:

- All of the medicines you take, including prescribed and over-the-counter medicines, vitamins, supplements, and herbal products
- Things to help keep you busy, such as a book, laptop, or tablet computer. Wi-Fi is available in the clinic.
- Light snacks are provided in the ATC, but you may also want to bring your own snacks and drinks.
- Paper or notebook to write notes and any questions you have for your transplant team

Possible Problems

With an allogeneic transplant, problems could occur, such as the conditions listed here.

Graft Failure

Graft failure is when the immune system rejects the transplant. This is not common because the chemotherapy and radiation that is given before the transplant destroys (suppresses) the patient's immune system.

Graft-Versus-Host Disease

Bone marrow cells are unique to each person. When bone marrow stem cells (the graft) are transplanted in the recipient's body (the host), the stem cells recognize the host as foreign. The cells may attack the cells in the body. This process can cause a reaction in your body called graft-versus-host disease (GVHD). There are 2 types of GVHD: early (**acute**) and late (**chronic**).

Acute GVHD

Acute GVHD can occur anytime following engraftment, with most cases developing within the first 100 days. It can vary from mild to serious and could threaten your life. Acute GVHD may affect the skin, gastrointestinal tract or liver and show with these signs and symptoms:

- Skin rashes (red, flat, thick or bumpy) or blisters on the body
- Redness in the palms of the hands and soles of the feet
- Yellowing of the skin and eyes
- Changes in liver function tests
- Nausea and vomiting, stomach cramps, or bloody or watery diarrhea

The care team will give you GVHD medicines before, during and after the transplant to help prevent or treat this condition. The prescribed medicine depends on your diagnosis and treatment type. Your doctor will review this with you and discuss common side effects of these medicines. These GVHD medicines may include:

- Tacrolimus, methotrexate with or without antithymocyte globulin
- Tacrolimus, cyclophosphamide with or without mycophenolate mofetil
- Other combinations of medicines may be used and depends on your condition.

While on GVHD medicines, your blood levels will be checked 2 times a week to determine if the dose is right for you. If you develop GVHD symptoms, a steroid medicine may be given to treat it. Other medicines may be added based on your response.

Chronic GVHD

Chronic GVHD can usually develop after 3 months, with most cases developing by 2 years. Signs and symptoms usually occur after you have returned to your home community. It can affect multiple body parts. It is important that you watch for signs and symptoms.

Tell your stem cell transplant team **right away** if you develop any of the following:

- Skin color changes
- Hard and thick patches of skin
- Skin or joint tightness

- Changes in liver function tests
- Dry mouth or sores or new mouth burning/pain
- Dry or gritty eyes
- Hair loss
- Genital pain or sores, or pain with sexual intercourse
- Diarrhea
- Weight loss
- Changes in breathing or lung function, such as wheezing, coughing, shortness of breath or lips turning blue

If you develop GVHD signs or symptoms, you may be referred to see a specialist who can help advise treatment for GVHD and improve your symptoms. Chronic GVHD often requires the need to continue taking immune suppression medicines and starting new medicines.

Weakened Immune System

Your immune system will be very weak for several months after an allogeneic transplant. It takes over a year for the immune system to recover. The first 3 months after a transplant are the most serious. Doctors usually prescribe antibiotics during this period and monitor patients closely for infections.

Long Term Follow-Up

You must stay in Houston for the first 100 days after your stem cell transplant as this is when your new immune system is very weak and possible problems could occur. It may take your immune system a year or more after your treatment to return to normal. The goal is for you to go home after the first 100 days, but some patients may need continued monitoring and symptom management. If this is the case, you will need to stay within 30 minutes of MD Anderson until your doctor tells you it is okay.

Survivorship

About day 80 after transplant, you will have your first stem cell transplant survivorship program visit. This visit is very important to your recovery. Your care team strongly suggest that a caregiver, family member or friend attend this visit with you. This visit allows time for you to ask questions about what to expect during the next 2 years of recovery. If you live outside the Houston area, the care team will give you a packet to take with you when you are released to return home. It includes your medical records, treatment summary and transplant care information. Be sure to share this packet with the doctor you see at home.

You must schedule regular follow-up appointments and lab tests with your doctor, which may be weekly for the first few months. Your doctor will need to send copies of your lab results to your MD Anderson care team. If you live in the Houston area, you will continue having regular appointments with your SCT clinic doctor at the Stem Cell Transplant and Cellular Therapy Center. If you have any non-urgent medical problems in between follow-up appointments, contact your SCT care team by phone or send a message using your MyChart account.

Returning to MD Anderson

Your SCT care team will let you know how often you should return to MD Anderson for follow-up appointments. Most times, you are asked to return for an appointment about 1 month after you leave the Houston area. Then, how often you need to come back for appointments depends on how closely the care team needs to monitor your recovery. It is common to have appointments every 3 to 6 months for the first year and then less often as time goes on.

At your follow-up visits, you may have a bone marrow aspiration and biopsy test as well as lab tests and scans to look for disease and assess your immune system. You will also have survivorship clinic appointment when you come for your follow-up appointments at 6 months, 12 months, 18 months, 24 months and 36 months after your transplant. Return follow-up appointments may require a 2-day stay in Houston if traveling from out of town. Talk with your care team if you have questions about this.

Re-Vaccination after Allogeneic Stem Cell Transplant

You will need to get re-vaccinated after your SCT. Vaccinations usually start 6 months after your transplant. You receive 4 sets of vaccines over a period of about 18 months. Your SCT doctor will tell you when to begin your vaccination schedule. The care team prefers that you receive the vaccinations in the SCT clinic on your return visits to MD Anderson.

Be sure you follow these instructions:
- Avoid all live vaccines for at least 2 years after transplant. Your immune system must be tested and confirmed that it is safe for you to receive a live vaccine. Your SCT doctor can advise you about live vaccines.
- Varicella (chicken pox), measles-mumps-rubella (MMR), and rotavirus are live virus vaccines that may be harmful to you if you are exposed to someone who has had these vaccines in the last 4 weeks. Be aware that infants and children from 2 months old to 5 years old usually receive these live vaccines. Avoid close contact and talk with your SCT care team.

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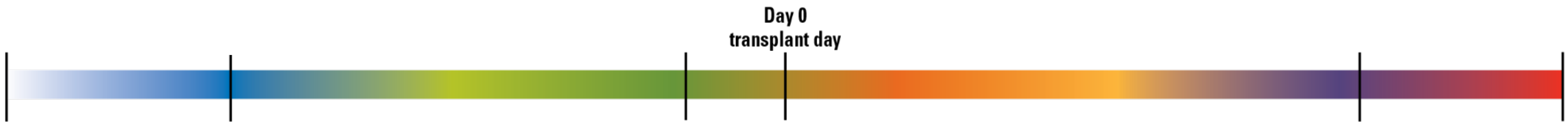
PATIENT EDUCATION

Allogeneic Stem Cell Transplant

Estimated Timeline



Day ±30 to Day -7

- Testing
- Doctor visit
- CVC insertion
- Outpatient chemo
- Caregiver encouraged
- Local housing required

Day -7 to Day +25

- Inpatient chemo and transplant – about 30 days
- Caregiver optional while you are hospitalized

Day +25 to Day +100+

- Frequent follow up in ATC, then follow up with SCT doctor
- Caregiver and local housing required

Important Information

- You must have housing and a caregiver secured before you start the stem cell transplant timeline.
- The stem cell transplant timeline may change based on your needs.

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PATIENT EDUCATION

Outpatient Allogeneic Stem Cell Transplant

Estimated Timeline

Day ±30 to Day -2
- Testing
- Doctor visit
- CVC insertion
- Outpatient chemo
- Caregiver and local housing required

Admit to Hospital
Day -1 to Day +24
- Inpatient transplant
- Caregiver optional while you are hospitalized

Day +25 to Day +100^{+}
- Frequent follow up in ATC, then follow up with SCT doctor
- Caregiver and local housing required

Important Information
- You must have housing and a caregiver secured before you start the stem cell transplant timeline.
- The stem cell transplant timeline may change based on your needs.

CAR T Cell Therapy

Chimeric antigen receptor (CAR) T cell therapy is a type of immunotherapy that uses human T cells to recognize and kill cancer cells. The immune system is made up of 3 sub-types of white blood cells (lymphocytes): B lymphocytes (B cells) to fight infection, T lymphocytes (T cells) and natural killer cells (NK cells) to kill infected or cancerous cells.

With this type of therapy, T cells are removed from either the patient's blood or a donor and altered in a lab to have a specific receptor called chimeric antigen receptors (CARs) made on the surface of the T cells. These receptors will attach to proteins on the surface of cancer cells. The altered T cells are multiplied in the lab, frozen and when there are enough of them, they are given back to the patient through an IV infusion. Then, these CAR T cells can seek out the cancer cells and attack them.

Apheresis

If your own T cells will be used for therapy, you will need to go through a procedure called **apheresis** for the collection process. During apheresis, an intravenous (IV) line slowly removes your blood from a vein in one arm, filters it through the apheresis machine and returns the blood back into your bloodstream through an IV line in your other arm. The apheresis machine collects just the T cells that are needed. It chooses cells of a certain size as they move through the machine. The procedure takes about 4 hours. Be sure to drink plenty of fluids, so you are well-hydrated the day of your consult and procedure.

Chemotherapy

Chemotherapy is given first to prepare you for the CAR T cell infusion. Chemotherapy can be given as an inpatient or outpatient. Your doctor will decide if your therapy will be done inpatient or outpatient based on your condition and treatment.

After CAR T Cell Infusion

Plan to stay within 2 hours of the hospital with a caregiver, family member, or friend who can stay with you at all times for the first 4 weeks after your infusion. This person must monitor your well-being and contact your doctor if you develop a fever or your condition changes.

Possible Problems

Cytokine release syndrome (CRS) is a serious condition related to CAR T cell therapy. Cytokines are proteins that are released by the T cells. They communicate with other special immune cells to kill cancer cells. Cytokines can cause inflammation, similar to a severe infection. Possible signs and symptoms of CRS include:

- Fever of 100.4°F (38°C) or higher, increased fatigue and not feeling well

- Shortness of breath, rapid breathing, and fast heart rate related to low oxygen supply in the blood
- Abnormal heart rate or rhythm, low blood pressure, congestive heart failure related to low or high ejection fraction (measurement of the amount of blood pumped in or out of the heart)
- Nausea, vomiting, or diarrhea
- Liver damage, injury, inflammation and elevated liver enzymes
- Kidney damage, injury, decrease urine output
- Skin rash
- Bleeding disorder in which the body is unable to form blood clots and can lead to extreme or prolonged bleeding

Treatment of CRS symptoms is based on a grading scale. Grade 2 or more is treated with the following medicines:

- Tocilizumab (Actemra®)
- Siltuximab (Sylvant®)
- Steroids

Immune effector cell associated neurotoxicity syndrome (ICANS) is a serious neuro (brain) toxic condition that may be related to cytokine release syndrome (CRS). Possible side effects include:

- Confusion, delirium, agitation, hallucinations
- Problems with speech or unable to use and process language
- Tremor (shakiness) or seizure
- Weak muscles
- Unable to control urine and bowel function
- Increased pressure inside the skull
- Increased pressure in or around the brain that causes the optic nerve inside the eye to swell
- Problems with walking or balance

B cell aplasia is a condition in which the B cell counts are low or absent. This occurs with CAR T cell therapy because it targets antigens on both cancerous B cells as well as normal B cells. When B cells are low or absent, your body is not able to make antibodies that protect against infection. To help prevent infection, patients may have immunoglobulin (blood plasma) IV therapy.

Tumor lysis syndrome is a metabolic condition that occurs when cells breakdown, die and release their contents into the bloodstream. It usually takes place at the start of CAR T cell therapy. It can be serious and life threatening but can be managed with standard supportive therapy. This includes fluids, lab tests and electrolyte checks (calcium, magnesium, potassium, sodium, phosphate, and chloride).

NK Cell Therapy

Natural killer (NK) cells are a type of white blood cell and are a part of the immune system. These cells can be used to recognize and destroy cancer cells in the body. Depending on the specific treatment available for your disease, these cells can be genetically modified to express a receptor that will target cancer cells or can be given in combination with an antibody that will guide them to cancer cells in your body.

With this type of therapy, NK cells are removed from healthy, donated umbilical cord blood after the birth of a baby. These NK cells are then sent to a lab where they are genetically altered or bound to an antibody in preparation for a patient's treatment.

Chemotherapy

Before you receive the changed NK cells, you will receive chemotherapy for a few days in a row in order to prepare your body for these cells. The chemotherapy is not used to fight the cancer. It is used to enhance your body's response to the NK cells.

After NK Cell Infusion

Most often, there are very few side effects from NK cell therapy. However, the care team will watch you closely after you receive these cells for possible problems. The most common symptoms after treatment are low blood counts and nausea, which is often related to the number of days you received chemotherapy before the cell infusion. These side effects can be managed in the hospital with medicines and transfusions, if needed.

Other Serious Side Effects

Cytokine release syndrome (CRS) is a serious condition caused by an over-excited immune response in the body. Cytokines are proteins that are released by white blood cells. They communicate with other special immune system cells to kill cancer cells. Cytokines can cause inflammation, similar to a severe infection.

Possible signs and symptoms of CRS include:

- Fever of 100.4°F (38°C) or higher, increased fatigue and not feeling well
- Shortness of breath, rapid breathing and fast heart rate related to low oxygen supply in the blood
- Abnormal heart rate or rhythm, low blood pressure, congestive heart failure related to low or high ejection fraction (measurement of the amount of blood pumped in or out of the heart)
- Nausea, vomiting, or diarrhea
- Liver damage, injury, inflammation and elevated liver enzymes
- Kidney damage, injury, or decrease urine output
- Skin rash

- Bleeding disorder in which the body is unable to form blood clots and can lead to extreme or prolonged bleeding

Treatment of CRS symptoms is based on a grading scale. Grade 2 or more is treated with the following medicines:
- Tocilizumab (Actemra®)
- Siltuximab (Sylvant®)
- Steroids

Immune effector cell associated neurotoxicity syndrome (ICANS) is a serious neuro (brain) condition that may be related to CRS. Possible signs and symptoms include:
- Confusion, delirium, agitation, or hallucinations
- Problems with speech or unable to use and process language
- Tremor (shakiness) or seizures
- Weak muscles
- Unable to control urine and bowel function
- Increased pressure inside the skull
- Increased pressure in or around the brain that causes the optic nerve inside the eye to swell
- Problems with walking or balance

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PATIENT EDUCATION

Cellular Therapy

Estimated Timeline

Therapy: ________________________________

Week1
- Work up
- Doctor visit

Week 3 to 5
- Doctor visit
- Inpatient chemo and cell infusion

Week 5 to 7
- Personalized outpatient follow up, local

Important Information

- You must have housing and a caregiver secured before you start the cellular therapy timeline.

Cellular Therapy: Estimated Timeline

Reviewed 01/2025, Patient Education

Donor Information

Stem Cell Donation

What Donors Need to Know

Stem cell donation is a way to collect blood-forming cells, which are the stem cells, from a healthy donor to use for stem cell transplant. The stem cells are taken from a donor's blood or bone marrow. The donation is voluntary and done as a standard outpatient medical procedure. There are no long-term adverse effects and the donor's stem cells grow back and fully recover.

Human Leukocyte Antigen

Human leukocyte antigens or HLA, make up a person's tissue type. It is not the same as A, B and O blood types. It is a protein found on most cells in the body. The immune system recognizes HLA proteins and knows which cells belong to the person's body and which do not.

When a patient and donor have the same HLA types, it is called a match. Having a close HLA match is important because it improves the patient's chances for successful stem cell transplant outcomes.

HLA Typing

HLA typing is a special test used to determine the HLA type. It is done by having a sample of blood drawn or by giving a saliva sample. The care team will tell you which type of sample is needed for the donation. The lab draw can be performed at any stand-alone lab center. You will receive an HLA typing kit that contains the test supplies and more information. You will take the kit to any local stand-alone lab center to complete the HLA typing. A small fee is charged to the donor for the lab services.

The HLA typing test results may be shared with the patient and their care team before they are given to the donor.

Stem Cell Transplant

Blood Cells

The body constantly makes new blood cells. Each of these cells begins as a basic stem cell. As stem cells mature and grow, they develop into one of three blood cell types:

- Red cells, which carry oxygen throughout the body
- White cells, which fight infections in the body
- Platelets, which help the blood clot properly after a cut, injury or surgery

A stem cell transplant is an effective treatment for certain blood and immune diseases. This includes cancers such as leukemia, lymphoma and multiple myeloma. A stem cell transplant involves taking a donor's healthy stem cells and infusing them into the patient's bloodstream.

The infusion process for the patient is like getting blood or medicine through an IV catheter. The donor's stem cells grow to make healthy red and white blood cells and platelets for the patient.

Donor Testing

The first step in the donation process is testing. Each donor must do a series of simple medical tests before the collection process to make sure they are in good health and able to donate their stem cells. Tests include:

- A blood test to check overall health
- An electrocardiogram to check the heart function
- A chest x-ray to check the lungs

After the tests, you will meet with a doctor for a complete physical exam and a review of the test results. More tests or other medical appointments may be needed. Based on the results, you may or may not be a candidate for donation.

Female donors that are at an age when pregnancy could occur will have a pregnancy test before they are accepted as a donor. Pregnant women cannot be donors.

Donation Types

There are two methods of stem cell donation: peripheral blood stem cell or PBSC, and bone marrow. The doctor will decide which type of donation and source, either blood or bone marrow, is best.

Peripheral Blood Stem Cells

PBSC donation is a non-surgical procedure. A few days leading up to donation, you will take injections of a medicine called filgrastim G-CSF or similar medicine to increase the number of stem cells in your bloodstream. This medicine helps move the stem cells from the bone marrow into the bloodstream. The doctor also will discuss the medicine's side effects. Most donors do not have serious side effects from taking G-CSF, but some may have aches and pains in their bones and joints. The doctor may recommend an over-the-counter medicine to manage these symptoms.

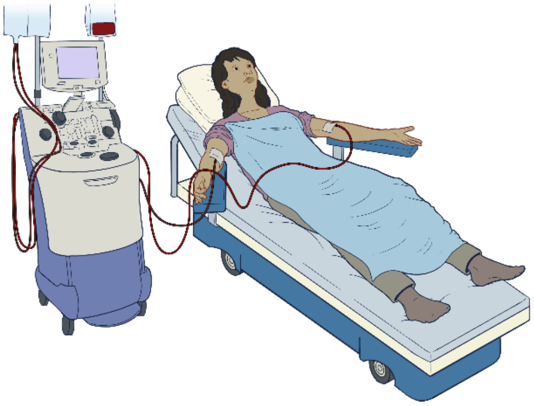

Figure. Stem Cell Donation
©MD Anderson Cancer Center

On the day of donation, a nurse will insert a needle into a vein in each arm. The needles are connected to tubes and the tubes are connected to an apheresis machine. See Figure. For some donors with very small veins in the arms, it may be necessary to have a surgeon insert a tube called a catheter into a larger vein. When the procedure starts, the blood is removed through a needle on one arm and passed through a machine. The machine separates out the stem cells and returns the blood to you through the needle in your other arm.

The collection process takes about 3 to 4 hours for each donation. You are asked to stay resting in a bed or reclining chair during this process. You can go home each day after your tests or collection is done. You may be asked to return to the hospital and donate over a period of several days. After each donation, the stem cells are stored in a special freezer until the patient is ready for the stem cell transplant.

Bone Marrow

Bone marrow donation is a surgical procedure. It takes place in a hospital operating room. The doctor uses needles to remove and collect bone marrow stem cells from a bone in the hip. General anesthesia is used so that you are asleep and feel no pain during the donation. Blood transfusions may be needed to replace the bone marrow that is removed.

The bone marrow stem cell donation procedure usually takes about 2 hours. The doctor will make about 80 to 100 punctures to collect 1 to 2 quarts of bone marrow cells. This may sound like a large amount, but it is only about 5% percent of your total marrow cells. The bone marrow is sent to the lab for processing.

Once the procedure is complete, a dressing is placed over the puncture sites. You are watched closely in the recovery room and may go home the same day. All donors must come back to the hospital the next day for a follow-up visit and to check on the procedure site.

After the Procedure

While recovery times vary depending on the person, most donors recover within 7 to 10 days of donation. The care team will follow up as needed during your recovery period.

More Information

Plan to stay in Houston for 7 to 10 days to complete testing before the donation, also referred to as pre-donation testing and then the donation. Bone marrow stem cell collection may require an extended stay or require many visits.

Travel Expenses

Stem cell donation requires the donor to come to MD Anderson to complete pre-donation testing and donation. MD Anderson does not provide or cover travel or lodging costs. If you need help, ask the patient to contact their social worker.

Insurance/Financial

The donor is linked to the patient’s medical insurance. The patient’s medical insurance will cover pre-donation testing and the donation process.

Letters of Medical Necessity

The related stem cell transplant coordinator can provide medical necessity letters for the donor’s employer and for travel requirements.

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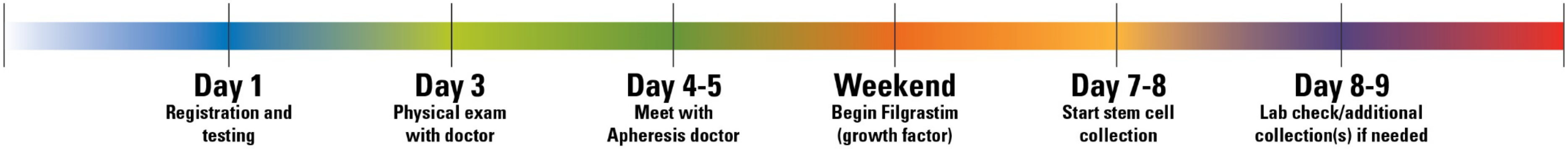
PATIENT EDUCATION

Peripheral Blood Stem Cell (PBSC) Donor

Estimated Timeline



Advance Care Planning

Advance Care Planning

Advance care planning helps you think about future health care choices. It is important that you receive care that aligns with your values and goals of care. Work with your doctor and your loved ones to identify and understand what is important to you.

The planning process helps you to consider and share your values, goals and wishes as they relate to your health care.

Advance care planning allows you to:

- Think about what is important to you.
- Share your values and goals with your loved ones and care team.
- Decide what types of treatment you would or would not want to receive.
- Choose who will make decisions about your medical care if you are unable to speak for yourself.
- Record your decisions in writing.

Making decisions may take time and you may not know all the answers. It is important that you talk about these topics with the people you trust. Ask for help and talk with your loved ones as well as your care team.

The following information is an overview of the advance care planning process. Ask your care team to learn more about advance care planning and for help accessing more resources.

Thinking About Medical Decisions

The goal of advance care planning is to make sure you receive medical care that aligns with your wishes. An important step is to know your values and goals.

You may start by asking yourself:

- What is important to me?
- What does a good quality of life mean to me?
- What are my goals or values and how do they affect my wishes about health care?

Thinking through these questions may help you decide your wishes about:

- Use of life-sustaining treatments such as breathing support, eating and drinking support, dialysis, and cardiopulmonary resuscitation (CPR)
- Where you would like to receive care if you are dying. For example, would you like to be at home or in the hospital?

Advance Directives

Advance directives are documents that record your wishes about future medical treatment.

Advance directives include:
- Medical Power of Attorney
- Medical Living Will (directive to physicians and family or surrogates)
- Out-of-Hospital Do-Not-Resuscitate (DNR) Order

Medical Power of Attorney

This advance directive names someone to make decisions for you if you cannot speak for yourself. In the event that you cannot make decisions for yourself, this person will be able to make decisions for you.

The person you choose is also called your medical power of attorney.

Choosing a medical power of attorney may not be an easy choice, but it is important. It is especially important for individuals who are separated, not legally married, or have more than one adult child.

Choose someone who will honor, respect and follow your wishes. Your medical power of attorney should be someone who:
- You have spoken to about your wishes and is willing to speak on your behalf
- Is willing to act according to your wishes
- Can be there for you when you need them
- Understands what is important to you
- Is willing to ask important questions and understand the possible outcomes of medical decisions
- Is willing to talk with you about sensitive or difficult issues
- Can handle conflicting opinions between family, friends and medical providers

Talk about your goals of care, values and wishes with the person before you complete and sign any forms. Make sure you tell them if you change any of your wishes.

Living Will

This advance directive is an outline of your health care wishes. It gives specific details about what treatment you do and do not want.

A living will takes effect only when you are in the terminal or irreversible phase of illness or injury.

A living will may address topics such as:
- Artificial nutrition and hydration, such as a feeding tube
- Dialysis (a process to clean the blood when the kidneys are not working)
- The use of a ventilator for breathing
- Comfort care

Out-of-Hospital Do-Not-Resuscitate (DNR) Order

This is a medical order that tells the health care team not to perform CPR when the patient is outside the hospital. This is an order signed by a doctor. It is permanent unless the patient cancels the order.

If you do not have an Out-of-Hospital DNR order and your heart or lungs stop working, the health care team may do everything medically possible to restart your heart and help you breathe. Emergency personnel perform CPR unless an Out-of-Hospital DNR order is in effect.

To show you have an Out-of-Hospital DNR order, you must have a copy of the DNR order, DNR bracelet or DNR necklace with you at all times.

Be sure to give a copy of your Out-of-Hospital DNR to your care team.

Each state has different DNR forms and laws. **An Out-of-Hospital DNR will only be honored in the state it was filed in.** Ask your doctor about DNR orders for another state if your home is outside of Texas or you plan on traveling outside of Texas. Your social work counselor can also help you find answers about DNR orders in different states.

Talk with your doctor or social work counselor to obtain an Out-of-Hospital DNR order.

Patients with an Out-of-Hospital DNR order still need an In-Hospital DNR order if they are admitted to the hospital.

Tips to Remember

- Give your medical power of attorney access to your advance directive documents.
- Give copies of your advance directive documents to all medical providers.
- You may update your documents as often as you wish. It can be helpful to review them from time to time. Talk about any changes with your support system and doctor. Be sure to update your advance directive forms to reflect any changes made.

Making plans for future health care decisions can give you peace of mind. It may reduce confusion or disagreement among loved ones. If your loved ones know your wishes, they will be able to honor them.

Additional Resources

Learn more about advance care planning online at www.MDAnderson.org/AdvanceCarePlanning.

Ask your social work counselor for a copy of the Patient Education workbook, **Advance Care Planning**.

If you have questions, talk to your social work counselor or call Social Work at 713-792-6195.

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PATIENT EDUCATION

Advance Care Planning Before Stem Cell Transplant

Advance care planning is an important part of the stem cell transplant process. It involves talking about your health care goals, values and preferences. This helps prepare you, your caregivers and the care team before, during and after your treatment. You care team will talk with you about this at one of your clinic appointments, when you are admitted to the hospital and if there is any change in the course of the disease. This may be difficult and unclear at times, but it is important so the care team can make sure your goals are aligned with the medically appropriate goals.

Advance Directives

An advance directive is one way for you to make your wishes known about serious medical treatment before you need such care. Advance directives include selecting a medical power of attorney, completing a living will and Out-of-Hospital Do Not Resuscitate Order (DNR). It may be difficult and sometimes scary to think about situations or problems that could happen. It is important to think about this before you need care that is not aligned with your preferences or values. If you have questions, talk with your social work counselor, or call Social Work at 713-792-6195.

Stem Cell Transplant

Stem cell transplant is an aggressive treatment that comes with some risk of serious problems. Some can be life-threatening. You may have already read or talked with your doctor about some of these risks. The care team knows that every patient is different. Your care team will discuss your medical condition with you and your family throughout your treatment. This includes plans and options to treat problems as they occur.

All the members of your care team evaluate your health and medical condition and discuss how to safely get you through the treatment. The care team offers this treatment because they feel you can get through it and possibly control or cure the disease. With any type of treatment, problems may occur.

The following are some of the risks or problems that may occur during treatment.

Disease Relapse

There is a risk of relapse after the transplant. If this happens, your care team will discuss other treatment options with specialists who treat your type of cancer. These options may include other types of chemotherapy or new treatments being studied.

If you had a donor transplant, the immune-suppression medicines such as tacrolimus or steroids may be reduced or stopped. This allows the donor stem cell's immune system to fight your disease, also called **graft versus tumor effect**. Your doctor may also ask your donor to donate cells again. This is called a **donor lymphocyte infusion**.

If the medicines are stopped or if you are given a boost of donor cells, you could develop graft versus host disease, also called GVHD for short. If you develop GVHD from your initial transplant, your care team may not be able to stop the medicines or give you more donor cells because it will make the GVHD worse.

Graft Failure

Your blood counts may take 2 or more weeks to recover. This does not happen very often and depends on the type of stem cells you received. Sometimes blood counts do not recover because the new graft or stem cells do not take hold in the bone marrow. This is not common. If the counts do recover, they may stay very low for a long time. If this happens, the care team may retrieve more stem cells from your donor or use the stem cells that were frozen and stored, if available. Blood products (platelets and red blood cells) and antibiotics are also given to help your own cells do their job. With graft failure, there is a high risk for serious or life-threatening infections and bleeding.

Infection

After transplant, your immune system must rebuild itself. This process can take many months. This means that you are at an increased risk of infection for months to several years after the transplant, depending on the type of transplant you received.

Anti-bacterial, anti-viral and anti-fungal medicines are given at the start of the transplant to prevent infections. Patients often still develop a fever and infection and need to go back to the hospital for treatment. IV antibiotics are used to fight the infection. Sometimes, treatment-resistant infections may occur. Patients with an active fungal infection or a recent history of fungal infections are at high risk for having repeat infections. Fungal and viral infections may require long-term treatment, which can take weeks or months to manage. **Certain viral infections can be resistant to treatment or have no available treatment.** Even a simple infection can be life threatening for a stem cell transplant patient. Talk with your care team about vaccines to protect you against common infections during cold and flu season and a plan for re-vaccination of childhood vaccines after transplant.

Graft Versus Host Disease

When stem cells - the graft, are transplanted in the recipient’s body - the host, the stem cells recognize the host as foreign. The cells may attack the cells in the body. This process can cause a reaction in your body called graft versus host disease, GVHD. There are 2 types of GVHD: acute and chronic. Acute GVHD usually occurs in the first 3 to 4 months after transplant. Chronic GVHD usually develops from 3 months to several years after the transplant. The type of GVHD is based on the symptoms and organs affected. GVHD can affect the eyes, throat, esophagus, mouth, lips, skin, hair, nails, gastrointestinal (GI) system, lungs, joints, muscles and vagina.

Treatment depends on how much of the body is involved and how serious it is. Most often, treatment includes giving steroid medicines. If GVHD does not respond to the steroids, this is called **steroid-refractory GVHD**. Other immune-suppression medicines are then used to treat the GVHD. The risk of infection also increases as new medicines are added. If the patient does not respond to any of the standard treatments or new treatments still under study, this could be life-threatening.

Infections and Multiple Organ Failure

- Pneumonia is a common problem that may occur after transplant. Some types of infections, such as fungal and viral, are more serious than others. Sometimes, an infection may not respond to even the best therapy. This can be life-threatening.

- Bleeding into the lungs could happen with an infection. It is very serious because it can make it hard for the lungs to work right. A breathing machine called a ventilator may be used if this occurs.

- Some patients may need small amounts of oxygen while in the hospital as an inpatient. If more oxygen is needed quickly or at higher amounts, the care team will consider placing a tube in the airway – intubation and use of a breathing machine. If this happens, you will receive care in the intensive care unit (ICU).

- You may also need intubation and the use of a breathing machine to help you while you wait for treatment to work. Your care team will explain and discuss this with you. Even if you have a living will, your care team will review your options with you because your condition may improve with aggressive support. Some patients do not respond despite all forms of treatment. Your doctors will discuss these matters and concerns with you or your medical power of attorney if you can no longer talk when this happens.

- Multiple organ failure may occur if a patient has a serious infection or problem. If organs do not work right, this can be a severe, life-threatening condition. This condition can affect the kidneys, lungs, liver, heart, brain and the blood system. Each of these organ systems are vital for the body to work right.

Treatment Goal

The goal with a stem cell transplant is to cure or control your disease. It is a treatment with risks and cure or control of the disease may not always be possible. The approach is to hope for the best, but to also prepare for all possible events. This includes the chance of not getting better.

It is vital that you and your family prepare for the chance of having serious medical problems occur. Discuss your thoughts and values about life support, such as using breathing machines and kidney dialysis. This will help your family and the care team make the best treatment decision based on your personal wishes. This will only be offered if medically appropriate.

The care team strongly encourages you to have a medical power of attorney and a living will that states your wishes before treatment begins. The care team's common approach is to use all available treatments if there is a chance for recovery. This includes life support measures. If a situation occurs and recovery is not possible, a breathing machine, cardiac resuscitation or invasive procedures may not be used.

Treatment Considerations

Communication is important. Your doctors will keep you and your family informed about your condition and recovery. The goal is to provide the best treatment based on your condition and to support your full recovery. Despite best efforts, some patients do not get better, which makes recovery and survival not likely. If this happens, your care team may change your treatment goal and focus treatment on your comfort, quality of life and end-of-life care.

The care team will talk about these matters with you in detail. Your care team will work with your family or the person with medical power of attorney to make decisions that are medically indicated if you are unable to discuss these matters with your care team.

Your care team will not do any new life-sustaining or invasive procedures once the decision has been made to focus on comfort and end-of-life care. The goal will be your comfort, dignity and helping you and your family cope during this difficult time.

Talk with your care team if you have any questions or concerns.

Resources

Resources for Stem Cell Transplant

Below is a list of some of the resources available to stem cell transplant patients and caregivers. If you are an inpatient, you must have your physician's approval before you leave the inpatient unit for any activities. For a complete list of MD Anderson resources, ask for a copy of the **Resources and Services** guide.

MD Anderson Resources

Stem Cell Transplantation and Cellular Therapy Department

For information about the Stem Cell Transplantation and Cellular Therapy Department, visit https://www.MDAnderson.org/Research/Departments-Labs-Institutes/Departments-Divisions/Stem-Cell-Transplantation.html or call 713-792-6100.

MyChart

MyChart is a secure, personalized website and mobile app that helps you take an active role in managing your care at MD Anderson. With MyChart, you can review your schedule and send secure messages to members of your health care team. You also can view your medical record and review patient education materials and videos to help you manage your care at home. Learn more at MyChart.MDAnderson.org. To create an account, call askMDAnderson at 877-632-6789.

Integrative Medicine Center

Consult with physicians to learn about using complementary therapies to support health during and after cancer care. Physician referral is required for additional services, which may include acupuncture, psychology, exercise counseling, mediation guidance, music therapy, nutrition counseling and oncology massage. Patient and caregiver classes are also available. For more information, call 832-750-3685.

Kim's Place

A unique spot for patients and their guests, ages 13-30. Enjoy video games, a pool table, karaoke, computers with internet access and free snacks. Kim's place is located in the Main Building on Floor 2, in The Park, Room B2.4309. Hours vary based on staffing. Call 713-563-3075 to confirm.

Volunteer Services

At MD Anderson, volunteers work to make a difference and to make cancer history. Our volunteers provide service and support in programs throughout the institution to help patients, caregivers and staff in various ways. To learn more, call 713-792-JOIN (5646) or visit our website at www.MDAnderson.org/Departments/Volunteer.

Reviewed 01/2025, Patient Education

myCancerConnection

myCancerConnection is MD Anderson's cancer support community of trained survivor and caregiver volunteers. Get matched with a trained survivor or caregiver volunteer in-person or by phone. You can discuss coping with your diagnosis and navigating life during and after treatment. For more information, call 713-792-2553 or 800-345-6324 or visit the website at www.MDAnderson.org/MyCancerConnection.

The Learning Center

The Learning Center is a patient education library and provides current and reliable information on cancer prevention, treatment, coping and general health.

- Theodore N. Law Learning Center, Main Building, Floor 4, 713-745-8063
- Levit Family Learning Center, Mays Clinic, Floor 2, 713-563-8010
- Holden Foundation Learning Center, Jesse H. Jones Rotary House International, 713-745-0007

Language Access Services

In-house interpreters are available to help non-English speaking patients communicate in their language. Interpretation is provided in Arabic, American Sign Language, French, Mandarin, Spanish and Vietnamese. With notice, interpreters will be provided for other languages. After hours, weekends and holidays, interpretation services are provided via phones or video devices. To ensure patient safety and exact translations, staff **cannot** use family members as translators. Patients may call Language Access Services at 713-792-7930 or after hours at 713-792-7090.

International Center

Multilingual staff help patients from around the world schedule appointments and provide them with lodging and transportation information. They are available to assist international patients and family members throughout their stay. To reach the International Center, call 713-745-0450, Monday through Friday, 8 a.m. to 5 p.m. From Mexico, call 1-800-811-6167. From Venezuela, call 1-800-12338.

Adolescent & Young Adult (AYA) Program

The Adolescent & Young Adult (AYA) Program offers a variety of services for patients, ages 15 to 39 years. The program has two child life specialists that provide supportive conversation, peer interaction and support groups. They also help prepare and explain what to expect when AYA patients are having procedures and tests. Call 713-792-6610 to learn more.

Cancer 180

http://www.Cancer180.org/Page/Home

Cancer180 is an MD Anderson program that provides a social environment where young adult patients, survivors, caregivers, family and friends in their 20's and 30's can find resources and information specific to their needs and to help them connect with other young adults affected by cancer. Email Cancer180@MDAnderson.org to learn more.

Other Community Resources

Be The Match (National Marrow Donor Program)
http://BeTheMatch.org
800-627-7692
This site provides updates and facts about unrelated marrow, cord blood and peripheral blood stem cell transplantation. A Facebook site called “Patient Connect” is also available.

Blood & Marrow Transplant Information Network
http://bmtinfonet.org
847-433-3313 or toll-free 888-597-7674
A non-profit organization dedicated exclusively to serving the needs of persons facing a bone marrow, blood stem cell or umbilical cord blood transplant.

Bone Marrow Foundation
http://www.BoneMarrow.org
212-838-3029 or toll-free 800-365-1336
A nonprofit organization created to provide financial assistance, education and support to bone marrow transplant patients and their families. Two unique parts of this site include a “Support Line” and “Ask the Expert” features.

Bone Marrow Donors Worldwide
https://www.wmda.info/
+31-88-505-7900
This organization collects the HLA phenotypes (tissue types) of volunteer bone marrow donors and cord blood units, and coordinates their worldwide distribution.

CancerCare
http://www.CancerCare.org
800-813-4673
A national nonprofit organization that provides free professional support services to anyone affected by cancer; people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs include counseling and support groups, education and financial assistance.

Dream Foundation
http://www.DreamFoundation.org
888-437-3267
A nonprofit organization that grants final wishes to terminally ill adults.

Hendrick Marrow Program
http://BeTheMatch.org
800-627-7692
A grant program to help patients pay for post-transplant costs that support the success of the transplant and relies on the social workers to screen patient finances and request assistance when needed.

Leukemia and Lymphoma Society
http://www.lls.org
800-955-4572
This organization supports cancer research and provides information and financial help to patients with leukemia. It also offers support groups for patients and their families and provides referrals to other sources of help in the community.

National Bone Marrow Transplant Link
http://www.NBMTLink.org/
800-546-5268
This site provides information on bone marrow transplants and publications designed to help you understand and deal with the logistics of bone marrow transplantation, finances and medical insurance. It includes frequently asked questions, BMT survivor stories and peer support program information.

Fertile Hope
https://www.LiveStrong.org/Tags/Fertile-Hope
Fertile Hope is a national, nonprofit organization dedicated to providing reproductive information, support and hope to cancel patients whose medical treatments present the risk of infertility.

Dan's House of Hope
Info@DansHouseOfHope.org
713-239-3464
Dan's House of Hope offers the warmth and comfort of home in a B and B-style accommodation for young adult cancer patients and caregivers receiving treatment at hospitals in the Texas Medical Center. The main house has 5 guest bedrooms (4 with private baths), a fully furnished shared kitchen, living room, dining room, media room, and library / game room. Guest bedrooms have 2 extra-long twin beds or a queen or king size bed. A separate 1 bedroom apartment is featured in a second smaller house on the property. A caregiver is required for each patient guest. Patient-guests must provide contact information for their doctor and HCF. There is no nightly stay fee charged, but donations are gratefully accepted.

Stupidcancer.org
http://StupidCancer.org
Stupid Caner, a nonprofit organization, is a leader in young adult cancer advocacy, research, and support. We offer a lifeline to the young adult cancer community by helping those in need feel normalized and connected to their peers.

Help Hope Live - National Transplant Assistance Fund
https://HelpHopeLive.org/
800-489-3863
This nonprofit organization's home page provides financial, social and emotional support to transplant candidates.

Stem Cell Transplant
Frequently Asked Questions

Below is a list of common questions. Talk with your care team if you have any other questions or concerns.

About Stem Cells

Are peripheral blood hematopoietic stem cells and bone marrow hematopoietic stem cells (HSC) the same?

Yes, hematopoietic stem cells from peripheral stem cells and bone marrow stem cells all form blood cells in the body. The transplant results may vary based on which HSC are used. Your transplant doctor will review this information with you.

What are the concerns about using stem cells?

There is debate about **embryonic** stem cells, which come from an early embryo. MD Anderson Cancer Center does not use or do research with embryonic stem cells. All of the stem cells used for transplant come from volunteer donors and from donated umbilical cord blood after a mother has given birth to a child.

How are hematopoietic stem cells infused into the body?

Stem cells are usually infused into a large vein under the collarbone using a central venous catheter, called a CVC, or a peripherally inserted CVC catheter called a PICC. The stem cells find their way to the bone marrow and begin to make red blood cells, white blood cells and platelets. Over time, the bone marrow releases the new blood cells into the bloodstream.

How long can hematopoietic stem cells be stored after collection?

Stem cells are frozen and stored in a refrigerated unit at MD Anderson until needed.

What happens to the hematopoietic stem cells that are not used?

Depending on the type of transplant, the care team often collects cells that may not be used. After 5 years, or if there is no need for the cells, then the cells may be used for research or destroyed. Your care team will review this practice with you during the consent process.

About Transplants

Is there an age limit for a transplant?

The age limit for a transplant depends on the diagnosis, type of transplant and treatment plan.

Does the transplant hurt?

The actual infusion of hematopoietic stem cells - the transplant, does not hurt. It is similar to receiving a blood transfusion. The transplant is not painful, but you may have some discomfort from certain tests or treatments used during the transplant process.

What are the chances of the transplant working?

Each patient has a unique medical history, disease and health concerns. Only the doctor can talk with you about your possible outcomes. Your doctor will talk with you about long-term disease-free survival and the chances for a complete remission 5 years after the transplant.

What will happen if I decide not to have the transplant?

It is important that you understand the possible risks and benefits of each treatment option. Like any medical treatment, you may choose not to have a transplant. It is not required. For example, your doctor may advise a watchful waiting approach to your treatment.

If you decide not to have a transplant, tell your doctor right away so they can plan a treatment that best fits your wishes.

Will everything go back to normal after the transplant?

Your doctor will talk with you about what to expect after the transplant. You may hear the phrase **new normal** when talking about what to expect. This is because some lasting effects could become a part of your daily life. The type of transplant you have, and any side effects, such as graft versus host disease, will affect your new normal. Also, you will need to be re-immunized. Your doctor will talk with you about which vaccines you will need and when you can get them.

Why do I have to live close to MD Anderson after the transplant?

The care team ask that patients stay within a 30-minute drive of the hospital during the post-transplant recovery phase, for at least 100 days for allogeneic and 30 days for autologous. This is needed for the following reasons:

- If there are problems, you need to come directly to the MD Anderson Acute Cancer Care Center.
- You will have appointments every day during the recovery phase and may need to come to the hospital on short notice.

Tell your doctor if you live near MD Anderson, but not within 30 minutes of the hospital.

About Donation

Are there risks to the stem cell donor?

The risks for the donor are small and depend on if the stem cells are collected from the blood or from the bone marrow. The doctor will review and discuss all possible risks related to each type of collection. The procedure will not be done if the donor's doctor decides they are not healthy enough to donate.

Is it painful to donate stem cells?

There is some discomfort if the stem cells are collected directly from the donor's bone marrow. The procedure is done while the donor is asleep under general anesthesia. They may have some soreness for a few days and possibly up to a week.

When stem cells are collected using apheresis, there is often some discomfort caused by the

G-CSF injections. This medicine helps move the stem cells from the bone marrow into the blood. Most donors do not have serious side effects from taking G-CSF, but some may have aches and pains in the bones and joints. The symptoms usually go away after the medicine is stopped. The doctor will suggest an over-the-counter medicine to ease these side effects.

How long does HLA typing take?

HLA typing takes about 2 weeks to complete.

About the Hospital Stay

Why do I have a different doctor when I am in the hospital?

A team of doctors, pharmacists and nurses provide care for patients in the hospital on a rotating schedule. Other teams care for patients in the outpatient clinic.

Why do I have a different social worker when I am in the hospital?

There is one social worker who works in the inpatient hospital and one that works in the outpatient clinic.

About Caregivers

Why do I need a caregiver 24 hours a day, 7 days a week?

The immune system is weak during the initial recovery phase, which is a 100 days for allogeneic and 30 days for autologous, after the transplant. Your condition could change quickly. This is why you must have a responsible caregiver with you at all times. This person will help watch for any changes and must bring you to the hospital right away if needed. A caregiver helps with daily needs, such as cooking, cleaning and giving your medicine. Your caregiver also serves as your advocate to help you make treatment decisions.

Does MD Anderson provide caregivers?

MD Anderson does not provide you with a caregiver when you leave the hospital. Most patients ask family and friends to be their caregivers. If your family and friends cannot provide around-the-clock care, tell your care team or social worker. The care team can talk with your family and friends about rotating caregiver duties. The care team can also contact your health insurance company to see if they cover home health or caregiver services.

The care team encourages you to also have a caregiver while you are in the hospital for support and to help you with daily activities.

About Finances and Health Insurance

Who do I speak with if I have questions about my health insurance, costs or medicine co-pays?

Ask to speak to a patient access specialist in the Patient Access Center. The patient access specialist is a financial counselor. This person works closely with your insurance company to confirm that they will pay for tests, procedures, medicines and the transplant. They are also available to meet with you to answer your finance questions about the transplant process.

About Appointments and Tests

Who do I speak with about my schedule for tests and procedures?

A patient service coordinator will help you with your appointment schedule. Be sure to refer to your patient appointment schedule.

How do I get a copy of my appointment schedule?

Log on to MyChart for a copy of your schedule. You may also call askMDAnderson at 877-MDA-6789 for your schedule.

About Other Resources and Services

Where can I find more information about MD Anderson resources and services?

For the most current information on MD Anderson resources and services, ask your care team for a copy of the **Resources and Services** guide or visit the MD Anderson website at www.MDAnderson.org

Stem Cell Transplant Glossary

Absolute neutrophil count: The actual number of neutrophils, a type of white blood cell, in the blood.

Advance directive: A legal document outlining your wishes should you be unable to communicate. Examples of documents that make up an advance directive include:
- Directive to physicians or Living Will
- Power of Attorney for Healthcare
- Out-of-Hospital Do Not Resuscitate or DNR

Allogeneic (A-loh-jeh-NAY-ik)**:** A graft or tissue from someone other than the patient, usually a matched sibling (a brother or sister), but may be a matched unrelated volunteer donor.

Allogeneic bone marrow transplant: Transplants of bone marrow from one person to another person who is of the same tissue type.

Allogeneic stem cell transplant: A procedure in which a person receives blood-forming stem cells, which are cells from which all blood cells develop, from a donor who has similar, but not identical, genes. It is often a sister or brother, but could be an unrelated donor. Stem cells can be harvested from a newborn's umbilical cord.

Antibody: A protein produced by the white blood cells, called leukocytes, to battle foreign substances, such as bacteria, that enter the body.

Antigen: A foreign substance that causes the production of antibodies.

Apheresis (af-uh-REE-sis)**:** A procedure in which peripheral blood stem cells (PBSC) are collected from the circulating blood. Blood is drawn from a donor or patient and then circulated through a machine that separates stem cells. The remaining blood is given back to the donor or patient. This procedure is done prior to treatment.

Autologous (aw-TAH-luh-gus)**:** A graft or tissue that is taken from the patient and then returned to the patient.

Autologous bone marrow transplant: A patient's own bone marrow is used for transplant after treatment.

B cells: Another term for B lymphocytes. These cells develop from stem cells and are involved in immunity and the secretion of anti-bodies.

Biotherapy: A type of treatment that uses biological agents that are natural or man-made substances that help your normal defenses fight cancer or cause the cancer cells to become normal cells.

Blood cell separator: An apheresis machine that spins blood and separates out the stem cells from the blood.

Bone marrow: A spongy tissue found in large bones of the body, such as the hip bones and breastbone that produces blood cells.

Bone marrow collection or harvest: A procedure that is performed while the donor is under general anesthesia. Multiple punctures are made into the posterior hip bone, and marrow is aspirated into a syringe and placed in the collection bag.

Clinical trials: Medical research studies conducted with volunteers. Each study is designed to answer scientific questions and to find better ways to prevent, detect or treat cancer.

Conditioning: A phase in the transplant process that involves combining high doses of chemotherapy and or radiation to destroy cancer cells more effectively than standard doses of chemotherapy.

Cord blood: Stem cells that are removed from the umbilical cord of a newborn baby.

Cryopreserve: A process that involves freezing items such as cells, sperm or embryos and preserving them for later use.

Cytokine (SY-toh-kine): A substance that is produced by cells of the immune system and can affect the immune response. Cytokines can also be produced in the laboratory using DNA technology and is given to people to affect immune responses.

Day 0: The day the patient receives a transplant.

Day - 1, 2, 3, etc.: The number of days prior to the day of transplant.

Day + 1, 2, 3, etc.: The number of days after the day of transplant.

DNR: Do not resuscitate. Used as a directive to the health care team not to perform CPR, known as cardiopulmonary resuscitation.

Engraftment: When the transplanted stem cells start to grow and make healthy levels of new blood cells.

Engraftment syndrome: Symptoms associated with engraftment, such as fever or red rash.

Erythrocytes (eh-RITH-roh-site)**:** A cell that carries oxygen to all parts of the body. Also referred to as a red blood cell or RBC.

Graft failure: A complication of stem cell transplant. The transplanted stem cells do not grow in the recipient's bone marrow and do not produce enough new white blood cells, red blood cells and platelets.

Graft-versus-host disease or GVHD: A reaction of donated bone marrow or peripheral stem cells against the recipient's tissue. A common occurrence with allogeneic transplant. Signs and symptoms include skin rash, redness, yellowing of the skin, cramps, diarrhea and fever.

Granulocytopenia (GRAN-yoo-loh-SY-toh-PEE-nee-uh)**:** A decrease in white blood cells**.**

Growth factor: Substances given to transplant patients to stimulate the production of blood cells. It is also given to stem cell donors to mobilize stem cells into the bloodstream for collection.

Haplo-identical: When a donor is the parent or child of the patient, and therefore only half of the human leukocyte antigens match.

Hematopoiesis (hee-MA-toh-poy-EE-sus)**:** The forming of new blood cells.

Hematopoietic growth factors (hee-MA-toh-poy-EH-tik)**:** A group of proteins that causes blood cells to grow and mature.

Hematopoietic progenitor cell: Stem cells obtained from marrow or blood, not embryo tissue.

Hemoglobin (HEE-moh-GLOH-bin)**:** A protein inside the red blood cells that carries oxygen from the lungs to the rest of the cells in the body.

Histocompatibility (his-toh-kum-pat-uh-bil-i-tee)**:** Similarity between the donor tissue and the patient or recipient tissue.

Human leukocyte antigen or HLA typing: A special blood test that is done to identify a person's key antigens and then compared with a donor's results to determine compatibility.

Hospice care: A program that provides special care that is focused on physical, emotional and spiritual comfort for people who are near the end of life and for their families. Care can be at home, in a hospice facility, or within a hospital.

Human leukocyte antigens or HLA: Proteins that are found in white blood cells that make each person's tissue typing unique. HLA plays an important role in activating the body's immune system to respond to foreign organisms.

Immunocompromised: An immune system that has been weakened or impaired by disease or treatment.

Immune system: Special cells, proteins, tissues and organs make up the immune system. It is the body's defense against disease and infections.

Immunosuppression (IH-myoo-noh-suh-PREH-shun)**:** Suppression of the immune system by using drugs or radiation to prevent the rejection of grafts or transplants, or to control autoimmune diseases.

Immunotherapy (IH-myoo-noh-THAYR-uh-pee)**:** Treatment of disease by stimulating, enhancing or suppressing an immune response to fight infections and other diseases. It is also used to lessen side effects that may be caused by some cancer treatments. Also referred to as biological therapy, biotherapy or biological response modifier or BRM.

Informed consent: A process in which a person learns about a specific clinical trial or medical procedure, including information about its design and potential risks and benefits, before deciding to participate or have the procedure. Patients are asked to sign a consent form documenting their understanding of the medical procedures or clinical trial.

Leukocytes (LOO-koh-site)**:** Cells that help the body fight infections and other diseases. Also referred to as white blood cells or WBCs.

Leukapheresis (LOO-kuh-feh-REE-sis)**:** Removal of the blood to collect specific blood cells. The remaining blood is returned to the body. Usually used in leukemic patients when the white cell count gets too high. This process is performed by using continuous flow cell separators or filtration techniques.

Living will: A directive that instructs the doctor not to use life support to extend the natural process of dying. This directive will take effect when a patient is in the terminal phase of an illness. Parents may complete a living will for a child under the age of 18.

Lymphocyte (LIM-foh-site)**:** A type of white blood cell. Lymphocytes have a number of roles in the immune system, including the production of antibodies and other substances that fight infection and diseases. B Lymphocytes directly attack virus infected cells.

Matched related or sibling donor (MRD or MSD) transplant: A stem cell or bone marrow transplant from a fully matched relative, usually a sibling.

Matched unrelated donor (MUD) transplant: A stem cell or bone marrow transplant from a matched unrelated donor.

Mobilization: Stimulating the bone marrow to increase the number of stem cells that circulate in the blood through chemotherapy and/or injecting a growth hormone.

Monoclonal antibodies (MAH-noh-KLOH-nul AN-tih-BAH-dee)**:** Antibodies that are made in the lab rather than by a person's own immune system. This type of treatment is considered a form of passive immunotherapy. These treatments do not require the person's immune system to start the fight against the cancer. Once the antibodies are given, they can then recruit other parts of the immune system to destroy the cancer cells. Monoclonal antibodies can be used alone, or they can be used to deliver drugs, toxins or radioactive material directly to a tumor.

Mucositis: A complication of some cancer therapies in which the lining of the digestive system becomes inflamed. Often seen as sores in the mouth.

Myelosuppression (MY-eh-loh-suh-PREH-shun)**:** A condition in which bone marrow activity is decreased, resulting in fewer red blood cells, white blood cells and platelets. Myelosuppression is a side effect of some cancer treatments.

Nadir (NEY-deer): The period of time when an antineoplastic drug has its greatest effects on the bone marrow.

Natural killer cells or NK cells: A type of white blood cell that contains granules with enzymes that can kill tumor cells or microbial cells. Also referred to as a large granular lymphocyte.

Neutropenia (noo-troh-PEE-nee-uh)**:** Neutropenia is when the number of neutrophils in the bloodstream is below normal. If this happens, you may be at high risk for getting an infection.

Neutrophil (NOO-tro-fil)**:** The most common type of white blood cell in the bloodstream, which helps defend against bacterial infections.

Peripheral blood stem cells (PBSCs) (peh-RIH-feh-rul)**:** Stem cells that circulate in the blood.

Peripheral blood stem cell transplant: Stem cells are removed from the blood and returned after high-dose chemotherapy. This can be done for both autologous and allogeneic transplant.

Plasma cells: A type of white blood cell that produces antibodies.

Platelet: A type of blood cell that helps prevent bleeding by causing blood clots to form. Also referred to as a thrombocyte.

Protective isolation: All persons entering the patient’s room must put on a mask and gloves to protect the patient from potential germs.

Protocol: A detailed plan that explains what will be done in a clinical trial and why. It outlines how many patients will take part in the clinical trial, what medical tests they will receive and how often, and the treatment and monitoring plan. Researchers must follow the protocol approved by the Institutional Review Board or IRB.

Purging: The process by which certain types of cells are removed from bone marrow prior to infusion into the patient. In an allogeneic transplant, the donor stem cells may be purged to remove the cells that cause graft-versus-host disease. In autologous transplants, marrow may be purged of lingering cancer cells.

Red blood cells (RBCs): Red blood cells carry oxygen to all parts of the body. Also see “erythrocytes.”

Reinfusion: The return of healthy stem cells into the body of the transplant recipient.

Stem cell: The “parent cell.” Every type of blood cell in the body begins its life as a stem cell. Stem cells then divide and form the different cells that make up the blood and immune system. Stem cells are found in both the bone marrow and the circulating blood. Also referred to as a hematopoietic progenitor cell.

Stem cell rescue process: Another term for stem cell transplant. Healthy stem cells are reinfused to “rescue” the marrow after high doses of chemotherapy or radiation.

Stem cell retrieval or stem cell harvest: The process of collecting stem cells from the circulating bloodstream after growth factors are given to increase their numbers.

Stem cell transplant: A method of replacing immature blood-forming cells that were destroyed by cancer treatment. The stem cells are given to the person after treatment to help the bone marrow recover and continue producing healthy blood cells. Also see “peripheral blood stem cell transplant.”

Syngeneic (SIN-juh-NAY-ik)**:** The graft of tissue that is genetically identical to the patient, such as an identical twin.

Syngeneic bone marrow transplant: A procedure in which a person receives bone marrow donated by his or her healthy identical twin.

Tacrolimus (ta-kruh-lee-muhs): A medicine used to help reduce the risk of organ or bone marrow rejection, referred to as graft-versus-host disease, by the body.

T cell: One type of white blood cell that attacks virus-infected cells, foreign cells and cancer cells. T-cells also produce a number of substances that regulate the immune response.

T-cell depletion: Treatment to destroy T-cells, which play an important role in the immune response. Removing T-cells from a donated stem cell graft may reduce the chance of an immune reaction against the recipient's tissues.

T lymphocytes: Cells within the bone marrow responsible for remembering and fighting bacteria and other substances foreign to the body.

Telemetry (tuh-LEM-i-tree)**:** Monitoring the heart using wires that are attached to the chest to transmit the rhythm of the heart using radio waves.

Thrombocytopenia (THROM-boh-sy-toh-PEE-nee-uh)**:** A decrease in the number of platelets in the blood. This condition can cause a person to bruise easily and bleed excessively from wounds, mucous membranes and other tissues.

Total body irradiation or TBI: Radiation therapy to the entire body. It is usually followed by bone marrow or peripheral stem cell transplantation.

White blood cells or WBCs: Refers to a blood cell that does not contain hemoglobin. White blood cells include lymphocytes, neutrophils, eosinophils, macrophages and mast cells. These cells are made by bone marrow and help the body fight infection and other diseases.

*Word pronunciations – https://www.Cancer.Gov/Publications/Dictionaries/Cancer-Terms

Notes and Questions

Questions to Ask My Doctor or Care Team

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