

Pediatric Stem Cell Transplant and Cellular Therapy Guide



Pediatric Stem Cell Transplant and Cellular Therapy Guide

Table of Contents

Welcome	1
<ul style="list-style-type: none">• New Patient Letter• Care Team Overview• Care Team Contacts• Stem Cell Transplant Overview	
Autologous Stem Cell Transplant	2
<ul style="list-style-type: none">• Autologous Bone Marrow or Stem Cell Transplant• Autologous Stem Cell Transplant Pathway• Autologous Transplant Possible Side Effects/Complications	
Allogeneic Stem Cell Transplant	3
<ul style="list-style-type: none">• Human Leukocyte Antigen (HLA) Typing• Allogeneic Stem Cell Transplant• Allogeneic Pathway• Allogeneic Transplant Possible Side Effects/Complications• Graft Versus Host Disease• Chronic Graft Versus Host Disease• Graft Versus Host Disease Diet• Graft Versus Host Disease Prevention Using Tacrolimus and Methotrexate	
Cell Therapy	4
<ul style="list-style-type: none">• CAR-T Cell Therapy• CAR-T Cell Therapy: Frequently Asked Questions• Immune Effector Cell Therapy: Discharge Information	
Caregivers	5
<ul style="list-style-type: none">• Caregiver's Role in Stem Cell Transplant	
Pre-Stem Cell Transplant Testing	6
<ul style="list-style-type: none">• Pre-Transplant Work-Up• Pre-Transplant Evaluations	
Hospital Stay	7
<ul style="list-style-type: none">• Cheerful Hints for a Long Hospital Stay• Daily Care• Lung Exercises	

- Skin Care
- Infection Prevention
- Hand Washing
- Mouth Care
- Nutrition
- Food Restrictions and Safety Tips
- Pediatric Intensive Care Unit (PICU)
- Infection After Stem Cell Transplant

Discharge **8**

- Discharge Information
- Discharge Checklist
- Daily Monitoring Record
- When to Call Your Doctor
- Outpatient Prescription Service

Resources **9**

- Stem Cell Transplant Glossary
- Resources for Stem Cell Transplant
- Whole Blood Donation

New Patient Letter

Pediatric Stem Cell Transplant and Cellular Therapy

Dear Patient and Family,

Welcome to the University of Texas MD Anderson Cancer Center Children's Cancer Hospital. MD Anderson has served as a center of excellence in cancer patient care, research, education and prevention for more than 75 years.

This guide contains information about your child's stem cell transplant. It gives information about what you and your child can expect as we work together to treat your child's disease.

You may feel overwhelmed about your child having a stem cell transplant. Remember, your health care team can answer any questions or concerns you may have throughout the transplant process. You may contact us at any of the numbers below.

Outpatient Clinic

Robin Bush Child and Adolescent Center
Main Building, Floor 7, near Elevator C
713-792-6610

Inpatient Units

Ocean
Main Building, Floor 9, near Elevator F
713-792-5173

Mountains
Main Building, Floor 9, near Elevator F
713-792-5149

PICS Rainforest
Main Building, Floor 9, near Elevator F
713-745-0570

Care Team Overview

Pediatric Stem Cell Transplant and Cellular Therapy

MD Anderson Cancer Center uses a team approach to treat patients. Many experts from different clinical areas will work together to care for your child. This is called a multidisciplinary care team.

Please read this information to learn more about your Pediatric Stem Cell Transplant and Cellular Therapy (SCTCT) care team.

Physicians

A pediatric stem cell transplant doctor will assess your child at their initial consult and their treatment will be followed by our team of pediatric transplant providers. A member of the medical team will meet with you and your child in the Child and Adolescent Center during outpatient appointments. This is also where your child will receive follow-up care after the stem cell transplant.

Fellows are physicians who are receiving special training. They work with the Pediatric SCTCT physicians. You may meet a fellow during your appointments.

Inpatient Care

Any member of the pediatric SCTCT physician team may care for your child while he or she is in the hospital. The physicians work in the hospital on a rotating schedule and will update each other about how your child is doing.

Advanced Practice Practitioners

Advanced Practice Nurses and Physician Assistants

An advanced practice nurse (APN) will see your child during their hospital stay and post-transplant. An APN is a nurse who has an advanced nursing degree and special training.

Advanced practice practitioners will:

- Ask you about your child's medical history
- Do physical exams
- Teach you about transplant-related health issues
- Write and update prescriptions
- Help manage your child's care
- Work closely with the pediatric SCTCT physicians and multidisciplinary team

Nurses

Clinic Nurses

Our team of physicians will work with a clinic nurse in the Child and Adolescent Center to manage your child's outpatient care. The clinic nurse will see him or her during their pre-transplant work-up and follow-up visits.

At each visit, your clinic nurse will:

- Ask you and your child how they are feeling
- Ask if they are having pain
- Review the medicines your child is taking
- Assess their fall risk

Please tell 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 child's inpatient nurse will ask you about their health history and any special needs they may have. During the hospital stay, this information will help the nursing team plan your child's care. Your inpatient nurse will:

- Do physical exams
- Give required treatments
- Teach you and your child about their care
- Monitor their condition closely
- Give medications
- Contact your child's physician when needed

Please tell your inpatient nurse if you have any problems while you are in the hospital.

Research Nurses/Study Coordinators

A research nurse/study coordinator will determine if your child is able to join a clinical trial, based on the study criteria. The principle investigator is the person in charge of the clinical trial.

If you choose to join a clinical trial, the research nurse/study coordinator will report your child's progress to the principle investigator and their SCTCT physician. The research nurse will also report any side effects and will make sure that we perform the study correctly and safely.

SCTCT Coordinators

Pediatrics has 1 coordinator for Autologous and Allogeneic related and unrelated (MUD/Cord) transplants.

In some cases, patients may be their own stem cell donors. This is called an autologous transplant. Or, patients may receive stem cells from another person either related or unrelated to them. This is called an allogeneic transplant.

Pedi SCTCT Coordinators

An SCTCT coordinator is a registered nurse. You will work with a coordinator if your child is having an autologous or allogeneic transplant.

Before your child's transplant, the related coordinator will:

- Be your contact person for the pre-transplant evaluations
- Work with your child's physician to plan tests and procedures before they are admitted to the hospital
- Schedule the work-up appointments for your child's donor if they are receiving a transplant from a relative
- Work closely with the care team

Your pediatric coordinator works with an adult unrelated coordinator to help set up their donor if your child is having an allogeneic transplant from a donor who is not a relative or from a cord blood donor.

Before your child's transplant, the unrelated coordinator will:

- Search for unrelated donors through the National Marrow Donor Program and international registries
- Coordinate selection of the appropriate donor
- Work closely with the care team

Receptionists and Patient Service Coordinators

Receptionists

When you arrive to Child and Adolescent Center, the receptionist will greet you.

The receptionist:

- Answers your phone calls
- Confirms your arrival
- Collects co-payments, if needed
- Confirms your local contact information

Patient Service Coordinators/Schedulers

The SCTCT patient service coordinator (PSC) schedules your child's tests and appointments. The PSC also helps answer phones and performs general clerical duties. At each clinic visit, please ask for your child's updated appointment schedule. This is called a patient appointment letter. Contact the PSC to confirm, reschedule or cancel 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 that they will pay for all tests, procedures, medications and the actual transplant. They will also be available to meet with you to answer any financial questions you may 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, medications and the actual transplant.

Other Team Members

Pharmacists

Most pharmacists working in SCTCT have their Doctor of Pharmacy degree, or Pharm.D. Your pharmacist will:

- Work with the medical team to monitor your child's drug therapy
- Be involved with your child's care when they are in the hospital and when they are in any of the outpatient areas, such as the Pediatric Ambulatory Treatment Center and the Child and Adolescent Center
- Help write chemotherapy orders and review all of your child's prescribed medicines for possible allergies and drug interactions
- Work with you to find the most effective medicines to reduce treatment side effects, such as upset stomach, vomiting, diarrhea, pain and infections
- Speak with you about your child's medicines and answer your questions



Please tell your pharmacist about all of the medicines your child is taking. Include any over-the-counter medicines, herbal or natural supplements, teas and vitamin supplements. Many of these could have serious side effects when taken with your child's transplant medicines. There are 2 outpatient pharmacy Main Building locations: Floor 2, near Elevator C and Floor 10, near Elevator B.

Dietitians

A clinical dietitian evaluates your child's nutrition needs. This person

- Creates a nutrition care plan for your child during their treatment and recovery
- Meets with you during the hospital stay to find out if they are having problems eating. will
- Suggests other options when needed

You may also speak with a dietitian while your child is outpatient. Ask your clinic nurse to schedule an appointment for you.

Child Life Specialists

Child life specialists are part of our Child, Adolescent and Young Adult Life Program. They help young people and their families cope with and lessen the impact of cancer, procedures and hospital stays. They also help improve coping skills, provide education and support, and build relationships with patients and families throughout treatment and give families opportunities to express themselves. They also host regular events and activities.

Pediatric Education and Creative Arts Program

Certified, master-level teachers are part of our Pediatric Education and Creative Arts program. They work with young people from pre-k to 12th grade to meet the educational needs of our patients. We have an accredited on-site private school, tutoring for students enrolled in regular school, and support for students who are ready to return to school. Tutoring for AP classes, the

PSAT and English as a Second Language (ESL) for both patients and families are also available. Other programs include painting, pottery, yoga, and music therapy. Vocational counseling and help with college applications and scholarships are available for our young adult patients.

Social Workers

Social workers are licensed professional counselors. Your social worker is available to help you and your child cope with the stress and challenges of their care and issues such as housing and transportation. A social worker is assigned to you at your first visit to the Child and Adolescent Center. The Department of Social Work can also help you with advance directives, like medical power of attorney.

Case Managers

Case managers are licensed professionals. Your case manager is the contact for your health insurance company while your child is an inpatient. This person will also coordinate services for your child after you leave 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. If you would like to speak with a chaplain, please ask your nurse to contact the Spiritual Care and Education Department, or you may call them directly at 713-792-7184.

Psychiatric Services

Pediatric psychologists support patients while they are in the hospital for a transplant. A psychologist may meet with you and your child to do a pre-transplant evaluation before you are admitted. A psychiatrist also can help you and your family cope with special problems. Therapy is available. Ask your physician or psychologist for a referral.

Physical and Occupational Therapists

Some patients may have less strength and endurance during their treatment. Rehabilitation Services offers physical and occupational therapy to inpatients and outpatients. Your physician may refer your child for therapy or you can ask for a referral.

Patient Advocates

Patient Advocates help patients and family members who are having problems or concerns with MD Anderson. A patient advocate is assigned to you and available to help. Patient Advocacy is located in the Main Building, Floor 3, near Elevator D, Room B3.4324. Office hours are Monday-Friday, 8 a.m. to 5 p.m. Call 713-792-7776 for more information. Call the page operator at 713-792-7090 after hours and on weekends.

SCTCT Management/Leadership Team

The Pediatric Management/Leadership team is available to assist you with any questions, suggestions or concerns that you may have during your child's transplant journey. Contact the receptionist if you need to speak with a member of the leadership team.

Care Team Contacts

Pediatric Stem Cell Transplant and Cellular Therapy

It can be hard to keep track of who your team members are or who to contact for questions you may have. Use this sheet to help. We want to make sure you get the care you need and answer your questions. Talk with your team and always ask for help if needed.

Your Care Team

Transplant Physicians: _____

Nurse Practitioner: _____

Clinic Nurse: _____

Pediatric Transplant Coordinator: _____

Unrelated Transplant Coordinator: _____

Patient Access Specialist (Insurance/Financial): _____

Social Worker: _____

Patient Advocate: _____

See the handout “Care Team Overview: Pediatric Stem Cell Transplant and Cellular Therapy” for a description of each team member’s responsibilities. Your transplant coordinator will also provide you with business cards and phone numbers for each team member. If you have any questions, you may also contact:

Child and Adolescent Center

Monday through Friday, 8 a.m. to 5 p.m.
713-792-6610

Stem Cell Transplant Overview

Pediatric Stem Cell Transplant and Cellular Therapy

This handout gives basic information about the different types of stem cell transplants that we do at MD Anderson Cancer Center.

About Bone Marrow

In order to understand stem cell transplants, it is helpful to know about blood cells and bone marrow. Bone marrow is the blood cell “manufacturing plant” of the body. 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 constantly produces stem cells, which 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.)

- 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.

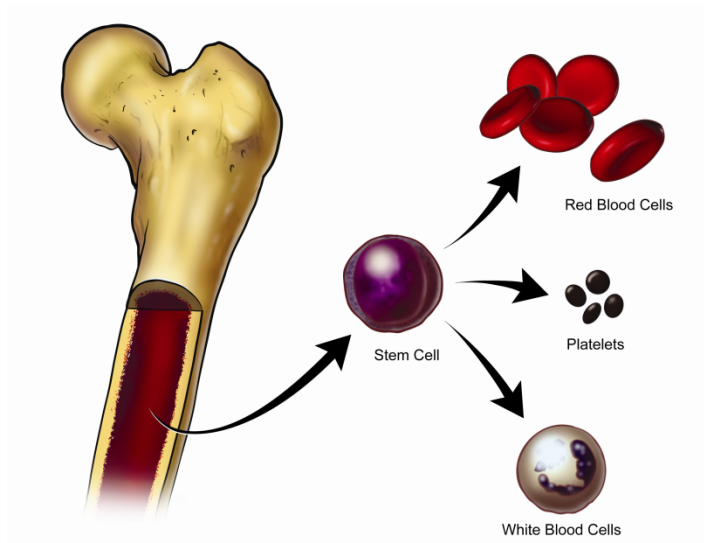


Figure
 Stem Cell Differentiation
 ©MD Anderson

Each different 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. In addition to the bone marrow, they are also found in the blood and in a newborn baby’s umbilical cord blood.

What can damage or destroy bone marrow?

Chemotherapy, other drug treatments, radiation and bone marrow diseases may damage and destroy 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 situations can be life threatening. Examples include:

- Anemia (not enough red cells to carry oxygen)

- Neutropenia (not enough white cells to fight infection)
- Thrombocytopenia (not enough platelet cells to help with normal blood clotting)
- Leukemia (too many immature white 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 variety of different cancers, including:

- Leukemia
- Lymphoma
- Multiple myeloma
- Solid tumors, such as:
 - Kidney cancer
 - Brain Cancer
 - Ovarian cancer
- Other blood diseases such as aplastic anemia and Sickle Cell Anemia

How do people donate stem cells?

Stem cells are collected from three sources:

- Blood by a procedure called apheresis
- Bone marrow
- Newborn baby's umbilical cord

Your stem cell transplant doctor will decide which source of stem cells is the best for you.

Apheresis Collection

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

During apheresis, one 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.

An apheresis procedure takes about four hours. More than one procedure may be needed to collect the correct number of cells for the transplant. The patient/donor will be told if additional collection dates are needed.

Bone Marrow Collection (Harvest)

Physicians collect bone marrow while the donor is asleep under general anesthesia. Using a needle, punctures are made into the back (posterior) of the hip bone and marrow is removed. The marrow is then placed in the collection bag and processed before infusion. The procedure generally takes about an hour.

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. These cells are stored frozen in a cord blood bank facility until needed by a patient.

Are stem cells controversial?

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 we use come from volunteer donors and from umbilical cords that women have donated after giving birth.

What are the steps of a stem cell transplant?

Having a stem cell transplant enables doctors to treat diseases with high doses of chemotherapy and radiation. The stem cell transplant process generally follows these steps:

1. A healthy person donates stem cells.
2. The patient has chemotherapy and/or radiation to destroy 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 lasts from 30 minutes to several hours.
4. In a successful transplant, 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

With this type of transplant, the patient is his or her own donor. The stem cells are collected, frozen and stored in the lab.

Then the patient 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, potentially more effective dose of chemotherapy than he or she could otherwise tolerate.

Allogeneic

With this type of transplant, the patient receives a transplant from a donor. A special test called human leukocyte antigen (HLA) typing is done to determine if a patient and donor match.

There are four types of allogeneic transplants:

- **Syngeneic** – 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 (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.

- **Matched Unrelated Donor (MUD)** – The patient receives a transplant using stem cells from an unrelated donor. This involves searching for a donor using donor registries.
- **Umbilical Cord Blood** – The patient receives a transplant using stem cells from a newborn's umbilical cord. This may be an option for patients who do not have a donor.
- **Non-myeloablative** – This is also called a “mini” transplant. This type of transplant uses lower doses of chemotherapy and radiation. Cells collected from the donor and the patient coexist, working together to fight cancer cells. Side effects might be less severe, and patients may have a shorter hospital stay. Non-myeloablative transplants also require a matched donor (related or unrelated) or umbilical cord blood.

Autologous Bone Marrow or Stem Cell Transplant

Pediatric Stem Cell Transplant and Cellular Therapy

Bone marrow or stem cell transplant is being used more and more as a treatment option for certain cancers. Having a transplant is a big decision and we want you to carefully consider all the risks and benefits.

General Information

Stem cells are found in bone marrow, peripheral blood or umbilical cord blood. Some patients whose disease does not involve their bone marrow directly (breast cancer, ovarian cancer or some lymphomas), may be able to use their own stem cells for transplant. This is called an “**autologous**” transplant. The cells are collected during a time of complete or near complete remission, and then given back (infused) after high-dose conditioning chemotherapy.

This information will explain the pre-transplant phase, the stem cell collection process, the hospital inpatient phase and the outpatient recovery phase.

Pre-transplant Phase

The pre-transplant phase involves a few needed steps before a transplant can be offered. We need to confirm financial approval and make sure the disease stage will respond to treatment.

The pre-transplant phase can be very short for some patients, or the process can take months for others. This depends on problems or delays with financial clearance or disease control. Your child’s stem cell transplant coordinator will guide you through this process.

Peripheral Blood Stem Cells or Bone Marrow Collection

Stem cell collection involves separating and collecting stem cells from the blood, and then storing them for transplant.

There are two main ways to collect stem cells:

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

1. Mobilization Phase

During the mobilization process, stem cells are made available for collection. The donor receives growth hormone injections, such as G-CSF (Neupogen®) or G-CSF with Mozobil™, under the skin. This medicine triggers the body to make stem cells and increases the numbers of stem cells in the blood. A stem cell transplant clinic nurse will teach you or a family member about how to give the medicine.

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 OK.

Some patients who donate stem cells for themselves may receive chemotherapy before mobilization. This is normally done in the hospital. Your child's doctor will explain why chemotherapy is needed and if they will need to be in the hospital.

2. Monitoring Phase

When your child receives the growth factor prescription, they will also get an appointment for an upcoming lab visit, usually a couple days after starting the shots. At 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 your child is ready to start the collection. If there are not enough stem cells, you will come to the lab daily 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 cells.

3. Collection Phase

Your child will have a central venous catheter (CVC) inserted for the procedure. Donors will have two peripheral IV catheters placed for the collection procedure. This procedure takes about 4 hours, but may take longer. After the procedure, the apheresis nurse will give you an instruction sheet about self-care.

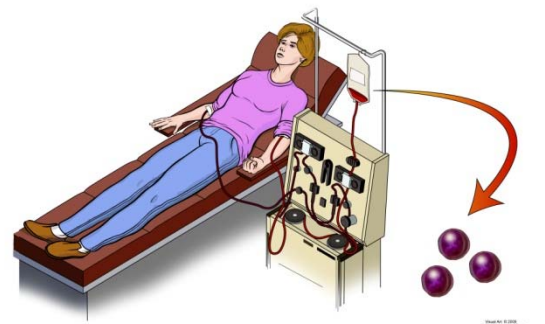


Figure. Apheresis
©MD Anderson Cancer Center

Bone Marrow Collection (Harvest)

Bone marrow collection is usually done by the physician in an operating room while your child is asleep under anesthesia sedation. The physician uses a special needle to remove marrow from the back of the hip. The process takes about 2 hours to collect all the bone marrow needed for the transplant. Your child's stem cell transplant coordinator and clinic nurse will help prepare you and answer any questions about the procedure.

Admission for Stem Cell Transplant

Pre-admission Testing

Your child will need a series of tests before they are admitted for stem cell transplant. All of the tests evaluate their disease status or personal health. Some of the tests may be repeats of tests they have already had, but may need to be done within 30 to 45 days of your child's transplant.

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

Some common tests are:

- Echocardiogram: looks at blood flow through the heart
- Pulmonary function test: checks the health and strength of the lungs
- CAT/PET scan: checks location and activity of some diseases
- Bone marrow aspiration: checks for disease in the bone marrow
- Blood and urine tests: check blood counts
- Dental exam: checks for dental concerns or problems, like gum or tooth infection. The dental exam can be done with your child's dentist before the work-up appointment.

Your child's stem cell transplant coordinator and treatment team will tell you about what test results are needed and will help coordinate tests before the transplant. The inpatient hospital stay is usually 3 to 4 weeks once admitted.

Hospital Admission and Stay

Your child will stay in a private room on the George E. Foreman Pediatric and Adolescent Inpatient Unit (G9), in the Main Building. There is a TV, PlayStation®, Wii®, small closet and private bathroom. The Unit has a kitchen, laundry, family room, child life activity room, school and a large play and activity area called the Pedi-dome.

Your child's hospital admission will take place about 7 to 10 days before their transplant. During that time, chemotherapy with or without radiation, is given to help destroy current bone marrow cells to make room for new, healthy cells and any present tumor cells if there is cancer or a tumor.

Once your child completes chemotherapy and possibly radiation, they will be ready to receive the transplant. A transplant uses a central venous catheter (tube) to deliver the stem cells into the blood. The stem cells go into the blood and travel to the bone marrow where they produce new blood cells in the bone marrow. The day of the transplant or IV infusion is called "Day 0." The infusion can last from 30 minutes to several hours.

Protective Isolation

On the day of admission for transplant, your child will be placed in protective isolation. The door to their hospital room will remain closed and your child cannot leave the room except for x-rays or procedures. Anyone entering the room must wear a mask and gloves. Isolation is stopped

when your child's blood counts reach a high enough level. Your child must wear a mask and gloves when leaving the room even after the isolation phase is done.

Side Effects

Your child may stay in the hospital another 3 to 6 weeks after the transplant. During this time, he or she may have treatment side effects. This may include:

- Mouth and throat sores
- Nausea, vomiting, and diarrhea
- Skin color changes, and
- Weak, brittle fingernails.
- Liver, kidney, heart and lung problems

A decrease in appetite, changes in taste and not eating at all may also occur. A dietitian will evaluate your child's nutritional needs and may recommend options to make sure your child gets enough calories. This may include tube feeding, oral supplements and TPN (nutrition through the vein).

Veno-occlusive disease (VOD) is a liver condition that develops when clots form in the small blood vessels of the liver. It can be a serious problem. VOD treatment helps to prevent further liver function problems.

Pain is another possible side effect. Pain medicine and other techniques can help treat pain. Tell your child's doctor or nurse about any pain your child is having and whether or not the treatments help to reduce it.

Blood Counts

Your child's blood counts will drop very low and will stay low until the new bone marrow or stem cells start to grow and produce new cells.

Your child will also be on a medicine called G-CSF (Neupogen[®]). It helps the white blood cells grow faster. G-CSF is given as an injection under the skin 1 or two times daily.

One or more blood transfusions, mainly platelet, may be needed during this time because your child's red blood cell count may decrease as a result of the transplant. It helps to prepare ahead of time and find family members, friends or others that can donate blood and platelets for your child.

Family and friends may donate blood in honor of their loved one. Patients receive a monetary credit issued to their MD Anderson billing account for every successful donation. MD Anderson does not provide direct blood donations. This means we do not reserve blood donations by family members or friends to give to a specific patient. Each patient is transfused with the best matched blood product for his or her needs from our supply of volunteer blood donors. All blood donations help to ensure an adequate blood supply for all our patients.

A low white blood cell count can lead to many infections that sometimes could become life-threatening. Your child's ability to fight infection will remain low (immunosuppressed) for up to 1 year, even after their white blood cell count comes up. This means he or she will be more prone to viral and fungal infections and will need to be watched closely. For example:

- Low hemoglobin can lead to fatigue, high heart rate, and sometimes heart failure.
- Low platelet count can lead to easy bruising and bleeding. We will give your child platelet transfusions to try and prevent serious bleeding into vital organs, such as the lungs or brain.

The time it takes for new white blood cells to grow depends on the type of stem cell transplant. On average, it takes 10 to 21 days for the blood count to rise after a peripheral blood stem cell transplant. White blood cell counts come back the fastest after a peripheral blood stem cell transplant (10 to 21 days), followed by bone marrow stem cells (14 to 28 days), and then umbilical cord blood stem cells (19 to 42 days).

Discharge

The length of hospital stay varies for each patient and depends on the type of stem cells, side effects and problems that occur. Your child will be discharged when he or she can take medicines and food by mouth, is fever free, and has a good white blood cell count. After discharge, your child will return to the clinic often. At these visits, blood counts will be checked, and the care team will look for signs of infection, and assess the need for IV infusions and transfusions.

Hospital Visitation Policy

Transplant patients can get life-threatening infections very easily and are placed in strict protective isolation when they receive their transplant. All staff and visitors must wash their hands, and wear a mask and gloves before entering the hospital room. Also, no visitors under 12 years of age are allowed. We ask that you also follow these guidelines:

- Limit the total number of visitors - only 2 at a time.
- 1 parent, guardian, or adult family member must stay overnight if the patient is a minor. 2 parents may choose to stay overnight if the room size permits.
- Parents should not sleep in the same bed as their child.
- Persons under 18 years of age (minor) are not allowed to stay overnight at any time.
- **Live plants and fresh flowers are not allowed in the hospital room or on the inpatient unit.**



Child Care for Siblings

It is important to make childcare arrangements for sibling(s) (brother or sister) as soon as possible; well before your child's hospital admission. It is best for siblings to stay at home or with a relative or friend. If this is not possible, a responsible adult over 18 years of age must stay with them at all times.

Local Housing

There are many nearby hotels and apartments that offer shuttle service to MD Anderson. Plan to stay in the Houston area for at least 60 days after an autologous transplant.

The Rotary House is the hotel connected to MD Anderson. The Ronald McDonald House is located down the street within walking distance of the hospital. Contact your social worker for help with housing needs and for placement at Ronald McDonald House, if needed.

Texas Medicaid and some other insurance providers can suggest certain places and help with housing costs.

After Transplant

There are certain precautions and instructions your child will need to follow after transplant to help prevent and reduce their chance of infection.

Diet and Activities

- No eating raw fruits and vegetables that cannot be washed and peeled easily, such as berries or lettuce.
- No drinking tap water for at least 60 days after the transplant.
- No attending community school for 3 to 6 months after transplant. Speak with the school coordinator to arrange home or hospital schooling during this time.
- **Always check with our child's doctor first before you allow your child to swim.** No swimming for at least 100 days after transplant. Six months after transplant, he or she may swim in a well-maintained private pool. Avoid swimming in the ocean or lakes for at least 1 year after transplant.
- Avoid pets and animals for at least 100 days after transplant.
- Avoid direct sun exposure. Use sunscreen and wear protective clothing and sunglasses.

Immunizations

- Your child will need to be immunized again about 6 months after the transplant.
 - The transplant doctor will discuss the timing and schedule of immunizations with you.
 - Immunizations can be given by your child's primary care physician, or at your local public health clinic.
- **Siblings and household members:**
 - Are encouraged to get yearly flu shots.
 - May get the MMR vaccine. They do not have to be isolated from the patient.
 - May get the varicella vaccine. If a rash develops after the vaccine, the sibling or household member must be separated from the patient for at least 3 weeks or until all lesions scab over and disappear.
 - **Should not** receive the live, oral polio vaccine. Make sure the inactivated polio vaccine injection is used.

Relapse

Some transplant patients will have a relapse, which means their disease has come back, despite our best efforts. The care team may recommend certain treatment options, such as more chemotherapy and radiation therapy or a second transplant. This usually depends on how soon after the transplant this occurs and the overall condition of your child.

Long-term Effects

Stem cell and bone marrow transplant patients may have long-term side effects. Side effects may include:

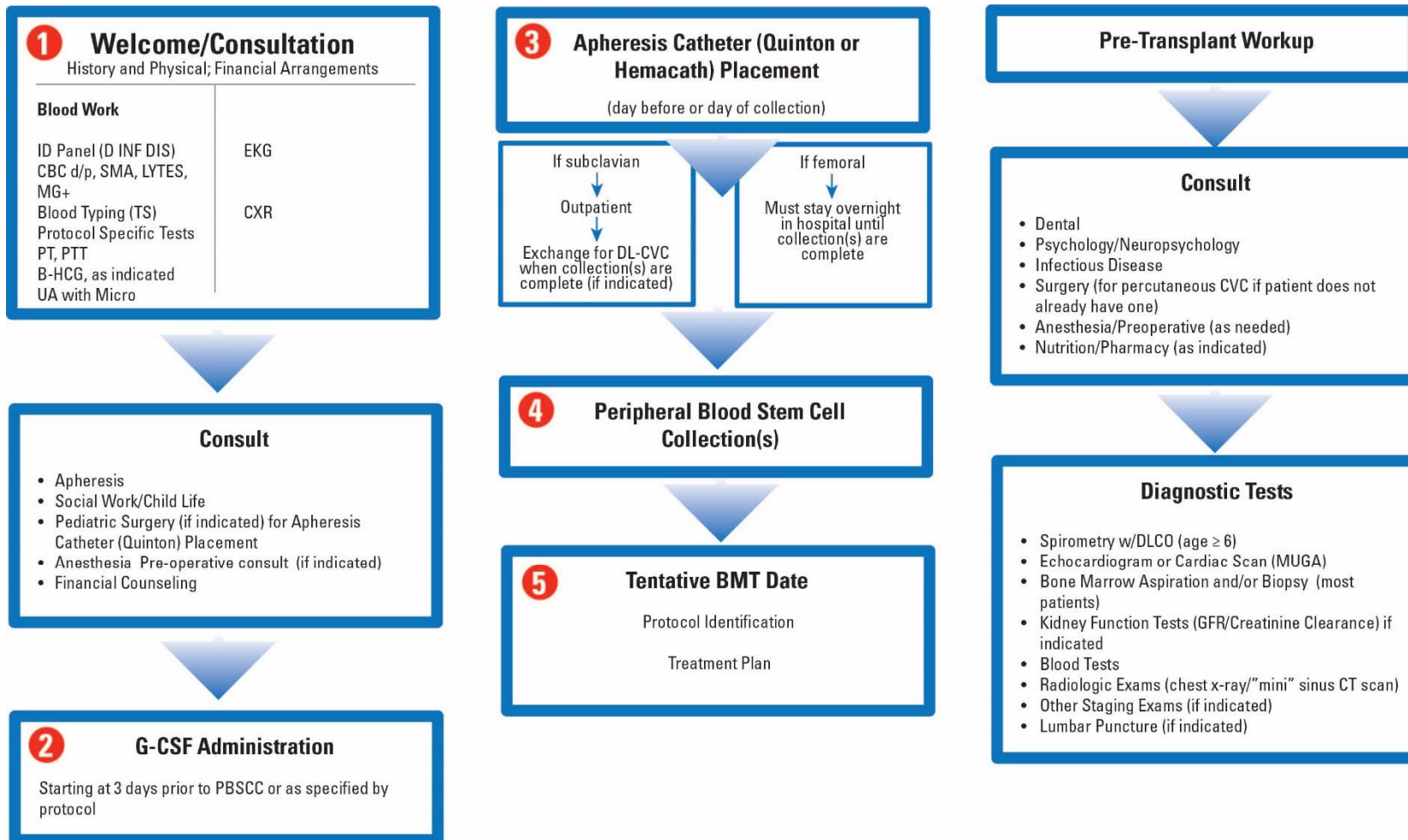
- Abnormal or low hormone levels that can lead to problems with growth, and thyroid and adrenal function
- Damage to the kidney or lungs that can lead to abnormal kidney function, fibrosis (stiffening) of the lungs, or less air exchange in the lungs because of inflammation.
- Cataracts
- A second cancer
- Less blood supply to the joints from prolonged steroid therapy
- Trouble with school work or thinking and memory

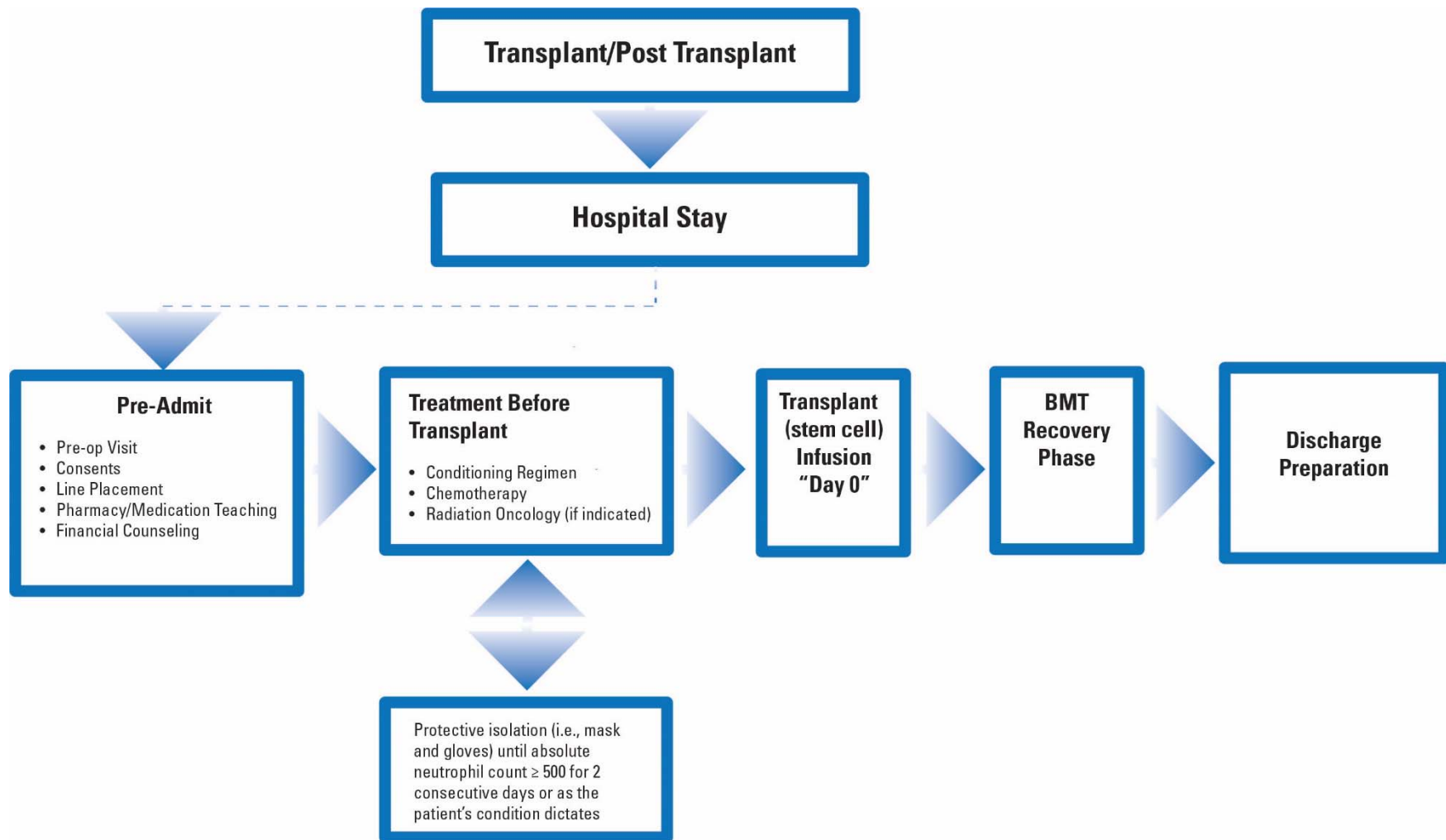
Fertility

Fertility is the ability to have children. Transplant patients often have issues with fertility because cancer treatments can damage the reproductive system. But, there are options to help preserve fertility that may make childbearing possible in the future. Talk with your care team to learn more about ways to preserve your child's fertility.

Autologous Stem Cell Transplant Pathway

Pediatric Stem Cell Transplant and Cellular Therapy





Post BMT Phase

Lab Work

Day 30-60

- Restage Disease
- Radiographic tests as indicated
- Bone Marrow Aspiration and/or Biopsy (BMA/Bx) if indicated

Day 60-365

Periodic restaging as needed or required by protocol.

Lab Work

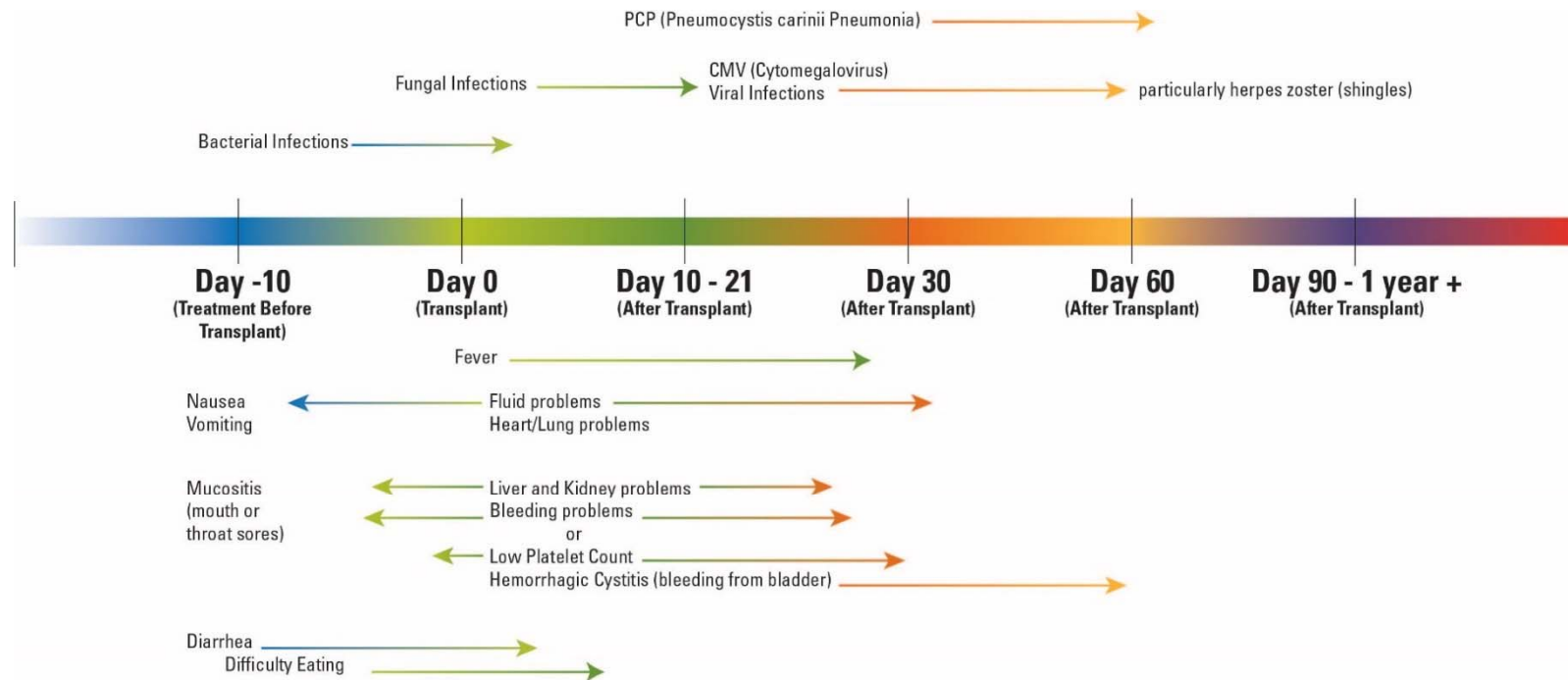
Day 365 and annually thereafter

- Neuropsychological Testing (as indicated)
- Restage Disease
- Radiographic Tests (if indicated)

- Bone Marrow Aspiration and/or Biopsy (BMA/Bx) (if indicated)

- Dental
- Endocrine (if indicated)

Autologous Transplant Possible Side Effects/Complications Pediatric Stem Cell Transplant and Cellular Therapy



Intensive Care

If your child's condition becomes unstable or critical, he or she will be transferred to the pediatric intensive care unit. (G9 Rainforest Pod)
 Some patients must be transferred to the Pediatric Intensive Care Unit at Hermann Hospital.

Human Leukocyte Antigen (HLA) Typing

Pediatric Stem Cell Transplant and Cellular Therapy

What is HLA?

HLA stands for Human Leukocyte Antigens. These are markers on the surface of white blood cells that are part of the body's immune system. White blood cells help to identify invading organisms and other foreign matter. They protect the body by starting an immune response to fight off the organisms or destroy the foreign matter. HLA antigens play an important role in how well the patient's body accepts the donated bone marrow/stem cells and how well the donated bone marrow/stem cells accept or react against being in the patient's body.

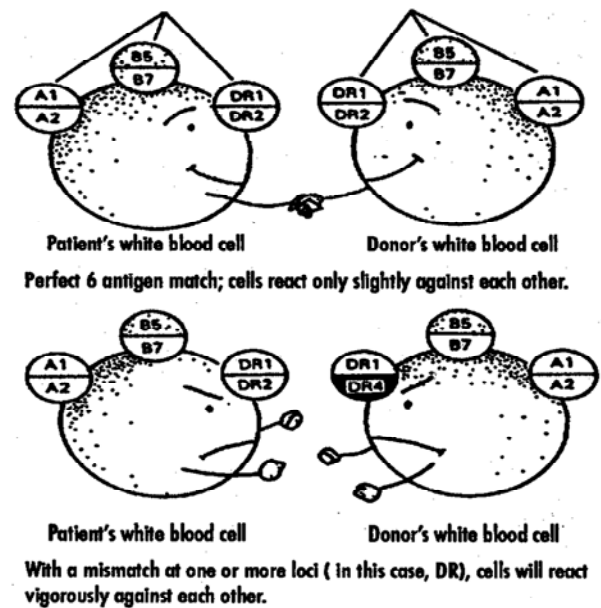
What is HLA Typing?

HLA typing is done through blood collection. The patient's results are compared to every potential bone marrow donor (family or unrelated donor registries). This determines if there is a "perfect match." There are 10 antigens we compare. If the patient and the donor share the same antigens we call them a **10/10 match**. If one of the numbers is different, we call them a 9/10 match because 9 of the 10 numbers match, or a 1 antigen mismatch because 1 of the 10 numbers is different. If 2 numbers are different, it is an 8/10 match or a 2-antigen mismatch, and so forth.

Even if a patient and donor are a 10/10 match, there is still a chance that the donated cells (graft) may recognize the patient's body (host) as foreign and attack it. This condition is called graft versus host disease or GVHD.

When the patient and donor are less than a 10/10 match, the chances increase for a more severe GVHD reaction and graft rejection.

Each person inherits one set of HLA antigens from each parent. There is a 25% chance that a sibling (brother or sister) will have the same HLA type as the patient. A sibling match is preferred. However, if there is no sibling match, an unrelated donor registered in the NMDP (National Marrow Donor Program) or an umbilical cord blood bank may match.



Reprinted with permission from BMT Infonet

Should everyone in the family be typed?

The patient, full siblings and the parents should be typed. We do not type cousins, aunts, uncles or grandparents because the chance of them being a match is very low.

How long does it take to get the results back?

It normally takes 2 to 4 weeks to complete HLA typing.

What if HLA typing has been done elsewhere?

Please bring the results with you. The patient and all possible donors will be retyped here. This confirms the typing results. It is required by the National Marrow Donor Program (NMDP).

Having the outside HLA results can help speed up donor searches. It also give us a better idea of who the donor will be.

For more information about GVHD, refer to the education sheet “Graft Versus Host Disease: Pediatric Stem Cell Transplant and Cellular Therapy.”

Allogeneic Stem Cell Transplant

Pediatric Stem Cell Transplant and Cellular Therapy

This section is for patients who may be receiving stem cells from a donor's peripheral blood or bone marrow.

General Information

Stem cells are collected from 3 sources:

- Blood
- Bone marrow (spongy tissue found inside the large bones of the body)
- Newborn baby's umbilical cord

With an allogeneic transplant, physicians collect stem cells from a donor and infuse them into a patient. A special blood test called HLA (human leukocyte antigen) typing checks if a patient and a donor are a match. The donor may be one of the following:

- An identical twin (a syngeneic transplant)
- A relative
- Someone who is not a relative. This is called a matched unrelated donor or MUD transplant
- A newborn baby (umbilical cord blood transplant)

Before the transplant, the patient receives high doses of chemotherapy and/or radiation to destroy the disease. However, it also damages other parts of the body, including the bone marrow and immune system. The immune system is the body's defense against disease and infection. Also, the body is not able to make healthy blood cells.

The transplant repairs these effects and creates an environment to accept the donor's stem cells.

Graft-Versus-Leukemia Effect

Graft-versus-leukemia or graft-versus-disease effect (GVL/GVD) occurs when the donor's cells destroy the patient's cancer cells because it "sees" them as foreign and different. This is a major benefit of an allogeneic transplant.

Types of Allogeneic Transplants

Your child's doctor will talk with you about the type of transplant that is best for them.

1. Related Donor

This type of transplant is done if a family member, usually a brother or sister, is a HLA match.

2. Syngeneic Transplant

A syngeneic transplant is done when a patient has an identical twin. Since the patient and the donor's genes are the same, there is much less risk of problems. Patients usually tolerate this type of transplant well.

3. Matched Unrelated Donor (MUD) Transplant

If a family member is not a match, the patient's doctor might recommend doing a search for a matched unrelated donor (MUD). The search looks at donor HLA typing from registries in the United States and around the world to find a possible donor. The registries keep lists of volunteer donors and are updated often.

Finding an identical HLA-matched donor is a challenge, but the odds are better than ever. Worldwide donor registries, advances in tissue typing and enhanced computer data collection has grown and improved the chances of finding a possible donor.

New volunteer donors register each month with the National Marrow Donor Program. Patients with minority ethnic backgrounds, such as African Americans, Hispanics and Asians, often have a greater challenge of finding a MUD. This gap has prompted a worldwide awareness and recruitment campaign aimed at minority donors.

4. Umbilical Cord Blood Transplant

Use of stem cells for transplant from umbilical cord blood has increased, mainly because of public cord blood banks.

A cord blood transplant may be an option for patients who do not have a donor. One of the benefits of using cord blood for transplant is it is likely to be available right away. One drawback though is that the number of available stem cells in one umbilical cord is low, and there may not be enough to do a transplant.

5. Non-myeloablative Transplant

A non-myeloablative transplant, or a "mini" transplant, is a type of an allogeneic transplant. It uses lower doses of chemotherapy and radiation. Cells from the donor and the patient "co-exist" for a time and work together to fight cancer cells. Side effects are usually less severe, and patients may have a shorter hospital stay. This type of transplant also requires a donor or umbilical cord blood.

Pre-transplant Phase

The pre-transplant phase involves these steps:

- Confirm financial approval
- Make sure the stage of the disease will respond to treatment
- Find a suitable donor, which can be a lengthy process

For some patients, the pre-transplant phase is quite short. But, the process for others may take months, depending on if there are problems or delays. For example, there may be problems with

disease control, finding a donor match or with finances. Your transplant coordinator will guide you through this process.

HLA Typing

Your child will need HLA typing if he or she is being considered for an allogeneic transplant. HLA typing is a special blood test that finds antigens and then compares them to the donor's. Antigens are proteins found in white blood cells that make each person's tissue type unique. Both the patient and all eligible family members should be HLA typed to find a suitable donor. Also, financial approval for HLA typing is needed before the test is done.

Finding an HLA-Matched Donor

It is important to find the best matched donor available. There is less risk of problems if the donor and patient are HLA-matched.

An HLA-matched sibling (brother or sister) is the best donor for an allogeneic transplant because parents pass on one-half of their HLA typing to their children. This means that each brother or sister has a 25 percent chance of being a match with the patient. (See Figure 1.)

HLA Inheritance	Mother-Haplo 1	Mother-Haplo 2
Father-Haplo 1	Mother Haplo 1 Father Haplo 1	Mother Haplo 2 Father Haplo 1
Father-Haplo 2	Mother Haplo 1 Father Haplo 2	Mother Haplo 2 Father Haplo 2

Figure 1. HLA Matching

A parent, child or distant relative has about a 1 percent chance of being matched with the patient.

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

If a Family Member Is a Match

If a family member is a match, the pediatric stem cell transplant coordinator will be the main contact. The stem cell transplant coordinator reviews the family member's health history to see if he or she is healthy enough to be your child's donor. Common concerns, such as high blood

pressure, diabetes or cholesterol, will often need assessment, but these rarely keep someone from being able to donate.

The pediatric stem cell transplant coordinator will coordinate the transplant process and the collection of the donor's stem cells. Donors come to MD Anderson for the stem cell collection procedure. It can take up to 2 weeks to complete the collection process.

A recent cancer history or an autoimmune disease, such as rheumatoid arthritis or multiple sclerosis, will need further assessment by the treatment team. This may prevent the family member from being a donor.

If your child has more than one sibling that is a match, their treatment team will decide the best donor based on age, gender, health and social limitations, as needed.

If You Do Not Have a Family Member Match

If your child does not have a family member who is a match, the “unrelated” stem cell transplant coordinator will assist the pediatric coordinator and begin the process of finding an unrelated donor.

Searching for an Unrelated Donor

Preliminary Search for an Unrelated Donor

We can find potential donor matches quickly using a worldwide donor database. However, this only gives us a snapshot of information. Further HLA testing is required to find a donor.

Formal Search for an Unrelated Donor

The unrelated stem cell transplant coordinator and your child's transplant doctor will work to find the best donor for them. They start the search after you have given permission and after financial clearance is complete.

The cost for a donor search can be costly, and your insurance company will review your claim. If a donor search is not a covered benefit, the unrelated stem cell transplant coordinator will estimate the cost for the search and a financial counselor will review it with you.

Once a search begins, the unrelated stem cell transplant coordinator will help with the following:

1. Look at the potential donor list and choose the most suitable donors for further testing. The donor registries provide results from the HLA typing as early as 2 weeks, or it could take longer.
2. Ask selected donors to send a blood sample to MD Anderson for HLA typing. Once the blood arrives at MD Anderson, it can take 7 to 10 business days to confirm the donor's HLA typing. The timeframe also depends on when the donor gives a blood sample.
3. Review the test results and support the health care team in making a decision on whether the donor is a good match.

When a Donor Is Found

Once we find a donor, you and your health care team will decide the best time for the transplant. This depends on many factors, such as:

- Your child's disease status
- The date of their last course of chemotherapy
- Whether they have an infection
- Availability of the donor

If you are having a special event in your life, such as a wedding, birth of a child or holiday, we will try to plan your child's transplant around it. Please talk with your child's doctor about this.

Collecting Stem Cells

Related Patient and Donor Transplant

For donors who are relatives, the pediatric stem cell coordinator will schedule the stem cell collection as close to the transplant date as possible. The team may allow the collection to happen weeks to months before the transplant for special circumstances.

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. In the meantime, your child will begin testing and chemotherapy. Your child's stem cell transplant coordinator will discuss all of the details with you so you can prepare for your stay in Houston. See the table below for more details about the process:

	Steps for Working with an Unrelated Donor
1. Contacting the Donor	<ul style="list-style-type: none">• The donor is contacted because he or she is a match. If the donor is interested in donating, he or she attends an information session about the donation process.
2. After Donor Consent	<ul style="list-style-type: none">• If the donor agrees to donate, he or she receives a complete physical exam by a doctor from the donor center.• Once donation dates are set, your child's care team will contact you and begin planning for transplant admission.
3. If the Donor Cannot Donate	<ul style="list-style-type: none">• If the donor decides not to donate or is unable to donate, then your child's doctor and stem cell transplant coordinator will discuss other options, such as looking for another donor.
4. After Transplant Approval	<ul style="list-style-type: none">• Once all testing for donor and patient have been approved by the care team, your child will begin the admission process.
5. Transplant Day	<ul style="list-style-type: none">• On the transplant day, a certified collection center will collect the stem cells and send them to MD Anderson for the lab to process.• On the transplant day, your child will receive the donor's stem cells.

Some patients may have an interest in contacting their donor. However, guidelines vary from donor center to donor center. Talk with your unrelated stem cell 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 then storing them for transplant.

There are 2 main ways to collect stem cells:

- **Apheresis** – a process that collects peripheral blood stem cells (PBSC) from the bloodstream.
- **Bone marrow collection (harvest)** - process that collects the 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 made available for collection. The donor receives growth factor injections, such as G-CSF (Zarxio®) or G-CSF with Mozobil™, under the skin. This medicine triggers the body to make stem cells and increases the number of stem cells in the blood. A stem cell transplant clinic nurse will teach the donor or a member of his or her family about how to give the medicine.

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 an upcoming lab visit, usually a couple of days after starting the shots. At 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 daily 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 cells.

Collection Phase

Related donors usually donate cells through an intravenous catheter (IV) in each arm. One arm is used to draw the blood out of the body and into the apheresis machine. The machine filters out the stem cells, and then the other arm is used to return the blood to the body. (See Figure 2.)

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

This procedure normally takes about 4 hours, but 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.

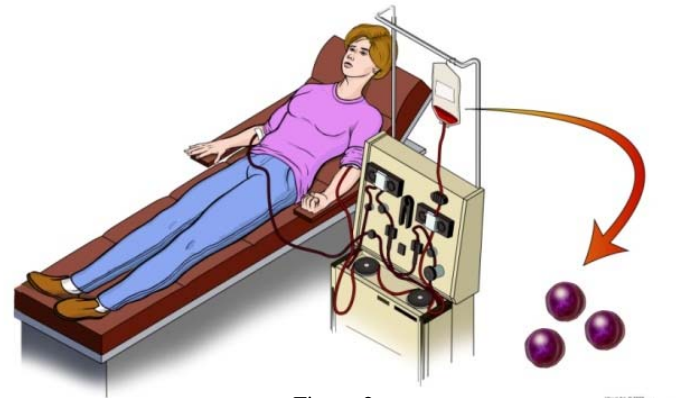


Figure 2
Stem Cell Collection
©MD Anderson Cancer Center

Bone Marrow Collection (Harvest)

Doctors generally 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. 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

Your child will need a series of tests before being admitted for the stem cell transplant. All of the tests evaluate their disease or personal health. Some of the tests are repeats of tests your child has already had, but they need to be done within 30 to 45 days of the transplant.

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

Common tests include:

- Echocardiogram: looks at blood flow through the heart
- Pulmonary function test: checks the health and strength of the lungs
- CAT/PET scan: checks location and activity of some diseases
- Bone marrow aspiration: checks for disease in the bone marrow
- Blood and urine tests: check blood counts
- Dental exam: checks for dental concerns or problems, like gum or tooth infection. The dental exam can be done with your child's dentist before the work-up appointment.

Your child's stem cell transplant coordinator and treatment team will tell you about what test results are needed and will help coordinate tests before the transplant. The inpatient hospital stay is usually at least 4 to 6 weeks once admitted.

Hospital Admission and Stay

Your child will stay in a private room on the George E. Foreman Pediatric and Adolescent Inpatient Unit (G9), located in the Main Building. There is a TV, PlayStation, Wii, small closet and private bathroom. The unit has a kitchen, laundry, family room, child life activity room, school and a large play and activity area called the Pedi-dome.

Protective Isolation

On the day of admission, your child will be placed in protective isolation. The door to their room will be closed and your child cannot leave the room except for x-rays or procedures. Anyone entering the room must wear a mask and gloves. Isolation is stopped when your child's blood counts reach a high enough level. Your child must wear a mask and gloves when leaving the room even after the isolation phase is done.

Conditioning Phase

Your child will be admitted about 7 to 10 days before his or her transplant. Chemotherapy, with or without radiation, will be given at that time. This helps to:

- Eliminate the existing bone marrow cells to make room for the donor's new, healthy cells
- Destroy any existing tumor cells if there is cancer or a tumor

Stem Cell Infusion

Your child will be ready to receive the transplant once the chemotherapy and radiation is done. A transplant involves the delivery of stem cells through a tube called a central venous catheter (CVC). The stem cells go into the blood and travel to the bone marrow. These stem cells produce new blood cells in the bone marrow. The day of the transplant or IV infusion is called "Day 0." The infusion lasts from 30 minutes to several hours.

Initial Recovery Period

After the stem cells are infused:

- Your child will stay in the hospital for about 3 to 4 weeks while their counts recover.
- The treatment team will monitor your child's blood counts daily and help manage any side effects.
- Several IV medicines and fluids may be given.
- Your child will be discharged from the hospital once he or she has "engrafted," meaning that their white blood cells have recovered, and they are eating and drinking well.
- Each patient is evaluated on an individual basis and circumstances vary. For example, your child may need to stay in the hospital if they have a fever or other condition that requires care.

Potential Complications of an Allogeneic Transplant

Side Effects

Your child may stay in the hospital another 3 to 6 weeks after the transplant. During this time, he or she may have treatment side effects. This may include:

- Mouth and throat sores
- Nausea, vomiting, and diarrhea

- Skin color changes
- Weak, brittle fingernails
- Liver, kidneys, heart and lung problems

A decrease in appetite, changes in taste, and not eating at all may also occur. A dietitian will evaluate your child's nutritional needs and may recommend options to make sure your child gets enough calories. This may include tube feeding, oral supplements and TPN (nutrition through the vein).

Veno-occlusive disease (VOD) is a liver condition that develops when clots form in the small blood vessels of the liver. This can be a serious problem. VOD treatment helps to prevent further liver function problems.

Pain is another possible side effect. Pain medicine and other techniques can help treat pain. Tell your child's doctor or nurse about any pain your child is having and whether or not the treatments help to reduce it.

Blood Counts

Your child's blood counts will drop very low and will stay low until the new bone marrow or stem cells start to grow and produce new cells.

Your child will also be a medicine called G-CSF (Zarxio®). It helps the white blood cells grow faster. G-CSF is given as an injection under the skin 1 or 2 times daily.

One or more blood transfusions, mainly platelet, may be needed during this time because your child's red blood cell count may decrease as a result of the transplant. It helps to prepare ahead of time and find family members, friends or others that can donate blood and platelets.

Family and friends may donate blood in honor of their loved one. Patients receive a monetary credit issued to their MD Anderson billing account for every successful donation. MD Anderson does not provide direct blood donations. This means we do not reserve blood donations by family members or friends to give to a specific patient. Each patient is transfused with the best matched blood product for his or her needs from our supply of volunteer blood donors. All blood donations help to ensure an adequate blood supply for all our patients.

A low white blood count can lead to many infections and sometimes could become life-threatening. Your child's ability to fight infection will remain low (immunosuppressed) for up to 1 year, even after their white blood cell count comes up. This means he or she will be more prone to viral and fungal infections and will need to be watched closely. For example:

- Low hemoglobin can lead to fatigue, high heart rate, and sometimes even heart failure.
- Low platelet count can lead to easy bruising and bleeding. We will give your child platelet transfusions to try and prevent serious bleeding into vital organs, such as the lungs or brain.

The time it takes for new white blood cells to grow depends on the type of stem cell transplant. On average, it takes 10 to 21 days for the blood count to rise after a peripheral blood stem cell transplant. White blood cell counts come back the fastest after a peripheral blood stem cell

transplant (10 to 21 days), followed by bone marrow stem cells (14 to 28 days), and then umbilical cord blood stem cells (19 to 42 days).

Weakened Immune System

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

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 suppresses (damages) the patient's immune system.

Graft-Versus-Host Disease

Bone marrow cells are unique to each person. When bone marrow (the graft) is transplanted into the recipient's body (the host), the cells recognize the host as a foreign. The cells attack the new body. This process can cause a reaction in your child's body called Graft Versus Host Disease (GVHD).

GVHD ranges from mild to severe and can be life-threatening. GVHD risk increases with unrelated donor transplants and with non-HLA identical related donor transplants. The higher the degree of HLA "mismatch", the higher the chance of developing severe GVHD. Medicines will be given to your child before, during, and after the transplant to help prevent and treat GVHD.

There are 2 types of GVHD: **acute** and **chronic**. The 3 main organ systems that may be affected are the skin, gastrointestinal (GI) system (stomach, intestines), and the liver. **Acute GVHD** usually occurs within 3 months following the transplant. **Chronic GVHD** usually develops 3 months or more after the transplant.

Acute GVHD (Can Happen During the First 90 Days after Transplant)

Watch for:

- Skin rashes (red, flat, 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
- Diarrhea that can lead to dehydration and poor absorption of nutrients

We will give your child medicine to help with the reaction. This is called immunosuppression. Some treatments may make your child more prone to infection. Some may even cause liver and kidney problems. You will need to watch your child closely while on anti-GVHD medicines.

Tacrolimus is given 2 days before the transplant. It helps prevent and treat Graft-Versus-Host Disease (GVHD) after transplant. The medicine is given by IV first and then later by mouth. Your child will remain on this medicine for 4 to 6 months after the transplant.

While on this medicine, your child's blood levels will be checked often, **usually 2 to 3 times per week. This may require a blood draw from a vein.** Sometimes, another medicine called Cyclosporine is used instead of Tacrolimus.

Your child will be watched carefully for GVHD signs.

- If your child has a disease, such as leukemia, some GVHD may be good. It can help fight off any leukemia cells that are left in the body. But, too much GVHD is not good and can lead to serious problems.
- It is important to tell your child's doctor right away if he or she develops any GVHD.

Chronic GVHD (Usually Can Happen After the First 3 Months)

Watch for:

- Changes in lining of the mouth, like white patches, dry mouth, or ulcers
- Skin color changes
- Hard and thick patches of skin
- Skin or joint tightness
- Changes in liver function tests
- Dry mouth
- Dry eye syndrome
 - Lack of tear production
 - Red eyes (conjunctival irritation)
- Possible hair loss or premature graying of hair
- Diarrhea
- Weight loss
- Changes in breathing or lung function, such as wheezing, coughing, shortness of breath, or lips turning blue

The most common medicines used to prevent and treat chronic GVHD are tacrolimus, methotrexate, corticosteroids, antithymocyte globulin (ATG) and cyclosporine. Other medicines used include infliximab (Remicade[®]), daclizumab (Zenapax[®]), rapamycin (Rapamune[®]), Sirolimus[®]) and pentostatin. Your child's medicines will depend on their diagnosis and type of transplant. He or she may need more than one type of medicine.

Hospital Visitation Policy

Transplant patients can get life-threatening infections very easily and are placed in strict protective isolation when they receive their transplant. All staff and visitors must wash their hands, and wear a mask and gloves before entering the hospital room. Also, no visitors under 12 years of age are allowed. We ask that you also follow these guidelines:

- Limit the total number of visitors – only 2 at a time.

- 1 parent, guardian, or adult family member must stay overnight if the patient is a minor. 2 parents may choose to stay overnight if the room size permits.
- Parents should not to sleep in the same bed as their child.
- Persons under 18 years of age (minor) are not allowed to stay overnight at any time.
- **Live plants and fresh flowers are not allowed in the hospital room or on the inpatient unit.**

Child Care for Siblings

It is important to make childcare arrangements for sibling(s) (brother or sister) as soon as possible; well before your child's hospital admission. It is best for siblings to stay at home or with a relative or friend. If this is not possible, a responsible adult over 18 years of age must stay with them at all times.

Local Housing

There are many nearby hotels and apartments that offer shuttle service to MD Anderson. Plan to stay in the Houston area for at least 100 days after an allogeneic transplant.

The Rotary House is the hotel connected to MD Anderson. The Ronald McDonald House is located down the street within walking distance of the hospital. Contact your social worker for help with housing needs and for placement at Ronald McDonald House, if needed.

Texas Medicaid and some other insurance providers can suggest certain places and help with housing costs.

Hospital Discharge, Recovery and Follow-Up

There are certain precautions and instructions that you will need to follow after your child is discharged from the hospital and during their recovery.

- Your child **must** have a caregiver with them 24 hours a day.
- The length of hospital stay varies for each patient and depends on the type of stem cells, side effects and problems that occur. Your child will be discharged when he or she can take medicines and food by mouth, is fever free, and has a good white blood cell count.
- After discharge, your child will return to the clinic often. At these visits, blood counts will be checked and the care team will look for signs of infection and assess the need for IV infusions and transfusions. Your child's immune system will be very weak. Your child will need to do things to help prevent infection, such as wear a mask and gloves for 60 to 100 days after the transplant.
- Our goal is for your child to go home after the first 100 days, but this may vary and depends on their needs and condition. Once your child is cleared to leave the Houston area, he or she will continue to have follow-up visits with their cancer or primary care doctor in your home community. 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 child's doctor tells you it is OK to be further away.

Follow-Up

After the first 100 days, your child will continue to have regular lab tests done. Results will need to be sent to MD Anderson for review. Your child will need to come back for tests and exams every 3 to 6 months for at least the first year and then every 6 to 12 months thereafter. Again, this varies for each patient and depends on their condition. Their doctor will make the follow-up plan for you.

Diet and Activities

- No eating raw fruits and vegetables that cannot be washed or peeled easily, such as berries or lettuce.
- No drinking tap water for at least 100 days after the transplant.
- No attending community school for 6 to 12 months after transplant. Speak with the school coordinator to arrange home or hospital schooling during this time.
- **Always check with your child's doctor first before you allow your child to swim.** No swimming for at least 100 days after transplant. About 6 months after transplant, he or she may swim in a well-maintained private pool. Avoid swimming in the ocean or lakes for at least 1 year after transplant.
- Avoid pets and animals for at least 100 days after transplant.
- Avoid direct sun exposure. Use sunscreen and wear protective clothing and sunglasses.

Immunizations

- Your child will need to be immunized again about 6 months after the transplant.
 - The transplant doctor will discuss the timing and schedule of immunizations with you.
 - Immunizations can be given by your child's primary care physician, or at your local public health clinic.
- **Siblings and household members:**
 - Are encouraged to receive yearly flu shots.
 - May receive the MMR vaccine. They do not have to be isolated from the patient.
 - May receive the varicella vaccine. If a rash develops after the vaccine, the sibling or household member must be separated from the patient for at least 3 weeks or until all lesions scab over and disappear.
 - **Should not** receive the live, oral polio vaccine. Make sure the inactivated polio vaccine injection is used.

Relapse

Some transplant patients will have a relapse, which means their disease has come back, despite our best efforts. The care team may recommend certain treatment options, such as stopping immunosuppression, biotherapy/cellular therapy, more chemotherapy and radiation therapy or a second transplant. This usually depends on how soon after the transplant this occurs and the overall condition of your child.

Long-term Effects

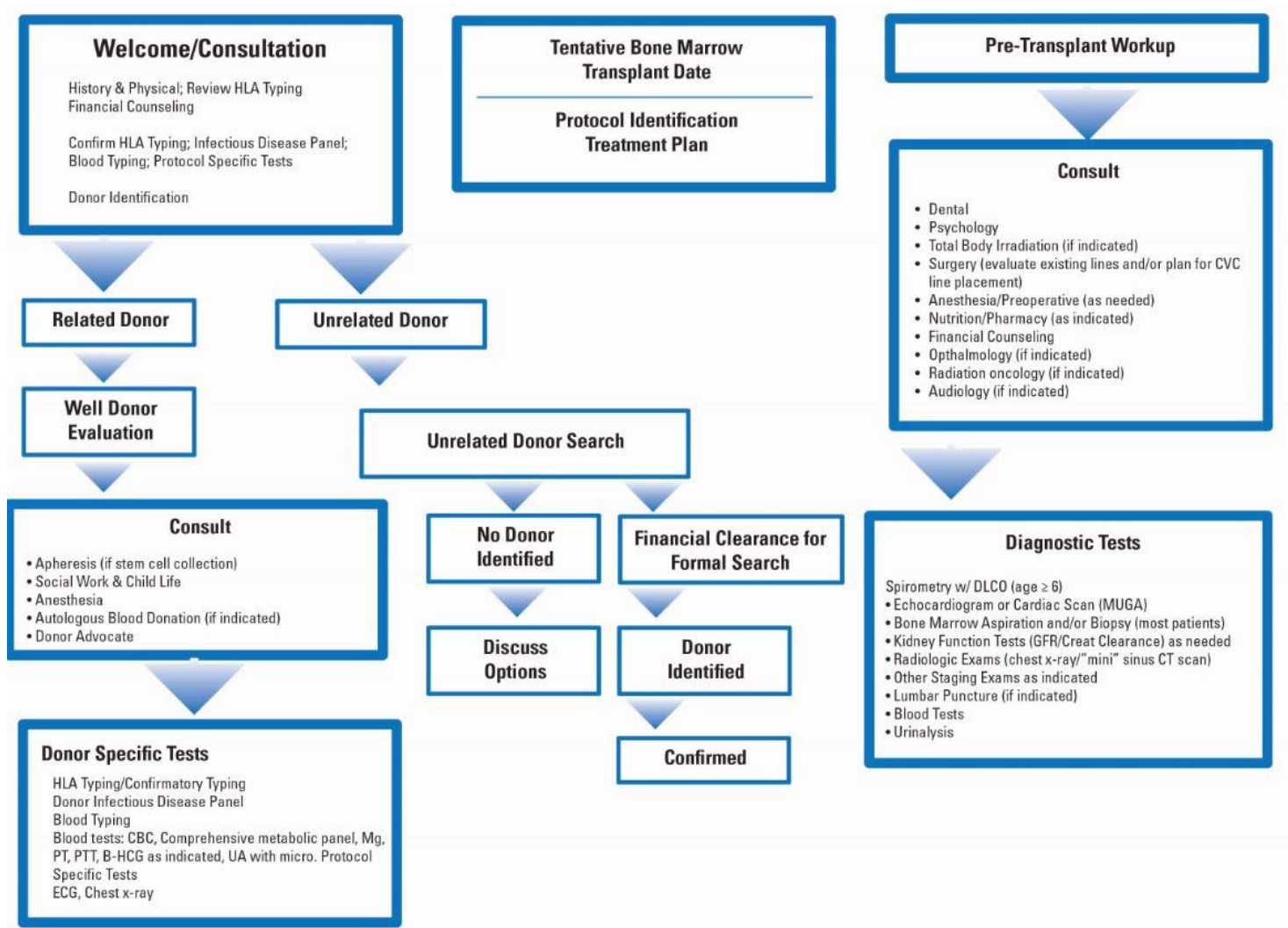
Stem cell and bone marrow transplant patients may have long-term side effects. Side effects may include:

- Abnormal or low hormone levels that can lead to problems with growth and thyroid and adrenal function
- Damage to the kidney or lungs that can lead to abnormal kidney function, fibrosis (stiffening) of the lungs or less air exchange in the lungs because of inflammation
- Cataracts
- Dry eye syndrome
- A second cancer
- Less blood supply to the joints from prolonged steroid therapy
- Trouble with school work or thinking and memory

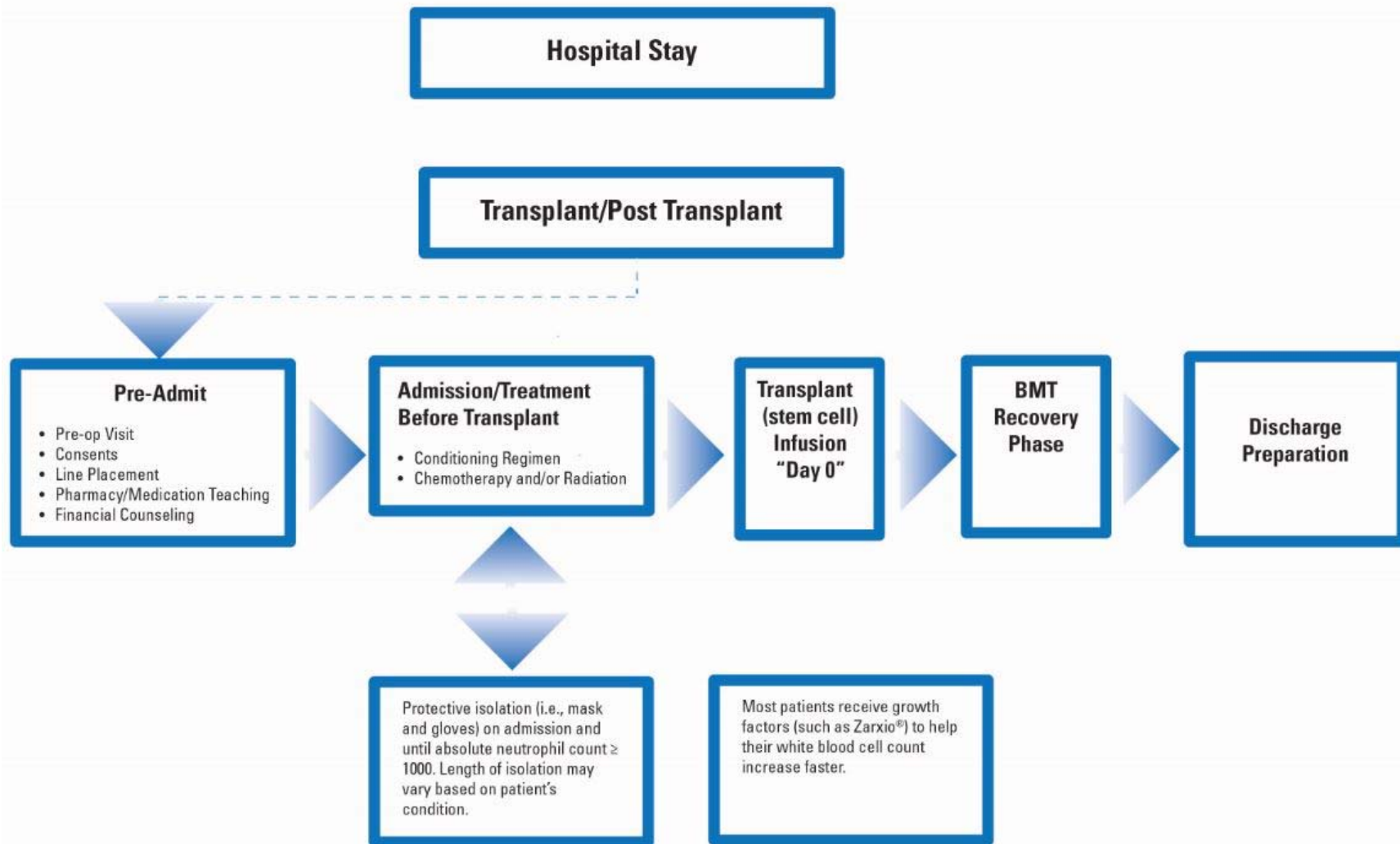
Fertility

Fertility is the ability to have children. Transplant patients often have issues with fertility because cancer treatments can damage the reproductive system. But, there are options to help preserve fertility that may make childbearing possible in the future. Talk with your care team to learn more and request a fertility consult in the Child and Adolescent Center.

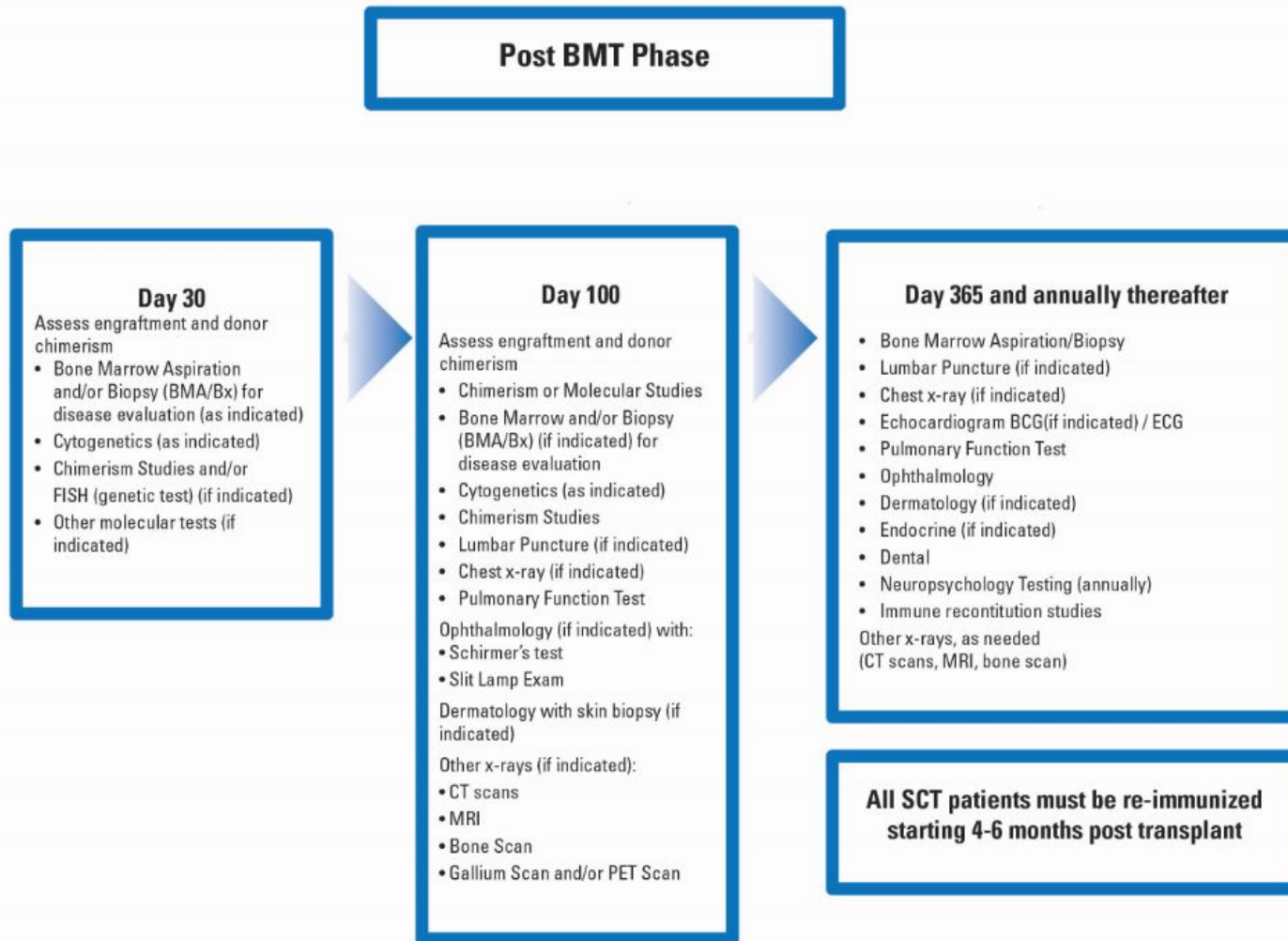
Allogeneic Pathway Pediatric Stem Cell Transplant



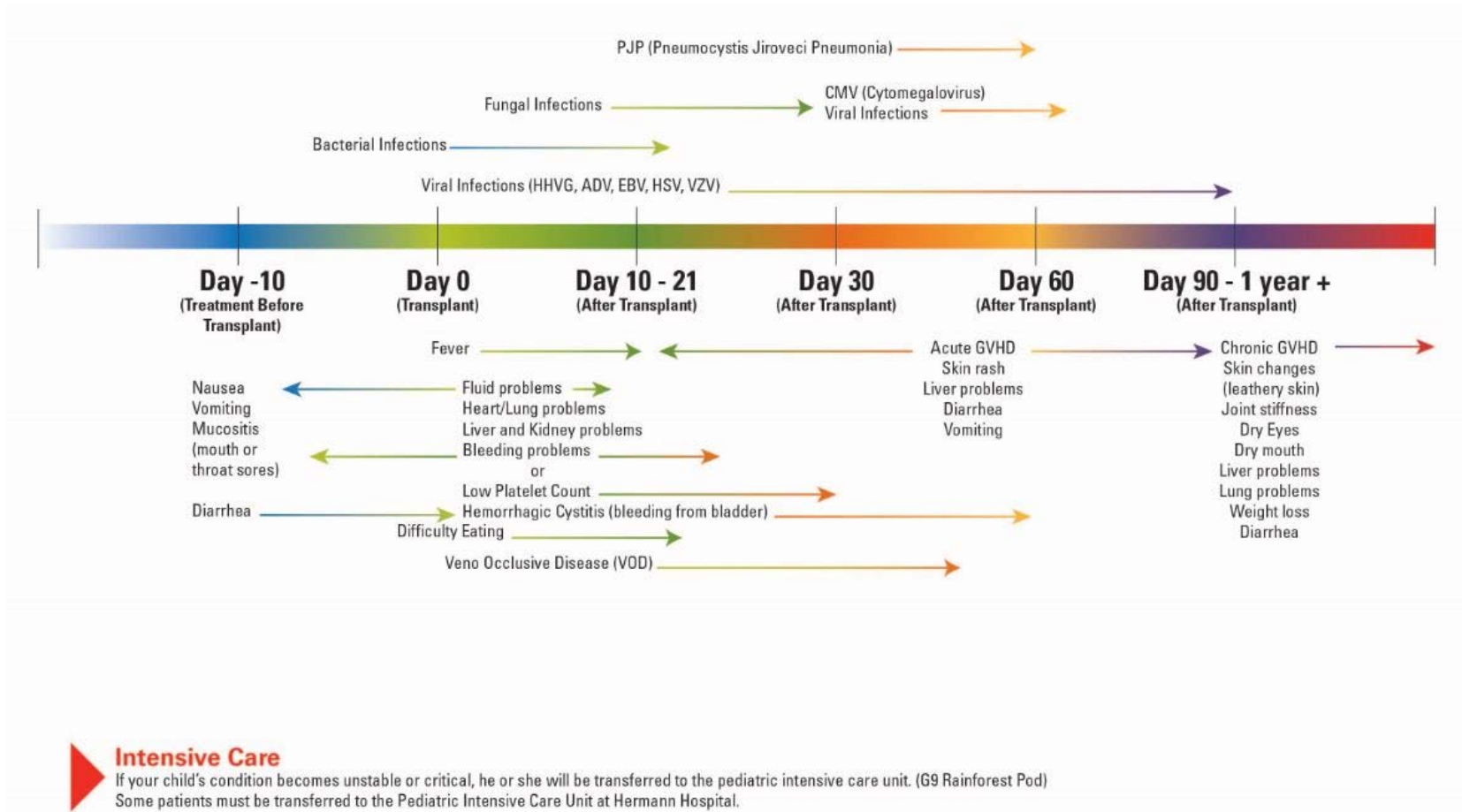
Allogeneic Pathway Pediatric Stem Cell Transplant



Allogeneic Pathway Pediatric Stem Cell Transplant



Allogeneic Transplant Possible Side Effects/ Complications Pediatric Stem Cell Transplant and Cellular Therapy



Graft Versus Host Disease (GVHD) Pediatric Stem Cell Transplant and Cellular Therapy

Bone marrow cells are unique to each person. When bone marrow (the graft) is transplanted into the recipient's body (the host), the cells recognize the host as a foreign. The cells attack the new body. This process can cause a reaction in your child's body called Graft Versus Host Disease (GVHD).

GVHD ranges from mild to severe and can be life-threatening. GVHD risk increases with unrelated donor transplants and with non-HLA identical related donor transplants. The higher the degree of HLA "mismatch", the higher the chance of developing severe GVHD. Medicines will be given to your child before, during, and after the transplant to help prevent and treat GVHD.

There are 2 types of GVHD: **acute** and **chronic**. The 3 main organ systems that may be affected are the skin, gastrointestinal (GI) system (stomach, intestines), and the liver. **Acute GVHD** usually occurs within 3 months following the transplant. **Chronic GVHD** usually develops 3 months or more after the transplant. GVHD symptoms for each type are:

Acute GVHD (Can Happen During the First 90 Days after Transplant)

- Skin rashes (red, flat, 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
- Diarrhea that can lead to dehydration and poor absorption of nutrients

Severe GVHD requires more intense the treatment. GVHD treatment can delay the recovery of the immune system. It can also lead to a higher chance of infection. The care team may restrict your child's diet if your child has GVHD of the GI system. Your doctor and dietitian will give you specific instructions.

Chronic GVHD (Usually Can Happen After the First 3 Months)

- Changes in lining of the mouth, like white patches, dry mouth, or ulcers
- Skin color changes
- Hard and thick patches of skin
- Skin or joint tightness
- Changes in liver function tests
- Dry mouth
- Dry eye syndrome
 - Lack of tear production
 - Red eyes (conjunctival irritation)
- Possible hair loss or premature graying of hair

- Diarrhea
- Weight loss
- Changes in breathing or lung function, such as wheezing, coughing, shortness of breath, or lips turning blue

The most common medicines to prevent and treat GVHD include:

1. Tacrolimus (FK506)
2. Methotrexate
3. Corticosteroids (Methylprednisone[®], Prednisone[®], etc.)
4. Antithymocyte Globulin (ATG)
5. Cyclosporine

Other medicines include Infliximab (Remicade[®]), Daclizumab (Zenapax[®]), Rapamycin (Rapamune[®], Sirolimus[®]), Etanercept (Enbrel[®]), Denileukin Diftitox (Ontak[®]), Hydroxychloroquine (Plaquenil[®]), Mychophenolate Mofetil (MMF) (Cellcept[®]), Thalidomide (Thalomid[®]), and Pentostatin (Nipent[®]).

The medicines that will be given depend on your child's diagnosis and type of transplant. One or more of the drugs listed above may be prescribed.

Other treatment options include photopheresis.

Call your nurse or doctor if your child has any GVHD symptoms.

Outpatient Clinic

Robin Bush Child and Adolescent Clinic

Main Building, Floor 7, near Elevator C
713-792-6610

Inpatient Units

George E. Foreman Pediatric Unit (G9)

Main Building, Floor 9, near Elevator F
Ocean Pod 713-792-5173
Mountains Pod 713-792-5149

Refer to the education sheet "Human Leukocyte Antigen (HLA) Typing: Pediatric Stem Cell Transplant and Cellular Therapy" for more information about HLA typing.

Chronic Graft Versus Host Disease (cGVHD)

Pediatric Stem Cell Transplant and Cellular Therapy

White blood cells in the body help fight infection. They find foreign cells, like bacteria and viruses, and attack them to keep the body healthy. This is a natural part of the immune system; the body's way of protecting itself.

But in a patient with graft-versus-host disease (GVHD), a type of white blood cells called T cells, attack parts of the body that are not foreign. This can happen after a bone marrow or stem cell transplant. The donated white blood cells (the graft) attack the patient's body (the host). The white blood cells react as though the body is foreign instead of protecting the patient's body.

The 2 types of GVHD are **acute** and **chronic**. Acute GVHD usually happens within 3 months after the transplant.

Chronic GVHD (cGVHD) usually develops 3 months or more after the transplant. It affects 3 main organ systems; the skin, the gastrointestinal (GI) system (esophagus, stomach and intestines) and the liver.

cGVHD has 3 sub-groups:

1. **Quiescent cGVHD** occurs after a prior episode of acute GVHD has gotten better
2. **Progressive cGVHD** occurs when acute GVHD becomes chronic GVHD
3. **De Novo cGVHD** occurs even though acute GVHD did not occur

What are the signs and symptoms?

cGVHD has many signs and symptoms. It may mimic other autoimmune disorders, such as lupus erythematosus or scleroderma.

Skin

- Rough and scaly
- Redness (erythema)
- Lighten or darken in color
- Hair loss (alopecia)
- Tight, stiff or loss of stretch
- Hardened or thickened (Lichenoid lesions)
- Open sores or ulcers
- Thick nails that split or have ridges

Liver

- Yellow appearance of skin and eyes (jaundice)
- High bilirubin levels
- High liver enzyme levels
- Inability to remove toxins or break down medications properly

Eyes

- “Dry eye” syndrome (unable to produce tears) that leads to
 - Dry, irritated or burning eyes
 - Conjunctival injection (eyes appear red)
 - Light sensitivity
 - Pain
 - Scrapes (corneal abrasion) or open sores in the eye due to lack of tears and constant irritation
- Eyelid changes (stiffening)

Mouth

- Dry mouth
- Plaques or white patches in mouth
- Mouth sores/pain
- Sensitivity to spicy or acidic foods
- Redness (erythema)

Lungs

Breathing problems such as wheezing, coughing or shortness of breath

GI Tract (esophagus, stomach and intestines)

- Loss of appetite or not eating (anorexia) or difficulty to eating
- Painful swallowing
- Weight loss
- Nausea or vomiting
- Heartburn type pain

Muscles or Nerves

- Muscle and joint stiffness or tightening of the skin, making it difficult or impossible to straighten joints (contractures)
- Muscle or joint pain or weakness

Other

- Vaginal dryness
- Low platelet count
- Increased risk of infection

Treatment

Treatments vary and may include:

- Skin lotions and creams to increase moisture and decrease inflammation, irritation or itchiness
- Stretching exercises or physical therapy to help soften tight skin
- Steroid mouthwash or Biotene® products to decrease dryness and sensitivity in the mouth
- Artificial tears, punctal plugs or eye protection with safety-type glasses for dry eyes (Punctal plugs block the tear ducts to make tears flow over the surface of the eye.)
- Lubricants and estrogen cream for vaginal dryness or tightness

Medicines

Medicines that may be used to prevent and treat cGVHD are:

- Tacrolimus (FK506)
- Sirolimus (Rapamune®)
- Cyclosporine
- Corticosteroids (Prednisone)
- Methylprednisolone (Solu-Medrol®)
- Antithymocyte globulin or antilymphocyte globulin (ATG)
- Infliximab (Remicade®)
- Dacluzimab (Zenapax®)
- Etanercept (Enbrel®)
- Denileukin diftitox (Ontak®)
- Pentostatin (Nipent®)
- Thalidomide (Thalomid®)
- Mycophenolate mofetil (MMF) (Cellcept®)
- Hydroxychloroquine (Plaquenil®)

Ask your nurse for a copy of the specific drug sheet to learn about its use and side effects.

ExtraCorporeal Photopheresis (ECP)

Extracorporeal photopheresis (ECP) may be used to treat skin, liver, gastrointestinal and lung symptoms of cGVHD. It can also be used to help lessen or stop the use of some medications that treat cGVHD, such as corticosteroids.

ECP involves the use of a machine that separates certain white blood cells (T lymphocytes) from the rest of your blood. These white blood cells are collected into a bag, injected with a special drug, and then exposed to ultraviolet A (UVA) light, similar to a tanning bed. The UVA light activates the drug and then destroys the white blood cells that cause the cGVHD. When the process is complete, the cells are given back to the patient. .

With ECP, your blood count levels and platelet count must be at a certain level. Also, you must have either a Quinton® or Hemacath® catheter in place. ECP treatments are initially done 2 to 3 times per week, and may last several months.

Graft Versus Host Disease (GVHD) Diet

Pediatric Stem Cell Transplant and Cellular Therapy

GVHD Diet

The GVHD diet is a 4 phase diet, that tries to make the most of what your child can eat and at the same time lessen his or her amount of frequent stooling (bowel movement). Your child’s diet will be based on how much or how little stool he or she puts out. A nutrition consult is strongly encouraged to help select the most appropriate diet. Below are the 4 phases of the GVHD diet.

GVHD Phase 1 – clear liquids, no caffeine

GVHD Phase 2 – complex carbohydrates, such as plain rice, pasta, potatoes, white bread, and some canned fruits

GVHD Phase 3 – introduce fiber and fat into diet, minimal lactose, low-fat meats, and low-fiber vegetables

GVHD Phase 4 – continue to increase fat, fiber, and some lactose-containing products

Tips to Help Your Child

- Have your child eat foods at room temperature to help lessen stomach cramps
- Have your child slowly add new foods into his or her diet (1 to 2 new foods per day)
- For 3 days in a row, keep a log of foods your child eats, at what time, and the number of stools he or she has per day to help the care team decide which diet is best
- Have your child eat 4 to 6 small meals per day
- If your child has trouble drinking liquids on the GVHD Phase 1 diet, watering down drinks with water may help him or her tolerate them better.
- On the GVHD 4 diet, milk is allowed. However, you should first see if your child can tolerate it. Have him or her drink ¼ - ½ cup milk. If your child has stomach cramps or stools after drinking the milk, Lactaid® milk or Lactaid® tablets can be used.

GVHD Diet (Examples of Foods Allowed)

GVHD 1	
Juice (no pulp, no prune juice)	Hot tea
Jello®	Decaf iced tea, coffee
Italian Ice	Broth/consommé
Popsicles	Gatorade®
Caffeine-free soda	Enlive®

<p>GVHD 2 All foods allowed on the GVHD1 diet Dry cereal (low-fat, low-fiber) Grits Cream of rice Canned peaches Jelly Honey Caffeinated beverages</p>	<p>White breads Crackers Pretzels White rice Plain pasta Baked Lays[®] potato chips Plain baked potato Angel food cake</p>
<p>GVHD 3 (Limited to 5 oz. of meat/day and 2 fat servings) All foods allowed on the GVHD 1 and 2 diets Cream of wheat Low-fat yogurt Eggs (counts as meat serving) Egg Beaters[®] Canadian bacon Promise[®] margarine Fat-free cream cheese</p>	<p>Soups (tomato, vegetable, chicken noodle) Rye bread Mayonnaise (counts as fat serving) Mustard Grilled chicken Salmon, tilapia Ham Spaghetti with marinara sauce Turkey deli meat Carrots, squash Boost[®]</p>

Graft Versus Host Disease (GVHD) Prevention Using Tacrolimus and Methotrexate Pediatric Stem Cell Transplant and Cellular Therapy

Graft versus host disease or GVHD, is a potential problem that may occur after marrow or blood stem cell transplant from a donor. The stem cells (the graft) your child received form their new immune (infection fighting) system. This new immune system may recognize them (the host) as being different. An acute episode of GVHD may occur in the first few months after transplant. Signs and symptoms may include:

- Nausea
- Vomiting
- Diarrhea
- Rash
- Abnormal blood tests for liver function

There is also a chronic form of GVHD. It normally occurs from about 3 months to 2 years (or later) after transplantation. Chronic GVHD may cause:

- Dry eyes
- Sore mouth
- Rash
- Skin tightening or joint stiffness
- Cough or shortness of breath when active or moving around
- Abnormal blood tests for liver function
- Weight loss

These signs and symptoms can be caused by other medical problems. This is why it is so important that the Stem Cell Transplant (SCT) doctor oversee your child's care. Always report any of these symptoms right away if they occur. You need to know how to get in touch with your child's SCT care team and who to call on the weekend or at night if your child should develop a new problem.

Prevention of GVHD

Inpatient

The treatment goal is to reduce GVHD related problems. This is done using 2 standard medicines called methotrexate and tacrolimus, also known as Prograf[®] or FK-506. Methotrexate is given as an intravenous (IV) injection through the central venous catheter (CVC) 3 to 4 times during the first or second week after transplant while your child is in the hospital. Prograf is also given by IV in order to keep the blood levels even. It is started 2 days before the transplant. Then, your child will be slowly weaned off this medicine to make sure GVHD does not occur.

Outpatient

Your child will stop taking Prograf through an IV and start taking it in a pill form when he or she is ready to be discharged from the hospital after recovery. If you forget to give your child a dose of Prograf, do not try to make up the dose. Tell your care team (doctor, physician assistant, advanced practice nurse or pharmacist) about the missed dose. Your child will need to take these pills for 6 to 8 months after transplant. It can be longer if your child has or has had GVHD.

Drug levels

GVHD is a serious problem and it is important that your child take the correct dose of Prograf. Dosing is guided by measuring the level of the drug in the blood 1 or 2 times a week. As an outpatient, your child's blood test is usually done **before they take the morning dose of Prograf**. When you bring your child to the lab to have their blood drawn, bring the medicine with you so you can give it to them right after the blood is collected. If you are bringing your child to the clinic in the afternoon for their appointment, talk to the pharmacist or clinical nurse specialist about when to have the blood tests and when to give the Prograf. Be sure to tell the care team if your child missed a dose of Prograf before the blood test.

Most common side effects of Prograf

- Abnormal kidney function (usually mild and reversible)
 - This is measured by monitoring the creatinine level, a test of kidney function.
 - To help prevent kidney damage, have your child drink at least 1 to 2 quarts (1 to 2 liters) of fluids a day.
- Low magnesium levels in the blood
 - If the Prograf level is too high or the magnesium level too low, your child is at risk for having a seizure.
 - To help maintain the magnesium level, give supplements by tablet or IV.
- High blood pressure
 - Your child may need to take medicine to control their blood pressure while taking Prograf®.

Less common side effects of Prograf

These side effects may occur if Tacrolimus levels are elevated in the blood:

- Tremors (shaking of the hands)
- Burning of the hands and feet
- Headache
- Nausea
- Confusion
- Difficulty sleeping

These side effects are usually reversible by lowering the dose of Prograf. Side effects can also be due to other causes. Be sure to report symptoms to your SCT care team.

Other precautions

Sunlight exposure can worsen GVHD. To help prevent GVHD, limit your child's sun exposure by having them use sunblock and wear protective clothing such as, hats, long sleeves and long pants for at least 1 year after transplant.



Refer to the “Updated Home Medication List” given to you by the SCT care team. These are the only medicines your child's doctor wants them to take. This includes over-the-counter medicines that could cause side effects when taken with Prograf.

Contact your child's SCT care team right away if he or she has any GVHD signs or symptoms.

Emergency Care

In case of an emergency, call 911 or go to the nearest hospital emergency center. The MD Anderson Acute Cancer Care Center is open 24 hours a day, every day. From Holcombe Boulevard, turn at Entrance Marker 3. The entrance is on Bates Street for patient drop off only. You can park in Garage 2. From inside the Main Building, go to Floor 1, near The Pavilion entrance.

For non-emergencies during business hours, call the Child and Adolescent Center at 713-792-6610.

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 to fight infection, T lymphocytes and natural killer (NK) cells to kill infected or cancerous cells.

With this type of therapy, T cells are removed from either the patient’s blood or possible 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.


Chemotherapy is given first to prepare the patient for the CAR T cell infusion.

Treatment Plan

Below is a common treatment plan for CAR T cell therapy. This plan could change based on your specific treatment. Talk to your doctor or nurse if you have any questions or concerns.

The days before the CAR T cell infusion are counted down. For example: -5, -4, -3, -2, and -1. The day of the infusion is **Day 0**. The days after the infusion are counted up as +1, +2, +3 and so on.

<p>2 to 6 Weeks Before CAR T Cell Infusion (Day 0)</p>	<p>Th patient is enrolled for treatment.</p> <p>Informed consent is completed.</p> <p>The patient is scheduled for apheresis T cell collection.</p> <p>Harvested T cells sent to lab.</p> <p>No steroids at least 1 to 2 weeks before cell infusion.</p> <p>The care team will provide a wallet card with patient safety instructions if you receive either Yescarta[®], Tecartus[®], or Kymriah[®] CAR T cell therapy.</p>
<p>Conditioning Chemotherapy (Days -5, -4, -3)</p>	<p>Chemotherapy can be given as an inpatient or outpatient. Your doctor will decide if your therapy will be inpatient or outpatient based on your condition.</p>

<p>Rest Day (Days -2, -1)</p>	<p>If you are on a clinical trial, the Clinical and Translational Research Center (CTRC) will draw blood samples for your specific study.</p> <p>Based on your treatment, you may need growth factor injections to stimulate your body to produce white blood cells. These will be self-injections or you will come to the clinic (based on insurance and preference).</p>
<p>CAR T Cell Infusion (Day 0)</p>	<p>You will receive your infusion.</p>
<p>After Infusion (Day 0 to Day +14)</p>	<p>What to expect after your infusion:</p> <ul style="list-style-type: none"> • Vital signs are taken every 4 hours. • You will perform daily hygiene (shower, mouth care, wash hands and foot care). • You will sit up in chair and walk at least 3 times a day. • You will use the incentive spirometer every hour at least 10 times while you are awake. • Your medical team may ask you to write a sentence every day as part of your neuro assessment. • You will increase your fluids by drinking at least 6 to 8 glasses a day unless you are on fluid restrictions. <p> Watch for possible side effects. These include:</p> <ul style="list-style-type: none"> • Cytokine Release Syndrome (CRS) – a serious condition related with CAR T cell therapy. Cytokines are proteins that are released by the T 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: <ul style="list-style-type: none"> – Fever of 100.4°F (38.0°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, and heart failure related to low or high ejection fraction (measurement of the amount of blood pumped in and out of the heart) – Nausea, vomiting and diarrhea – Liver damage, injury, inflammation and elevated liver enzymes – Kidney damage, injury, decreased urine output – Skin rash – Bleeding disorder in which the body is unable to form blood clots and can lead to excessive or prolonged bleeding

	<p>Treatment of CRS symptoms is based on a grading scale. Grade 2 or more is treated with the following medicines:</p> <ul style="list-style-type: none"> • Tocilizumab (Actemra[®]) • Steroids <p>You will receive an information sheet on each of these medicines. Also, some medicines may require you to sign a consent form.</p> <p>-----</p> <ul style="list-style-type: none"> • Immune Effector Cell Associated Neurotoxicity Syndrome (ICANS) – A serious neuro (brain) toxic condition that may be related to CRS. Possible side effects include: <ul style="list-style-type: none"> – Confusion, delirium, agitation, hallucinations – Difficulty with speech or unable to use and process language – Tremor (shakiness), seizure – Weak muscles – Unable to control urine and bowel function – Increased pressure inside the skull – Increased pressure in or around the brain that affects the optic nerve inside the eye to swell – Difficulty with walking and balance • B-cell Aplasia – A condition in which 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 (TLS) – A metabolic condition that occurs when cells breakdown, die and release its contents into the bloodstream. It usually takes place at the start of certain cancer treatments, but can occur one month or more after 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 checking your electrolytes (calcium, magnesium, potassium, sodium, phosphate, and chloride).
<p>After infusion (Day +15 to Day +25)</p>	<p>Possible Discharge Continue to check your temperature 2 times a day. Do your hygiene, walking, incentive spirometer and drink fluids every day. Continue to watch for and manage possible side effects of CRS and ICANS.</p>
<p>Discharge (Day +30)</p>	<p>Your doctor will order a PET Scan and lab tests to assess how you are doing and discuss your long-term follow up plan.</p>

CAR T-Cell Therapy

Frequently Asked Questions

Below is a list of common questions that we receive from patients. If you have any other questions or concerns, let us know.

About T Cells

What are T cells?

T cells protect us from disease. Their function is to help your immune system fight bacteria, viruses and cancer. They are a type of white blood cell.

What is CD 19 Specific T-cell gene therapy?

It is a form of cell therapy that targets cancer cells using **chimeric antigen receptor (CAR)** technology. This technology allows researchers to design and direct those T cells to attack B-cell cancers that have a protein (chemical marker) called CD 19. This type of therapy is different from chemotherapy and radiation therapy.

How are CAR T cells made?

Blood is taken from you. The blood is then sent to a lab where researchers separate out the T cells from the blood and then perform a gene transfer to change the cells' DNA. These changed T cells are CAR modified T cells (CAR T cells). The cells are CD19-directed genetically modified autologous T cells.

About the Infusion

How are the CAR T cells infused?

The cells are infused into your vein through a central venous catheter (CVC). You will be admitted to the hospital.

What are the side-effects of a CAR T-cell infusion?

Some of the possible side-effects **may include**:

- Lower immune system. This means that your chance of getting an infection increases after you receive your infused cells.
- An allergic reaction, such as hives, rash, difficulty breathing, low blood pressure, blood circulation problems, and/or breathing problems.
- Cytokine Release Syndrome (CRS). A serious condition related with CAR T-cell therapy. Cytokines are proteins that are released by the T cells. They communicate with other special immune system cells to kill cancer cells. Cytokines can cause inflammation, similar to a severe infection

- Tumor Lysis Syndrome (TLS). This is an imbalance in the blood chemistry caused by the sudden death of cancer cells. It can lead to possible changes in heart and muscle function, as well as kidney failure.
- Immune Effector Cell Associated Neurotoxicity Syndrome (ICANS). A serious neuro (brain) toxic condition that may be related to CAR T-cell therapy.

About the Hospital Stay

How long will I have to stay at or near the hospital?

You will stay at the hospital for at least 7 days for the infusion and you will need to stay within 2 hours of MD Anderson Cancer Center 4 weeks after the infusion.

Why can't my clinic doctor take care of me when I am in the hospital?

Teams of doctors, pharmacists and nurses care for inpatients in the hospital on a rotating schedule. The other teams care for outpatients in the clinic.

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

One social worker works in the clinic and the other works in the hospital.

About Discharge

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

We generally ask patients to stay within a 2 hour drive of the hospital during the infusion recovery phase for at least 30 days for the following reasons:

1. If you have a problem, we need the ambulance to bring you directly to MD Anderson's Emergency Center.
2. You will have daily appointments at the beginning of the recovery phase and may need to come to the hospital on short notice.

If you need assistance with housing, tell your physician.

Will everything be back to normal after the infusion?

Your physician will talk with you about what to expect after the infusion. 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 everyday life. The type of infusion you have and any side effects will affect your "new normal." Also, you will need to be re-immunized. Your physician will talk with you about which vaccinations you will need and when you can get them.

About Caregivers

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

The immune system is fragile during the initial recovery phase. Your condition could change quickly. Therefore, you are required to have a responsible caregiver with you at all times. He or she will help monitor any changes and bring you to the hospital right away if needed. Also, a

caregiver helps with daily needs, and he or she serves as your advocate to help you make treatment decisions.

Does MD Anderson provide caregivers?

MD Anderson will not provide you with a caregiver when you leave the hospital. Usually patients ask family or friends to be caregivers. If your loved ones are unable to give around-the-clock care, please tell your health care team or social worker. We can talk to your loved ones about caregiver rotations and contact your health insurance company to see if they cover home health or caregiver services. Also, we encourage you to have a caregiver while you are in the hospital for support.

How closely will I be monitored after my CAR T-cell infusion?

After your infusion, you will be seen often by your care team during the first month, then monthly for the next 2 months, then every 3 to 6 months for at least 2 years.

Who do I call if I have questions?

For questions or to learn more about this therapy, please call the cell therapy coordinator, Monday through Friday, 8 a.m. to 5 p.m. at 713-794-1883.

About Finances and Health Insurance

What should I do if I have questions about my health insurance? What happens if my health insurance changes?

Please ask the receptionist to speak to a patient access specialist in the Patient Access Center. The patient access specialist (PAS) is a financial counselor. The PAS works closely with your insurance company to confirm that they will pay for all tests, procedures, medications and the infusion. They will also be available to meet with you to answer any financial questions you may have about the infusion process.

Whom do I ask about the costs or co-pays of my medicines?

A patient access specialist or patient access coordinator can answer your questions.

About Appointments and Tests

Whom do I ask about my schedule for tests and procedures?

A patient service coordinator/scheduler will help you with your appointment schedule. Also, refer to your patient appointment letter.

How do I get a copy of my appointment schedule?

You will get a patient appointment letter in the mail with the date of your next appointment, or you may log on to MyChart for a copy of your schedule. You may also call askMDAnderson at 877-MDA-6789 for your schedule.

About Other Services and Resources

Can I get a parking pass if I'm visiting frequently?

If you will be at MD Anderson for an extended period, The Texas Medical Center parking system offers the following options:

- Prepaid SmartChips – provides in-and-out privileges at a discounted rate of \$52 or \$100. Smart Chips are available for purchase at these pay stations near MD Anderson Cancer Center: Garage 2 – Level 2 skybridge to St. Luke's Episcopal Hospital
- Garage 2 – Level 1 lobby east end
- Garage 10 – Level 3 skybridge to MD Anderson Cancer Center

For more information about parking, call 713-791-6161. Also, ask your social worker for other parking options that may offer discounted rates.

What is 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 communicate securely with your health care team, check appointments and schedules, view your personal health records and review patient education materials and videos to help you manage your care at home. Learn more at www.MyChart.mdanderson.org. To create an account, call askMDAnderson at 877-632-6789.

How do I get copies of my medical record?

If you need copies of your MD Anderson medical record, including medical images and lab tests, please contact the Release of Information Office:

- Main Building, Floor 3, near Elevator D, Room B3.4362
- Mays Clinic, Floor 2, near Elevator S, Room ACB2.1613

The office is open Monday through Friday, 8 a.m. to 5 p.m. For more information, call 713-792-6710.

You may also view your medical records on MyChart.

Immune Effector Cell Therapy



Discharge Information

Immune effector cells (IEC) are cells from the human body. These cells use a patient's own immune system to kill cancer cells. Immune effector cells are collected from the body and sent to a lab where they are changed into cancer fighting therapy. The cells are then given back to you through an infusion to treat the cancer. You may also receive chemotherapy before the immune effector cells are infused.

What to Expect After Treatment

- Stay close to the hospital for at least 4 weeks after your infusion. Talk with your health care team for suggestions.
- Have a caregiver, family member, or friend with you for the first 4 weeks after the infusion.
- Report any fever, new symptoms or changes in condition to your health care team **right away**.
 - Delayed cytokine release syndrome (CRS) and neurologic toxic condition called **immune effector cell associated neurotoxicity (ICANS)** may also occur. Refer to the infusion wallet card that lists all of the signs and symptoms to watch for. Go to the MD Anderson Emergency Center **right away** if you have any of these signs or symptoms.
 - Other possible side effects may occur. This includes flu-like symptoms, such as high fevers, chills, nausea, body aches, difficulty breathing or changes in blood pressure. These symptoms can be mild or severe and could lead to death. Contact your health care team and go to the MD Anderson Emergency Center if you have any of these side effects or changes in your condition.
- Do not drive or operate heavy machinery for 8 weeks after infusion or as instructed by your health care team. This treatment can cause temporary memory loss, difficulty with walking and balance, sleepiness, confusion, weakness, dizziness, and seizures.
- Do not donate blood, tissues and cells for a transplant.
- Tell the health care team **right away** if you become pregnant at any time.
- Your health care team will schedule follow-up visits. Tell your health care team if you have any changes in your condition or new symptoms.
- If you have an infusion wallet card, always keep it with you and show it to all health care providers. The wallet card lists signs, symptoms, precautions, possible life-threatening events and your health care team contact information.

What You Need to Know After Discharge

<p>Self-Care</p>	<p>Continue to check temperature every evening and as needed, perform daily hygiene, walk, use the incentive spirometer and drink fluids as advised.</p> <p>Continue to take your prescribed antiviral and antibiotic medicines for at least 1 year after your cell infusion. Refer to your after visit summary (AVS) for more details.</p> <p>Continue to watch for and report possible side effects of CRS and ICANS.</p>
<p>Side Effects to Watch For While at Home</p> <p> Important instructions:</p> <p>Go to the nearest emergency room right away if you have any of these possible side effects</p>	<p> Watch for possible side effects. Go to the nearest emergency room right away if you have any of these side effects. These may include, but are not limited to:</p> <ul style="list-style-type: none"> • Cytokine Release Syndrome (CRS) – a condition related with cell therapy. Cytokines can cause an inflammatory response affecting several systems. Possible signs and symptoms of CRS include: <ul style="list-style-type: none"> – Fever of 100.4°F (38.0°C) or higher – Shortness of breath and difficulty breathing – Fast or irregular heart rate and/or rhythm, palpitations, lightheadedness, dizziness, or low blood pressure with systolic number less than 90 mmHg. – Uncontrolled nausea, vomiting and/or diarrhea – Unable to control urine and/or decreased urine output – Uncontrolled, excessive or prolonged bleeding <hr style="border-top: 1px dashed black;"/> <ul style="list-style-type: none"> • Immune Effector Cell Associated Neurotoxicity (ICANS) <ul style="list-style-type: none"> – a neurologic toxic condition that may be related to cell therapy. Possible signs and symptoms include: <ul style="list-style-type: none"> – Confusion, delirium, agitation, hallucinations – Vision impairment – Difficulty with speech or unable to process language – Tremor (shakiness), seizure and chills or rigors – Difficulty with walking and balance – Inability to control urine and bowel function – Muscle or joint pain – Severe fatigue or weakness – Dizziness, lightheadedness or uncontrolled headache
<p>Follow-Up</p>	<p>A PET Scan and lab tests may be done after you are discharged.</p> <p>Report possible side effects of CRS and ICANS to your health care team right away and go to the nearest emergency room and show your infusion wallet card to the health care providers.</p>

Caregiver's Role in Stem Cell Transplant

Pediatric Stem Cell Transplant and Cellular Therapy

A stem cell transplant (SCT) caregiver provides vital physical and emotional support to the patient. Caregivers assist patients in their recovery and bring them to the hospital for appointments or emergencies. They also make sure they eat, drink, sleep, take their medicines as instructed, and help them stay safe during recovery.

This handout describes how you will help care for your child while in the Pediatric Stem Cell Transplant and Cellular Therapy Program. Read it and ask the health care team if there is something you do not understand.

Many health care team members will work with you to teach you about your role during inpatient and outpatient care. You will need to take time off from work if you are employed. Some caregivers use vacation time from work or take FMLA (Family Medical Leave Act) leave. You may contact your child's social worker if you need a letter or form completed for your employer or need help with the paperwork.

Make sure the health care team has your name and phone numbers and contact names and numbers if there are other caregivers.

Caregiver Duties

You will have many roles throughout the transplant period. This includes parent, driver, cook, cleaner, bather/dresser, entertainer, advocate and friend.

Responsibilities are:

- Learn central venous catheter (CVC) care. You must learn how to care for your child's CVC before hospital discharge. Regular scheduled classes are available during the week and weekends.
- Going to scheduled clinic follow-up visits once your child is discharged from the hospital.
- Shop for and prepare healthy meals and snacks. Also, encourage your child to eat enough food daily.
- Follow a no fresh fruits and vegetables diet and practice safe food handling.
- Make sure your child takes their medicines on time.
- Contact social workers, chaplains and community resources if needed.



In some cases, your child may not spot or be aware of problems that develop, or may fear going back into the hospital. **Always** contact the health care team about any changes in their condition, such as:

- Fever or chills
- Vomiting or diarrhea

- Trouble with eating or drinking
- Depression or mental changes



You child's safety and treatment outcomes may be at serious risk if you do not contact the health care team right away.

Daily Activities

The health care team may ask you to keep and provide a daily record of your child's activities. Encourage your child to safely do as much of their care as they can. Have them return to normal activities as soon as he or she is able. Talk with the health care team about physical or occupational therapy if safety, exercising or doing daily activities is a concern due to fatigue.

Communication

Although it may not be easy, it is important to keep family and friends up-to-date of your child's condition. Medical concepts and terms can be hard to understand. It can be frustrating to explain and repeat information over and over again. It may help to share information through a newsletter or email. Or, you may choose someone that can be in charge of sharing information, use church bulletins or other tools to keep people informed. The health care team can help you, your child or others explain information in simple, easy to understand terms.

Take Care of Yourself

Fatigue, weakness and trouble eating can be a challenge for both you and your child. Be sure to talk with the health care team about any concerns.

These duties can be a full-time job. Do not be afraid to ask for help if needed. Family members and friends are often willing to help with tasks and errands, such as child-care, paying bills, housework and yardwork. They can also help recruit blood donors if needed. Most family and friends want to feel like they are helping, so let them know what you need.

Caregiver duties require that you be physically and mentally fit so you are able to manage many tasks. Talk with your doctor about how to best manage your health if you have a medical condition that requires follow-up or monitoring. There are many Houston area hospitals and clinics you can contact directly if medical needs arise.

Take time to exercise, walk and eat right so you can stay in good health for you and your child. This will also help encourage your child's progress and treatment success.

Pre-Transplant Work-Up

Pediatric Stem Cell Transplant and Cellular Therapy

The pre-transplant period is the time between getting a donor and hospital admission. The Stem Cell Transplant (SCT) doctor or coordinator will let you know when a suitable donor has been found.

If the donor is a family member, MD Anderson will make arrangements as soon as possible. The donor registers as a patient and an MD Anderson doctor provides their care.

If the donor is found from the National Marrow Donor Program, a collection date is arranged from the donor center. The donor center will tell us what day the marrow is to be collected. The transplant and the collection date will be set for the same day. The marrow is collected from the donor and then delivered to MD Anderson. If it is a donor through the cord blood registry, the blood is sent from an U.S. or European blood-bank center. The transplant patient is not admitted to the hospital until the cord blood is received in good condition.

Next, we will prepare and schedule your child's hospital admission and transplant date. We will give you more education handouts about 2 to 3 weeks before hospital admission. Read the information and keep it for future use.

Tests and Exams



Your child will need several tests and exams. Some of these tests can be done near your home if you are coming from an outside facility. It takes at least 5 days to complete all of the tests and exams.

- Dental screening, which includes dental x-rays and cleaning. Antibiotics before and after the dental visit are needed if your child has a central line.
- Heart, lung, and kidney function tests. This includes an electrocardiogram (ECG), an echocardiogram or nuclear cardiac scan, pulmonary function test, and sometimes a 24-hour urine collection, or a nuclear medicine GFR (glomerular filtration rate) test.
- Tests to restage your child's illness. This may include a bone marrow aspiration to check for remission, lumbar puncture, computerized tomography (CT) scan and magnetic resonance imaging (MRI), if needed.
- Surgery consult to check your child's catheter or placement of a new catheter. A double or triple lumen catheter is needed for a transplant.
- TBI (total body irradiation) consult, if needed.
- Blood tests at MD Anderson.
- Chest x-ray and CT scan of the head area.
- Neuropsychology tests to assess your child's learning needs. Testing takes 2 to 3 hours and is done in the clinic before the transplant, if needed.

Your child's doctor will review the pre-transplant test results, discuss the conditioning phase and obtain written consent for the transplant. Then, a care conference will be held before admission. You will meet with the transplant team members to discuss your child's care during the transplant.

Child and Family Well-Being

Expect your child's hospital stay to be at least 28 days. We know removing your child from their normal setting and routine can cause distress for the whole family. Your child's emotional well-being is very important to the transplant process. We will help you and your child find helpful ways to cope during the transplant process. For example:

- A psychologist will meet with both of you to talk about the transplant. This person will provide continuous support throughout the hospital stay and recovery period.
- Your child can continue their education through our school at the hospital. Homebound instruction is also provided during recovery. Bring your child's school work and books on the day of hospital admission.
- A social worker will meet with you to discuss housing arrangements, sibling care, and extended work leave for family illness.
- Child Life Specialists will help your child prepare for the transplant. They will provide activities and other helpful distractions throughout the treatment and follow-up.

Pre-Transplant Evaluations

Pediatric Stem Cell Transplant and Cellular Therapy

Electrocardiogram

An **electrocardiogram (ECG)** is a diagnostic test to study the electrical activity of the heart.

Procedure

1. Go to the appropriate area as instructed.
2. We will take you and your child into a private room where he or she will undress from the waist up and put on a hospital gown. Females must also remove tights or stockings.
3. If you or your child have questions, be sure to ask before the test begins.
4. Your child will lie on an exam table.
5. Electrodes (small pads with wires attached) will be attached to your child's arms, legs, and chest. The other ends of the wires will be connected to the ECG machine. The electrodes receive electrical waves from your child's heart and send the electrical waves to the ECG machine, which records the waves on paper.

The procedure is painless. There is no danger of getting an electrical shock. The entire procedure usually takes no more than 5 to 10 minutes.

Echocardiogram

The purpose of the echocardiogram is to examine the heart using a special technique called ultrasound. This technique uses an examining probe and a monitor that forms a picture based on reflected sound waves.

Procedure

You will go to the Cardiopulmonary Center for this test. It is located in the Main Building, Floor 8, near Elevator C. No preparation is needed for this test.

Once you arrive, we will take you and your child into a private room. The technicians (tech) will ask your child to undress from the waist up and to lie on a bed. Wires that are connected to a machine are attached to your child's arms and chest. This is done so that a **picture** of the heart's electrical activity can be taken.

The tech will also put ultrasound jelly on different areas of the chest and then touch these areas with an examining probe to record the needed information. By using the probe, we can examine the anatomy and function of the heart.

The entire procedure is painless and usually takes no more than 30 to 45 minutes. If you have any questions, be sure to ask the tech before the test begins. **It is important for your child to feel relaxed during the test so that it will not have to be repeated.**

Pulmonary Function Test (Spirometry)

A pulmonary function test (spirometry) determines how well your child's lungs function. Test results can help the doctor find out how your child's lungs may be affected by surgery, drugs, or other tests. This test is usually not done with children under 6 years of age because it requires the child to actively participate with the test.

Preparation for Spirometry

Your child will need to:

- Eat a light meal if the test is scheduled for shortly after mealtime.
- Wear loose, comfortable clothing.
- Remove neck tie, if wearing one.
- Remove dentures during the test.
- **Not** smoke for at least 1 hour before the test.
- **Not** use inhalers for 4 hours before the test.

Procedure

We will give you a health history questionnaire to complete before your child takes the test if this is their first spirometry test.

For this test, we will ask your child to do the following several times:

1. Breathe normally through a mouthpiece.
2. Breathe in deeply until his or her lungs are full.
3. Breathe out as hard, fast, and as long as possible until his or her lungs are completely empty.
4. Breathe in rapidly again until his or her lungs are completely full.

A tech is with your child during the test and will give your child specific instructions.

Special Instructions

This is a scheduled procedure and it is important that your child arrive by the appointment time. Also, allow about 1 hour to complete the spirometry test. Your child's first test results may show that another, more detailed test is needed. Another appointment is usually not needed for the other test.

Bone Marrow Aspiration and Biopsy

Bone marrow aspiration and biopsy are tests that help a doctor to evaluate how well the bone marrow works. Bone marrow makes red blood cells, white blood cells, and platelets. A bone marrow biopsy helps the doctor identify malignant or benign conditions.

In a bone marrow aspiration, a sample of fluid is taken from the bone. In a bone marrow biopsy, a core sample of bone and bone marrow fluid is also removed. These samples are then examined under a microscope.

Sedation can be used if your child cannot be still for this test. An anesthesia provider can give medicine through an IV to help your child fall asleep during the test. MD Anderson's Anesthesia Department provides this service for patients regardless of age, if needed.

Precautions



Tell the nurse if your child is allergic to:

- Tape
- Iodine
- Local anesthetic

Procedure

- Your child **should not** eat or drink after midnight the day before the bone marrow test.
- Test samples may be taken from the breastbone (sternum) or the front or back of the hipbone. Depending on the test site, your child may lie on either their stomach, side, or back.
- We will clean your child's skin around the procedure site with a Betadine[®] (iodine) solution or alcohol wipes.
- The procedure site is then numbed with a local anesthetic, such as EMLA[®] Cream or injected with Xylocaine[®] or Novacain[®].
- A bone marrow fluid sample is aspirated - removed from the bone with a needle. Your child may feel some discomfort, such as a pulling sensation during the aspiration.
- A biopsy sample of bone marrow cells are also aspirated. Your child may feel heavy pressure with some discomfort during the biopsy.
- When a biopsy is needed, it is done right after the aspiration. The biopsy involves taking a small **bone core** from the bone marrow.
- The complete procedure usually takes about 15 to 20 minutes.

After the Procedure

- A pressure dressing is applied. Keep it on as directed to prevent infection.
- Your child may go to their next appointment.
- Your child may feel some discomfort at the procedure site after the local anesthetic wears off. Walking may reduce the discomfort.

Special Instructions

Bleeding

- If bleeding occurs while your child is still in the clinic, apply pressure to the procedure site and return to the area where the test was done. Ask the nurse to apply another dressing.
- If bleeding occurs after your child leaves the hospital, call the health care provider that ordered the test.

Bathing

- **Bone marrow aspiration only:** No tub bath or shower for 24 hours. Remove the bandage after 24 hours.
- **Bone marrow biopsy:** No tub bath or shower for 48 hours. Remove the bandage after 48 hours.

Problems to Report



- Bleeding through the pressure bandage
- Redness, swelling, or drainage from the bone marrow aspiration site
- Fever over 101° F (38.3° C)
- Discomfort that is not relieved by walking

Follow-up

Your child's doctor will discuss the test results with you when they are available.

Radiation Consult

Some bone marrow transplant patients will receive total body irradiation (TBI). This involves high doses of external beam radiation. We will arrange a consult if this procedure is needed as part of your child's treatment.

During the consult, the doctor will review and discuss your child's previous radiation therapy, if received, side effects, answer questions and obtain the treatment consent.

Then, a TBI schedule is planned. TBI is done once or twice a day for 1 to 4 days. Your child's treatment plan will determine the exact TBI schedule. Treatments are done early in the morning at the Radiation Treatment Center. It is not painful or uncomfortable. However, some patients may have nausea after treatment. We can give medicine to help.

Sometimes, whole brain irradiation is needed before or after a transplant. Your child's doctor will let you know if this type is needed. It may require a separate radiation consult.

Cheerful Hints for a Long Hospital Stay

Pediatric Stem Cell Transplant and Cellular Therapy

Things to Bring

- A notepad to write down questions as you think of them and to record your child's progress.
- A calendar to cross off days spent in the hospital and to make notes about important events during your stay.
- Books, needlework, magazines, and other leisure type items.
- Special movies (DVDs or other format) that your child enjoys. Also, home videos of family and friends.
- DVDs or device with music and recorded stories. If you do not have a music device, ask the Child Life staff if you can borrow one.
- A personal laptop or electronic device if your child would like to have one in the room.
- Photos (especially family photos), drawings, and any special posters to hang in the room.
- Digital or instant camera so that you can have instant pictures of your child, activities, and staff members.
- Your child's favorite toy or blanket or bedding.



As you gather items to bring to the hospital, please note that storage space in the room is limited. Be sure all items are as clean as possible.

Things to Do

- Be kind to yourself! Schedule a break for yourself at least once a day!
- Encourage phone calls from relatives and friends.

Daily Care

Pediatric Stem Cell Transplant and Cellular Therapy

What to Expect on a Daily Basis

- **Your child will be weighed every morning. This is very important** because it helps the doctor to see how well your child responds to IV fluids and medicines.
- **All stool, urine or diapers should be saved** for a staff member to measure or weigh before discarding.
- **Mouth care needs to be done every 2 hours while your child is awake.** This is also important because it keeps your child's mouth clean, decreases discomfort, and promotes healing.
- **Breathing exercises with the incentive spirometer need to be done at least 4 times a day.** If possible, your child should do these exercises every 2 hours while he or she is awake. The exercises help expand his or her lungs and prevent pneumonia.
- **Your child needs to get up and out of bed** to sit in a chair or walk around the room **at least 3 times a day.** This helps prevent lung infections.
- Your child's vital signs (temperature, pulse, respiration, and blood pressure) will be taken every 4 hours, around the clock, or more often as needed. This means that we will wake your child if asleep to take them. These vital signs help your child's doctors make decisions about his or her care.
- **Routine blood tests will be drawn each morning** between 1 a.m. and 4 a.m. Most times, the blood is drawn from the central venous catheter. Sometimes, blood is drawn directly from a vein for certain blood levels and cultures, or special tests. Blood draws for Tacrolimus blood levels may use either a vein or central line. This is usually done on Monday, Wednesday or Friday. Blood cultures will be repeated when needed.
- **Stem cell transplant patients may sometimes have pain.** We will ask your child about pain while in the hospital and during each clinic visit. An age-specific pain scale is used to help determine the amount of pain your child is feeling and response to pain treatment. **Pain medicine and other options are available to treat pain.** Tell your child's doctor or nurse if he or she is having pain and whether or not the treatments help reduce it.
- Your child will shower or bathe every day.

- **Oral medicines (by mouth) should be taken on time.** The nurse will need to see your child take the medicine.
- Child life staff and school teacher appointments are scheduled daily. These daily meetings help your child adjust to the hospital and maintain normal growth and development.
- Central venous catheter (CVC) dressing changes are done weekly. Daily classes are available to teach you and your child about central line care at home. You must attend the class and a return demonstration visit before discharge.

What to Expect During Rounds

- Each morning the Pediatric Stem Cell Transplant team makes rounds to see their patients.
- A physical exam is done and your child's status, test results, and care plans are discussed.
- Members of the care team will return to the room for more exams and discuss your child's care as often as needed throughout the day or night.

What to Expect for Overnight Stays

- No more than 2 persons (parent/guardian/caregiver) may stay in the room with the patient.
- **Do not** sleep in the same bed with your child. This increases your child's risk of infection.
- Your child will use a crib if he or she is 2 years old or younger.
- No minor (child under 18 years of age) is allowed to stay overnight at any time.

What to Expect During Isolation

- **Isolation** begins on admission and continues until your child's white blood cell (WBC) count has returned to an acceptable level.
- Everyone who enters your child's room must wear a mask and gloves.
- Visitors must change their mask and gloves each time they leave and re-enter your child's hospital room.
- Wash your hands well before you put on the gloves and each time you take them off.
- Primary caregivers are not required to wear a mask and gloves in the room during isolation. The main doctor or nurse will help you identify who the primary caregivers are.

Lung Exercises

Pediatric Stem Cell Transplant and Cellular Therapy

Lung exercises play a very important part in helping the lungs work better. They will help reduce fluid and mucus in the lungs and clear out any germs that may make your child sick.

Using the Incentive Spirometer

You will get this equipment from the nurse. The nurse will review the instructions with you and will help your child practice using it. The spirometer should be used at least every 2 hours while your child is awake. The nurse will tell your child to use it more often if needed.

Doing Deep Breathing and Coughing

At times your child may feel too tired or weak to take deep breaths and cough. Try to encourage him or her to do deep breathing and coughing, since this will help the lungs stay clear.

Walking

Even while your child is in isolation, we want him or her to be up and out of bed walking at least 3 times a day - morning, afternoon, and evening. Your child can walk around the bed and to the bathroom. After your child is out of isolation, try to get him or her to walk as much as possible.

Changing Positions in Bed

Try not to let your child lie in the same position. Try getting your child to change positions and lie on his or her other side or back. Your child can also sit on the edge of the bed or in a chair.

If you have any questions about these lung exercises, please ask your child's nurse.

Skin Care

Pediatric Stem Cell Transplant and Cellular Therapy

The skin serves as a “guard” to protect your child from infection. For this reason, it is important to check your child’s skin every day while he or she is in the hospital. You should pay special attention to all areas of the body with “creases.” These areas include:

- Around the neck
- Under the arms
- Under the breasts
- Elbow area
- Around the bottom or groin area
- Under the knees

Look for any signs of redness or tenderness, or areas of skin that are broken down. Your child should try to wear loose clothing while he or she is in the hospital. Here are some skin care hints:

Skin Care During Thiotepa Treatment

Refer to the sheet "Skin Care During Thiotepa Treatment." If your child’s skin begins to breakdown after taking Thiotepa, you may need to do a special treatment called Domeboro[®] soaks. Refer to the "Instructions for Domeboro[®] Soaks" sheet. **Do not** use lotion on your child during Thiotepa treatment or 2 days after his or her Thiotepa treatment.

Pericare (Care of Your Child’s Bottom)

After each bowel movement (or with each diaper change), wash with the soap solution your nurse gives you, rinse with the water squirt bottle and pat dry. There are protective creams you can use, such as Lanaseptic[®] and Desitin[®], to prevent or heal irritated skin.

Acne

Some medicines, such as steroids, may cause an increase in acne on the face, back, and other areas of the skin. These areas should be kept clean and dry. We will give a cream or lotion like Benzyl Peroxide[®] to help dry up your child’s acne. You may also be given an antibiotic ointment or lotion, like Cleocin[®], to help clear up your child’s acne and prevent it from getting infected.

Dry skin (With or Without Itching)

Dry, sensitive skin can be a side effect of cancer treatment. Use the instructions below to help treat and soothe your child’s skin.

- Bathe or shower your child daily in warm water. **Do not** use hot water.
- Use a mild soap sparingly and only on your child’s face, armpits, groin, hands, and feet. Often, soap is not needed on any other area of the body if his or her skin is dry or sensitive.

- Mild soaps include Dove[®], Tone[®], Basis[®], Lubriderm Body Bar[®], Lowila[®], Oilatum[®], or Emulave[®].
- Always apply moisturizing cream or lotion after your child’s bath while the skin is still damp.
 - Cream or lotion works best when it is applied to damp skin because it traps moisture in the skin and prevents moisture from escaping easily.
 - If your child’s skin is very dry, you may need to apply cream or lotion at other times as well.
 - Use creams or lotions, like Eucerin[®], Lubriderm[®], Vanicream[®], Aquacare[®], Complex 15 Hand and Body[®], or Aquaphor[®].
- Avoid lotions that are heavily scented or have perfume. These can often irritate and dry the skin.
- Your child’s doctor should check, diagnose, and treat any new rash that is red, itchy, or raw.

Infection Prevention

Pediatric Stem Cell Transplant and Cellular Therapy

Your child will be in Modified Protective Isolation during the bone marrow transplant. It is important that you, other family members and visitors observe these guidelines:

Room and Visitation

Mask and glove isolation begins on admission. All staff and visitors need to wear a mask and gloves while in the room. **No one under 13 years of age is allowed to visit.**

Try to limit visitors to immediate family members, one at a time. Check with the nurse if someone else would like to visit your child. If visitors or visitor's family members have a cold or any infections, ask them **not** to visit until they are well for at least 24 hours.

Keep your child's hospital room door closed at all times.

Do not sleep in the same bed with your child. Prolonged skin contact increases the risk of infection and may also cause increased pressure points on your child's skin. Body fluids are considered hazardous waste for 48 hours after your child's chemotherapy treatment. Use caution when handling your child's bedding and other items that may be exposed to your child's body fluids. Store all personal items neatly in the room.



Live plants and fresh flowers are not allowed in the room or on the G9 inpatient unit.

Hand and Body Hygiene

Good handwashing is very important. It helps prevent infection. Wash your hands with warm to hot water and scrub them for at least 30 seconds. Do this after you use the restroom and before you handle food in your child's room. Refer to the sheet "Handwashing" for more information.

Good body hygiene for you and your child also decreases the risk of infection. Be sure to bathe or shower daily.

Your child should wear loose, soft clothes, like large T-shirts. Change clothes daily. Wash all clothing in hot water with soap. Washing machines are available to use.

Food and Drink

Your child may not have any raw fruits or vegetables or tap water while an inpatient. It is okay to have ice from the machine behind the nursing station.

Do not wear fake fingernails. Bacteria can collect and stay under these and contaminate food or other surfaces.

Hand Washing

Preventing infection is critical to your health. It is especially important in the hospital. Many people are in close quarters and a sick body doesn't fight infection as well. **The most important way to prevent the spread of infection is through hand washing and using hand sanitizers.**

How to Wash Your Hands

Wet your hands and use enough soap for a good lather. Rub your hands together using friction for 20 seconds. Scrub all areas of your hands, including fingers. Then rinse well with water. Dry your hands with a clean paper towel. Use a paper towel to turn off the faucet to keep your hands clean.



© iStock; Lostinbids

Hand Sanitizer



Alcohol-based hand sanitizer kills the germs on your hands. Use it when your hands are not visibly dirty. Apply enough to cover your hands. Rub your hands together using friction for 20 seconds until the product is dry. If your hands dry in less than 20 seconds, there was not enough sanitizer. Get more sanitizer and repeat for 20 seconds.

When to Clean Your Hands

- When your hands are dirty
- Before and after contact with another patient, family member or health care worker
- Before eating and drinking
- Before and after handling food (especially raw meats)
- After handling dirty items
- After using the restroom
- After blowing your nose, coughing or sneezing

Patients with Increased Risk for Infection

- Cancer patients who are receiving treatment
- Neutropenic patients (patients with a low white blood cell count)
- Stem cell transplant (SCT) patients
- Leukemia, lymphoma and myeloma patients (blood cancers)

Other Ways to Protect Against Infections

- Remind members of your health care team to wash their hands.
- Remind visitors to wash their hands.
- **Do not** touch your nose, eyes or mouth with contaminated (unwashed) fingers.
- **Do not** share personal items, such as dishes, towels, creams, toothbrushes, etc.
- Avoid anyone who is ill.
- Avoid anyone who has a respiratory illness or the flu (sneezing, coughing, sore throat). If this is not possible, you and they should wear masks until their symptoms are gone.

Extra Precautions

Ask your health care team if the precautions below are recommended for you:

- Wear a mask when outside your hospital room and/or outside your home.
- Wear a mask in crowded public areas.
- Wear a mask in construction areas. (This includes any area where parts of buildings or streets are being repaired, torn down or constructed. Large amounts of dust and debris may be present in the air.)
- Ask your visitors or family members to wear a mask. (In many cases, visitors should always wear a mask while in a patient's room and should change the mask when it becomes damp.)

Ask your health care team if it is OK to:

- Visit public areas during peak hours (such as theaters, restaurants, indoor playgrounds)
- Visit animal facilities (such as zoos, butterfly museums, pet stores)
- Clean up after your pet (such as litter boxes, birdcages, dog waste)

More Information

If you have questions concerning how to prevent infections, ask your health care team or call:

Infection Control and Prevention

713-792-3655

Mouth Care

Pediatric Stem Cell Transplant and Cellular Therapy

Supplies/Medicines

- Medicine cups
- Squirt bottle
- Sterile water (1500mL bottle)
- Salt and baking soda mixture or baking soda alone
- If ordered - Nystatin[®] liquid, Mycelex Troche[®], or Sucralfate[®]

Instructions

1. Mix 5mL salt and soda powder or baking soda with 240cc sterile water in the squirt bottle.
2. Label and date the bottle.
3. Check your child's mouth for redness, sores, and white patches.
4. Tell your child to rinse their mouth with salt and baking soda solution **at least 4 times a day**.



If other medicines have been ordered, tell your child to:

- Swish and swallow with ordered amount of Nystatin[®] liquid (or let Mycelex Troche[®] dissolve completely in the mouth).
- Swish and swallow with ordered amount of Sucralfate[®] liquid. The doctor may tell you to stop the medicine if your child has repeated nausea or vomiting with Sucralfate[®].

Special Instructions

- Tell your child **not** to eat, drink, or take oral medicines for at least 15 minutes after mouth care.
- Soft foam pads, like Toothettes[®], may be used with younger children to apply the medicine.

Nutrition

Pediatric Stem Cell Transplant and Cellular Therapy

Nutrition plays an important part in your child's growth and development. A good intake of calories and protein helps lessen his or her weight loss that may go along with cancer treatment.

Have your child eat a variety of foods. However, treatment side effects may make eating difficult. During times when food intake is limited, nutrition focus will be on total calories and protein intake.

Ideas to Increase Your Child's Calories and Protein

- For calories, try adding extra butter, margarine, or oils to food (1 teaspoon = 45 calories).
- Add cheese to sandwiches, eggs, etc., to increase calories and protein.
- For more protein, try adding 2 to 4 tablespoons of skim milk powder or Carnation® instant breakfast to 1 cup whole milk.
- Peanut butter and beans are good sources of protein.
- Make milkshakes (add peanut butter or canned fruit to increase calories).
- Talk to your dietitian for more ideas.

Here are some suggested foods for your child to eat when side effects are a problem.

Sore Mouth or Throat

Try easy to swallow, easy to chew foods like:

- Ice cream
- Milkshakes
- Puddings
- Macaroni and cheese
- Mashed potatoes
- Pureed meats/baby foods
- Scrambled eggs

Avoid spicy, salty, acidic foods (like citrus fruits, juices, or tomatoes) and drinks with caffeine, like colas and teas.

Nausea and Vomiting

- Eat small amounts of food more often.
- Try foods that are easy on your stomach like toast, crackers, sherbet, angel food cake, and clear liquids.
- Eat during **good times** and try not to force foods past the point of tolerance.
- Avoid **favorite foods** so your child will not equate them with being sick.

- Ask your doctor about anti-nausea medicines.
- Avoid greasy, fatty, fried, and spicy food. Also, avoid foods with strong smells.
- Avoid food at extreme temperatures (either hot or cold).

Diarrhea

- If diarrhea is a problem, avoid milk and milk products. These may aggravate the situation. Try Lactaid® milk instead.
- Avoid greasy, fatty, or fried foods.
- Avoid high fiber foods, such as whole grain/brown breads and high fiber vegetables.
- Try plain noodles, white rice, or white bread.
- Encourage small frequent meals.
- Encourage clear liquids such as water, Jello®, popsicles, or Pedialyte® to replace fluid loss. However, avoid large volumes of juice because it may increase diarrhea.
- Call your doctor if diarrhea persists.
- Avoid drinks with caffeine.

Decreased Appetite

- Eat smaller meals, more often so it is less overwhelming.
- Nibble throughout the day.
- Eat in a relaxed atmosphere.

Nutrition Support

There are two methods of nutrition support available if your child is having difficulty maintaining or gaining weight. Your doctor and dietitian will decide which is best for your child.

Tube Feeding – a tube is placed in the nose for feeding. This tube may be placed in the stomach or in the small intestines.

Total Parental Nutrition – nutrition is given through an IV (intravenously).

After the Transplant

Once you return home after the transplant, continue to monitor your child's weight and eating patterns.

- Use a notebook to record your child's weight 1 to 2 times per week for the first year after the transplant.
- If your child is losing weight or over a few months' time does not start to gain weight, ask your doctor or nurse to schedule an appointment with the dietitian.
- Every so often you may be asked by the clinic dietitian to record your child's food intake for 3 days. For example, record amounts like $\frac{3}{4}$ cup Rice Krispies® with 1 cup whole milk.

Food Restrictions and Safety Tips Pediatric Stem Cell Transplant and Cellular Therapy

1. If your child is **immunosuppressed**, he or she is to **avoid** the following foods:
 - Raw or undercooked meat, fish, shellfish, poultry, game, eggs, hot dogs, tofu, sausage and bacon
 - Raw fruits and vegetables while your child is an inpatient
 - Fresh berries, such as strawberries, raspberries, and any food with visible mold.
 - Well or tap water, unless it is tested yearly and found to be safe
 - Raw, uncooked Brewer's yeast
 - Raw or unpasteurized honey
 - Unpasteurized or raw milk and milk products, including cheese and yogurt
 - Unpasteurized commercial fruit and vegetable juices
 - Unpasteurized beer, such as microbrewery beers and those not shelf-stable
 - Cold-smoked fish and lox; pickled fish
 - Aged cheese, such as Brie, Camembert, blue, Roquefort, sharp cheddar, Stilton.
 - Refrigerated cheese-based salad dressings, such as blue cheese which are not shelf-stable
 - Caesar salad dressing, hollandaise sauce, homemade eggnog, and homemade ice cream.
 - Mexican hot (i.e., hot chili pepper) and farmer's cheese; feta cheese
 - All miso products (i.e., miso soup); tempe (tempeh); Maté tea
 - All moldy and outdated foods. Check expiration date on food.
 - Leftovers that are more than 1 day old, especially meat products and foods cooked with eggs or cream.
2. Your child may eat fresh fruits and vegetables that can be peeled.
3. Always wash your hands before eating or handling foods.
4. Refrigerate foods, mainly dairy and meat products, right away after shopping or cooking.
5. Maintain foods at the proper temperature -- cold foods at less than 40° F and hot foods at greater than 140° F. Re-heat foods to at least 165° F to lower bacteria growth.
6. Cook all meats well done, including poultry, fish, and eggs.
7. Clean counter tops by washing with hot soapy water and rinse thoroughly. Then sanitize with a solution of chlorine bleach. Mix 1 cup chlorine bleach with 1 gallon of water.
8. Thaw meat and poultry in the refrigerator, not at room temperature. Prepare raw meat and poultry separately from other foods. Also, use separate cutting equipment (other than eating utensils) on meats. Avoid wooden cutting boards.

Use fully cleaned tableware, utensils, and cutting equipment during food handling.

Pediatric Intensive Care Unit (PICU) Pediatric Stem Cell Transplant and Cellular Therapy

Your child may have serious medical problems after their bone marrow transplant that requires special, intensive medical and nursing care. This special care is given in the Pediatric Intensive Care Unit (PICU). The PICU is located on the pediatric unit in the Main Building on Floor 9, near Elevator F, Rainforest Pod.

A team of doctors, advanced practice providers, nurses, respiratory therapists, pharmacists, physical therapists, social workers, child life specialists, dietitians and chaplains will take care of your child. You may have met some of the team members when you visited the Child and Adolescent Center or while your child was admitted to the inpatient unit.

The PICU team is committed to giving you and your child the best care possible. Our health care team will strive to:

- Offer a calm, quiet and comforting environment
- Treat your child with respect and honesty
- Provide age-appropriate care
- Offer age-appropriate toys, books or music in order to create a healing environment

The PICU staff will give you detailed information about the PICU and available resources. The information below answers some common questions.

Visitation

Visiting hours are 6 a.m. to 10 p.m.

Parents, siblings older than 12 years of age and primary caregivers may visit during this time. Siblings under the age of 12 may not visit unless approved by a Stem Cell doctor. Only 2 people can be in the child's room at the same time. After 10 p.m., only one family member is allowed to stay in the child's room. Beds are available if the parent wants to sleep in the child's room. Sometimes, parents and visitors may be asked to leave the room during procedures.

All visitors must wash their hands thoroughly before entering and leaving the unit. This helps limit the spread of germs.

We understand that there may be times when you are unable to be with your child. You may call your child's nurse or doctor for an update at any time.

Helping Your Child Feel More Comfortable

You may bring a few items for your child from home, such as a favorite stuffed animal, toy, music or game to help your child feel more comfortable.

You are welcome to take part in your child's care under the guidance of your child's nurse. Talk with your child's nurses to learn more.

Phone Calls

There is a phone in each inpatient room. Public phones are also available in the visitors' lounge. When using an MD Anderson phone to call an MD Anderson phone number, you only need to dial the last 5 digits. For local calls within Houston, first dial "9" and then the area code and telephone number. For long-distance calling card, credit card or overseas calls, dial "0."

Cell Phones

Cell phone use is **not** allowed inside the PICU patient care area. These could interfere with medical devices.

Special Care for Patients under 1 year of age

Sometimes, children under the age of 1 year may require even more specialized care. If this is the case, your child may be transferred to the PICU at Hermann Children's Hospital for their care. It is located at 6411 Fannin St., Houston, Texas 77030.

While there, your child will be seen by the MD Anderson pediatric bone marrow transplant doctor daily and direct his or her care. MD Anderson and Hermann Children's Hospital share many of the same doctors.

Infection After Stem Cell Transplant

Pediatric Stem Cell Transplant and Cellular Therapy

After your child's transplant, he or she is more likely to get an infection. This is because your child's resistance is low and his or her body cannot fight off infections very well. Your child's immune system (part of the body that fights infection) will remain very weak for 6 months to 2 years after his or her transplant.

The different types of infection that your child is more likely to get during the first year following his or her transplant include:

During Month 1	Herpes simplex Bacterial Fungal
During Months 2 to 3	Cytomegalovirus (CMV), other viruses Bacterial Fungal Pneumocystis carinii pneumonia (PCP)
During Months 4 to 12	Varicella zoster Bacterial Fungal Pneumocystis carinii pneumonia (PCP)

At the first sign of any of the changes listed below, report them to your child's doctor or nurse right away. Do not try to "tough it out" until your child's next appointment. If you notice other changes not listed here and you are not sure what to do, call your child's doctor or nurse for advice.



Fever is usually the first symptom of infection. Call your child's doctor or if your child develops a temperature of 101°F (38.3°C) or higher.

Changes in Skin

- Sores or redness at your child's catheter site.
- Skin rashes, blisters, or mouth sores.
- An infected hangnail or skin around your child's toenails or fingernails (look for redness and swelling).
- Irritation or sores around his or her genitalia or rectum.

Changes in Bowel Movements or Stool

- Loose, watery stools and stomach pain.

- Pain during bowel movements.
- Blood in the stool.

Respiratory Problems

- Shortness of breath, coughing up sputum (excess mucous or phlegm).

General Problems

- Headache or inability to bend your neck forward
- Sore throat, difficulty or pain when swallowing
- Earache
- Chills and fever
- Pain when your child urinates or if urine appears darker than normal
- Blood in the urine
- Blood in the stool or vaginal bleeding
- Any other bleeding such as nose bleeds
- Weight loss

Please refer to the "Discharge Information" sheet in the Pediatric Stem Cell Transplant Guide for more information about preventing infections.

Discharge Information

Pediatric Stem Cell Transplant and Cellular Therapy

Your child has had a stem cell transplant and is about to leave the hospital. There are some very important rules you and your child need to follow for the first 100 days after transplant. After day 100, talk with your child's doctor about what you can do.

How can I help my child prevent infections?

Do these things to help your child prevent infections:

- Wear a facemask and gloves when you leave home or the hotel.
- Wash your hands with soap and water before eating or handling food, after going to the bathroom, and after being outside.
- Ask people who are taking care of you to wash their hands.
- Eat canned and cooked fruits and vegetables, such as fruit cocktail and canned corn.
- Order your food (meat, seafood and other foods) well done when eating in a restaurant.
- Tell your child's nurse if he or she has been around someone who has the chickenpox, shingles, or measles.

Do Not let your child do these things:

Do Not Eat:

- Any raw meat or raw oysters.
- Any raw eggs.

Do Not Go:

- Near sick people.
- Near babies who have had their immunizations within the last month.
- To dusty-like places such as construction sites or house remodeling sites.
- Near fresh flowers or plants.
- Any place where there will be crowds of people, such as stores, shopping malls, movie theaters, restaurants, parties, school, churches, buses, etc.

Do Not:

- Play in the dirt or in a sandbox.
- Swim in public pools, lakes, or the ocean for 1 year after the transplant.
- Sit in a jacuzzi (hot tub).
- Go near animals, especially those that live outside.
- Touch animal droppings or go near litter boxes.

What can I do, as a parent or caregiver, to help prevent infections?

- Wash my hands with soap and water before eating or cooking.
- Tell others who come in contact with me or my food to wash their hands thoroughly.
- Use soap and water to wash the food preparation area and all utensils and dishes, before I start cooking.

Are there other special instructions I need to tell my child?

- **Do not** spend more than 30 minutes in the sun at a time.
- **Always** use sunscreen with a SPF of 30 or greater.
- Wear a hat and a long-sleeved shirt if possible.
- **Talk with your child's doctor about when your child should or should not wear his or her contact lenses.**
- Eat dairy foods (milk, cheese, ice cream) little by little. These foods may cause diarrhea.
- Maintain your weight by eating high-calorie foods.
- **Do not** stop taking your medicine without talking to your doctor.

Your child may be discharged with medicines that require a pump. Please ask your nurse about a complete set of pump instructions before you go home.

Clinic Visits

- After your child's discharge from the inpatient unit, he or she will need to return to the Robin Bush Child and Adolescent Clinic in the Main Building, Floor 7, near Elevator C often to have blood work, physical exams, and other tests as needed.
- Your child will be watched closely for any signs of infection or any other side effects or problems after the transplant.
- If your child has had an allogeneic transplant, he or she will be checked closely for any signs of graft versus host disease (GVHD).
- A bone marrow aspirate will be done from time to time to see how well the new cells are growing and to see if the new cells are the donor's cells.
- If your child is having tacrolimus blood levels drawn and or a blood test for CMV (cytomegalovirus), it is very important to check-in at the clinic no later than 8:00 a.m. on the day of his or her appointment. This ensures that accurate results are obtained on the same day.
- Your child may still need platelet or red blood cell transfusions after their discharge. Certain transplant patients also need a weekly or monthly IVIG (immunoglobulin G) infusion. Blood, platelets and intravenous infusions are given in the Pediatric Ambulatory Treatment Center (PATC), located in the Main Building, on Floor 9 near elevator F in the Meadows pod.
- Your child's infusion is a scheduled appointment. The PATC's hours are from 8:30 a.m. to 7:00 p.m. Monday through Friday. All infusions must be completed by 7:00 p.m. so please arrive on time to ensure adequate time for treatment.

Discharge Checklist

Pediatric Stem Cell Transplant and Cellular Therapy

Discharge after stem cell transplant can be an exciting and stressful time for most families. Your inpatient and outpatient team will plan for your child's discharge long before the day arrives. It is a team effort between the care team and you. Below is a checklist to help you prepare for your child's discharge and prompt you to ask any questions you may have before you take your child home.

CVC

- Have you attended 2 CVC care classes in the infusion therapy clinic **and** been checked off by a member of the IV team so that you are able to care for your child's central venous catheter (CVC) at home?
- Can you change the dressing weekly and flush each lumen daily with heparin?

Medicines

- Have you picked up your child's outpatient medicines from the pharmacy?
- Has each medicine been reviewed by a member of the team including the times of when to take the medicines, the doses and possible side effects?
- Do you know which medicines to stop before the blood lab draws in clinic?
- Will your child leave the hospital with IV fluids or antibiotics? Do you feel certain that you can give those medicines at home on your own or do you need help with home assistance?

Supplies

- Do you have a working thermometer at home to check your child's temperature regularly?
- Do you have all the supplies you need for CVC care, such as dressing change kits, heparin and saline flushes, alcohol wipes, and gloves?
- Does your child need any other supplies to help monitor their care, such as blood pressure machine?

Emergency Plan

- Did you receive an Emergency Wallet Card with information about your child's transplant and instructions for care providers outside of MD Anderson on how to care for your child?
- Do you have a plan for how you and your child will stay within 30 minutes of MD Anderson?
- Is anyone at home sick? If so, do you have a plan for keeping your child (the patient) away from those who are sick?

Just like in the hospital, your child will need a constant primary caregiver to ensure that medicines are given on time and to monitor for any possible problems. Signs and symptoms to report include:

- Fever greater than 100.7°F (38.3°C)
- Diarrhea
- Skin rash
- Uncontrolled pain,
- Nausea or vomiting
- Any exposure to a person who is ill

You know your child better than anyone, so if you have doubts about your child's health status, please call your care team.

Robin Bush Child and Adolescent Center

Monday through Friday, 8 a.m. to 4 p.m.
713-792-6610

Nights, Weekends and Holidays
Children's Cancer Hospital Inpatient Unit
713-792-5173 or 713-792-5149

Discharge Questions/ Notes:

Daily Monitoring Record

Pediatric Stem Cell Transplant and Cellular Therapy

	INTAKE			OUTPUT			
Time	Fluids	Food	Medication	Urine	Bowel Movement (Color/Diarrhea?)	Nausea or Vomiting	Temp
6:00 a.m.							
7:00 a.m.							
8:00 a.m.							
9:00 a.m.							
10:00a.m.							
11:00a.m.							
12:00 noon							
1:00 p.m.							
2:00 p.m.							
3:00 p.m.							
4:00 p.m.							
5:00 p.m.							
6:00 p.m.							
7:00 p.m.							
8:00 p.m.							
9:00 p.m.							
10:00p.m.							
11:00p.m.							
12:00 midnight							
1:00a.m.–5:00a.m.							

In the Last 24 Hours:

Did your child have any pain? If yes, where? _____

How did your child feel in general? _____

Are there any questions you want to ask your child’s doctor? If yes, please write them here. _____

When to Call Your Doctor

Pediatric Stem Cell Transplant and Cellular Therapy

You may have doubts about when to call your child’s doctor. If you are not sure, it is better to call and ask for advice. Contact your child’s doctor if he or she has any of the following:

<p>General Problems</p> <ul style="list-style-type: none"> • Unusually tired or irritable • Not feeling very good • Feel very weak • Not urinating for 8 hours • Chills and shakes 	<p>Fever Fever above 101°F (38.3°C)</p> <hr/> <p>Seizures Any seizures</p>
<p>Respiratory Problems</p> <ul style="list-style-type: none"> • Shortness of breath • Frequent cough • Chest congestion 	<p>Change in Level of Consciousness</p> <ul style="list-style-type: none"> • Loss of consciousness • Difficulty in waking up • Confusion
<p>Bleeding Problems</p> <ul style="list-style-type: none"> • Blood in his or her urine, stools, or vomit • External bleeding (from nose or a cut or sore) that does not stop with pressure after 10 to 15 minutes 	<p>Skin Changes</p> <ul style="list-style-type: none"> • Yellowing of your skin or in the whites of your eyes • Red rash on the palms of his or her hands or on the soles of his or her feet
<p>Nausea and Vomiting</p> <ul style="list-style-type: none"> • Repeated nausea and vomiting • Not able to keep fluids down 	<p>Pain Severe pain in your chest, belly, back, bones, or head</p>
<p>Signs of Dehydration</p> <ul style="list-style-type: none"> • Dry and cracked lips • Dry eyes and no tears • Sticky, rough, red, and dry tongue • Mouth feels sticky • Not urinating for 8 hours; urine color appears darker • Very dry skin • Feels weak, tired, and sleepy • Cold fingers and toes 	<p>Emotional Problems</p> <ul style="list-style-type: none"> • Feeling blue or depressed for more than a few days • Lack of interest in activities or surroundings • Mood changes (frequent crying) • Feeling anxious or nervous • Sleep disturbances
<p>Weight Loss Weight loss of more than 3 pounds (about 1.4 kg) in between clinic visits or greater than 5 pounds (2.3kg) over a one-month period.</p>	<p>Bowel Movement or Stool Changes Watery diarrhea 4 or more times a day</p>

Outpatient Prescription Services

Pediatric Stem Cell Transplant and Cellular Therapy

Outpatient Prescription Services

Main Building, Floor 2, near Elevator C
 713-792-6125

Monday through Friday, 8 a.m. to 8 p.m.

Saturday, 8 a.m. to 6 p.m.

Sunday, 8 a.m. to 5 p.m.

Holidays, call the pharmacy for hours

Main Building, Floor 10, near Elevator B
 713-745-7180

Monday through Friday, 8 a.m. to 7 p.m.

Closed Weekends and Holidays

Waiting Times

- Waiting times are shortest in the mornings before 11 a.m. Between 11 a.m. and 5 p.m., expect a wait time of about 2 hours.
- Friday is usually a very busy day for the outpatient pharmacy, so it is best to refill on other days.
- IV medicines or any medicines that must be mixed by pharmacy require extra time to prepare.

Refills

- When your child has less than a week’s supply of medicine, you should refill the prescription.
- Look on your child’s medication bottle to see if a refill is available. If so, call the outpatient pharmacy and request a refill. You must know the prescription number (on the medicine bottle) to get the medicine refilled.
- If you do not have a refill available, contact your child’s doctor, nurse or pharmacist to give you a new prescription.

The University of Texas	
M. D. Anderson Cancer Center	
1515 Holcombe Blvd., Houston, TX 77030 (713) 792-6125	
Prescription Number	RX 1700001
	Chan, KW 07/14/99
	Patient Name MR#
	Fluconazole Tablet
	INV #30
	Take 1 tablet orally every day.
	RPH:
	2 Refill Authorized

Doctor's Name and Date of Prescription

Number of Refills Left

Prescription Label
 ©MD Anderson Cancer

Outside Pharmacies

- You can fill any MD Anderson prescriptions at an outside pharmacy, **but call ahead to make sure they stock the medicines.**
- Some prescription plans require you to fill prescriptions at outside pharmacies.

Other Tips

- Find out if your medical insurance includes a prescription plan. If it does, learn about the plan and find out where you can have your prescriptions filled. Ask to speak with your child's case manager or a pharmacist to help you understand your prescription plan.
- When you pick up the medicine, you may be asked to pay a co-pay or service charge for the prescription or to pay in full for the prescription, depending on your medical insurance plan.

Stem Cell Transplant Glossary

Absolute neutrophil count (ANC): 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 (Living Will)
- Power of Attorney for Healthcare
- Out-of-Hospital Do Not Resuscitate (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 (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 (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/patient and then circulated through a machine that separates stem cells. The remaining blood is given back to the donor/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 (ABMT): 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 (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.

Cyclosporin (SY-klo-spor-een): A drug used to help reduce the risk of organ or bone marrow rejection (graft-versus-host disease) by the body. It is also used in clinical trials to make cancer cells more sensitive to anticancer drugs.

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 (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 (e.g., fever, 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 (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 (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 (HLA) 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 (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 (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 (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 (WBC).

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 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 (NK cell): 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 (PBSC) (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 (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 (RBC): 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 (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): 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.

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

White blood cells (WBC): 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>

Resources for Stem Cell Transplant Pediatric Stem Cell Transplant and Cellular Therapy

Below is a list of available resources for 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.

MD Anderson Resources

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](https://mychart.mdanderson.org). To create an account, call askMDAnderson at 877-632-6789.

The Integrative Medicine Center

The Integrative Medicine Center at MD Anderson Cancer Center is an environment where all persons touched by cancer may enhance their quality of life through programs that complement medical care and focus on the mind, body and spirit. The IM Center offers more than 75 complementary therapy programs. Most programs are offered free of charge, except acupuncture and full body massage, which require a nominal fee.

The IM Center is open to anyone touched by cancer, their family members and caregivers, whether or not they were treated at MD Anderson. No physician referral is required. For more information, please call 713-794-4700.

Beauty/Barber Shop

The Beauty/Barber Shop offers patients shampoos, haircuts, shaves, as well as wigs, scarves and hats to all current MD Anderson patients. Services are provided by Volunteer Services at no charge. Appointments are not necessary. The shop is located in the Main Building, Floor 6, near Elevator E and F, Room G6.3253. To learn more, call 713-792-6039.

Kim's Place

Kim's Place offers patients and visitors, ages 13-30, a unique place to hang out at MD Anderson. Visitors can play games, socialize and watch movies and TV. It also offers a quiet space for vocational and group counseling, as well as secondary and high school classes. Kim's Place is located in the Main Building on Floor 2, in The Park, Room B2.4309. Hours vary based on staffing.

Survivorship

Survivorship care is designed to prevent, detect and treat complications resulting from cancer or its treatment. Through the Child and Adolescent Center survivorship clinic, survivors will receive care based on specific guidelines designed for survivors who have been treated at MD Anderson. The clinic addresses physical and psychosocial care.

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 about volunteering, call 713-792-JOIN (5646) or visit our website at www.mdanderson.org/departments/volunteer.

myCancerConnection, a program of the Department of Volunteer Services, offers hope, support and understanding to all others challenged by cancer from those who have been there. For more information on myCancerConnection and its many programs, call 713-792-2553 or 800-345-6324, visit our website at www.mdanderson.org/myCancerConnection.

Visit our Hospitality Centers which are staffed by friendly cancer survivors who can offer a fresh pot of coffee and interesting conversation.

Hospitality Center – Main

Main Building, Floor 2, near The Sundial
Monday through Friday, 9 a.m. to 3 p.m.

Hospitality Center – Mays Clinic

Mays Clinic, Floor 2, near The Tree Sculpture
Monday through Friday, 8 a.m. to 3:30 p.m.

The Learning Center

The Learning Center is a patient education library. We provide 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 Assistance...We Speak Your Language

The Language Assistance department provides high-quality medical interpretation services to non-English speaking patients and hearing-impaired patients. To ensure patient safety and exact translations, staff **cannot** use family members as translators. Patients may call Language Assistance, Monday through Friday, 8 a.m. to 5 p.m., at 713-792-7930 or after hours at 713-792-7090.

The International Patient Center

Many patients coming to MD Anderson Cancer Center are from outside the United States. International Patient Center services include the following:

- Help to orient and transition patients to the hospital system
- Assist with the cultural and linguistic needs of patients
- Help patients find appointments, complete registration forms, understand how the care centers work and informing patients of special services
- Arrange for patients to meet with a financial counselor to help make financial arrangements for care
- Help patients with concerns, anxieties or fears about diagnosis or treatment
- Direct patients to appropriate resources and services
- Assist and answering questions about staying in Houston

The International Patient Center can be reached Monday through Friday, 8 a.m. to 5 p.m., at (713) 745-0450. From Mexico, call 1-800-811-6167.

Adolescent & Young Adult (AYA) Program

The Adolescent & Young Adult (AYA) Program offers a variety of services for patients, ages 15 to 29 years whether in active treatment or post-therapy survivorship. This program offers comprehensive, focused services and care specifically designed for adolescent and young adult patients and consists of physicians, nurse practitioners, social workers and vocational counselors. Together, they address the unique set of challenges for teens and young adults such as onco-fertility and fertility preservation, genetic testing and survivorship.

The AYA program also offers:

- Educational and vocational assessments
- Counseling to help with self-esteem, body image, emotions, health behaviors and other issues
- Social work and assistance identifying financial support
- Peer support

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.

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. Depends on 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 transplant and publications designed to help you understand and deal with the logistics of bone marrow transplant, finances and medical insurance. It includes commonly asked questions, BMT survivor stories and peer support information.

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.

Whole Blood Donation

Why is blood needed?

Cancer patients may require blood and blood components because of their disease or sometimes because of the required treatment.

Who is eligible to donate?

The following information lists the general requirements for donating blood:

- At least 17 years old
- In good general health and feeling well
- Weigh at least 110 lbs.
- Have a photo ID
- Not be pregnant

Most medicines are acceptable, including blood pressure, cholesterol, diabetes, thyroid and anxiety/anti-depressants. Call the Blood Bank if you have a concern about a medicine you take.

How often can blood be donated?

Persons in good health can donate whole blood every 8 weeks. Single donor platelets can be collected every 2 days, up to 24 times a year.

Are there risks in giving blood?

Almost none. It is **not** possible to catch any disease by donating blood, including AIDS or hepatitis. Disposable, sterile equipment is used for each donor. A very small number of donors may experience mild discomfort during or right after donating.

What do I need to do before I donate?

- Read all of the donor information carefully, especially travel restrictions.
- Complete a short Donor History Questionnaire, which includes your name, address, phone number, etc.
- Our staff will review your medical history in a private setting and take your blood pressure, temperature, pulse rate and hemoglobin level.

Do I need to know my blood type?

You do not need to know your blood type.

How long does it take?

The donation process takes about 30 to 45 minutes.

What happens next?

- You will sit in a donor chair and your arm will be cleaned with an antiseptic.
- A technician will apply a tight band around your arm. A needle will be inserted into a vein in your arm. All supplies are sterile, used only once and thrown away.
- We will collect about 1 pint of blood.
- When you are done, a bandage will be wrapped around your arm to stop the bleeding. You will stay in the donor chair until the staff release you to go.

Do I need to follow any special instructions after I donate?

The staff will give you instructions to follow. You will also receive a snack and drink to help replace lost fluids. Most persons do not have any discomfort after donation. It takes your body about 24 hours to replace the plasma from your donation and about 6 to 8 weeks to replace the red blood cells.

Please follow these suggestions to reduce your risk of a reaction:

- Eat well for the next 24 hours.
- Increase your fluid intake for the next 24 to 48 hours.
- Do not smoke or chew tobacco for 30 minutes.
- Do not lift heavy objects or perform strenuous physical activities for at least 12 to 24 hours.
- Leave your bandage on for at least 4 hours.

What happens to the blood?

After collection, the blood is placed in a machine and separated into components (Red Blood Cells, Plasma and Platelets). This process allows your donation to help up to 3 patients. The blood is then tested in our lab for safety. Blood is tested for:

- Blood type and Rh factor
- Hepatitis (B and C)
- HIV/AIDS viruses
- Syphilis (RPR)
- HTLV I and II viruses (Human T-cell Lymphotropic virus)
- West Nile Virus (WNV)

Test results are confidential. Donors are notified **only if a problem is detected**.

Once blood components are tested and deemed safe for transfusion, they are readily available for use with MD Anderson patients.

How long is donated blood kept?

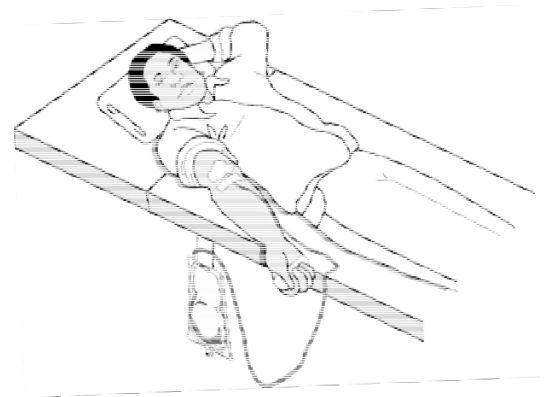
Donated blood is kept for a maximum of 42 days.

What is an “in honor” donation?

Family and friends may donate blood in honor of their loved one. Patients receive a monetary credit issued to their account for every successful donation. MD Anderson does not provide direct blood donations. This means we do not reserve blood donations by family members or friends for a specific patient. Each patient is transfused with the best matched blood product for their needs from our supply of volunteer blood donors. All blood donations help to ensure an adequate blood supply for all our patients.

Can a patient donate his/her own blood?

In special cases, a patient may donate blood for him/herself only if approved by the patient’s doctor and the blood bank doctor.



Where can I donate blood at MD Anderson?

Blood Donor Center – Main Building, Floor 2, near Elevator D

1515 Holcombe Blvd. Houston, TX 77030

Sunday, 10:00 a.m. to 3:00 p.m.

Monday through Friday, 10:00 a.m. to 5:00 p.m.

Saturday, Closed

Blood Donor Center – Mays Clinic, Floor 2 near the Tree Sculpture

1220 Holcombe Blvd., Houston, TX 77030

Tuesday through Thursday, 9:00 a.m. to 4:00 p.m.

Blood Donor Center – Holly Hall

2555 Holly Hall St. Houston, TX 77054

Tuesday – Thursday, 10:00 a.m. to 6:00 p.m.

Friday through Monday, 10:00 a.m. to 5:00 p.m.

How do I host a blood drive in my community?

MD Anderson mobile units are available for community blood drives at churches, businesses and schools. Contact a blood bank community representative at 713-792-7788 to learn more.

For more information about blood donation, please call 713-792-7777 or visit our website at <https://www.mdanderson.org/donors-volunteers/other-ways-to-help/give-blood.html>.