

UCLA Pediatric Bone Marrow Transplant Program



UCLA



Childrens Hospital

UCLA Pediatric Bone Marrow
Transplant Unit

Preparing for transplant

Protecting your health

Transplant day: what to expect

Getting ready to go home

Additional resources

Glossary of medical terms

Questions for my care team



Dear patient and family,

Welcome to the UCLA Mattel Children's Hospital Bone Marrow Transplant (BMT) Unit. We understand that the transplant process can be a difficult and confusing experience for patients and their families. We want to take this opportunity to assure you that we are committed to treating you and your family with compassion, respect and the best care possible.

As one of the most experienced transplant programs in the nation, our pediatric BMT unit is specifically designed with the needs of children, teens and young adults in mind. Our team will provide you all the support, information and guidance you will need — beginning with a thorough health evaluation.

Over the next few days, you will meet members of the transplant team who will be taking care of you during your hospital stay. This will be a very busy time for you and your family. You will receive a lot of information from doctors, nurses and social workers. We have designed this handbook to help you better understand the transplant process and provide a way for you to organize materials about your treatment, care team and other vital information. We encourage you to use this handbook to write down any notes or questions you may have. You will find blank paper at the end so you can keep track of your questions as they come up. Bring this handbook with you to your appointments so you can track your health and organize your information.

If you have any questions, please do not hesitate to reach out to your health care team. We look forward to accompanying your family through this journey, every step of the way.

Sincerely,

Your pediatric bone marrow transplant team

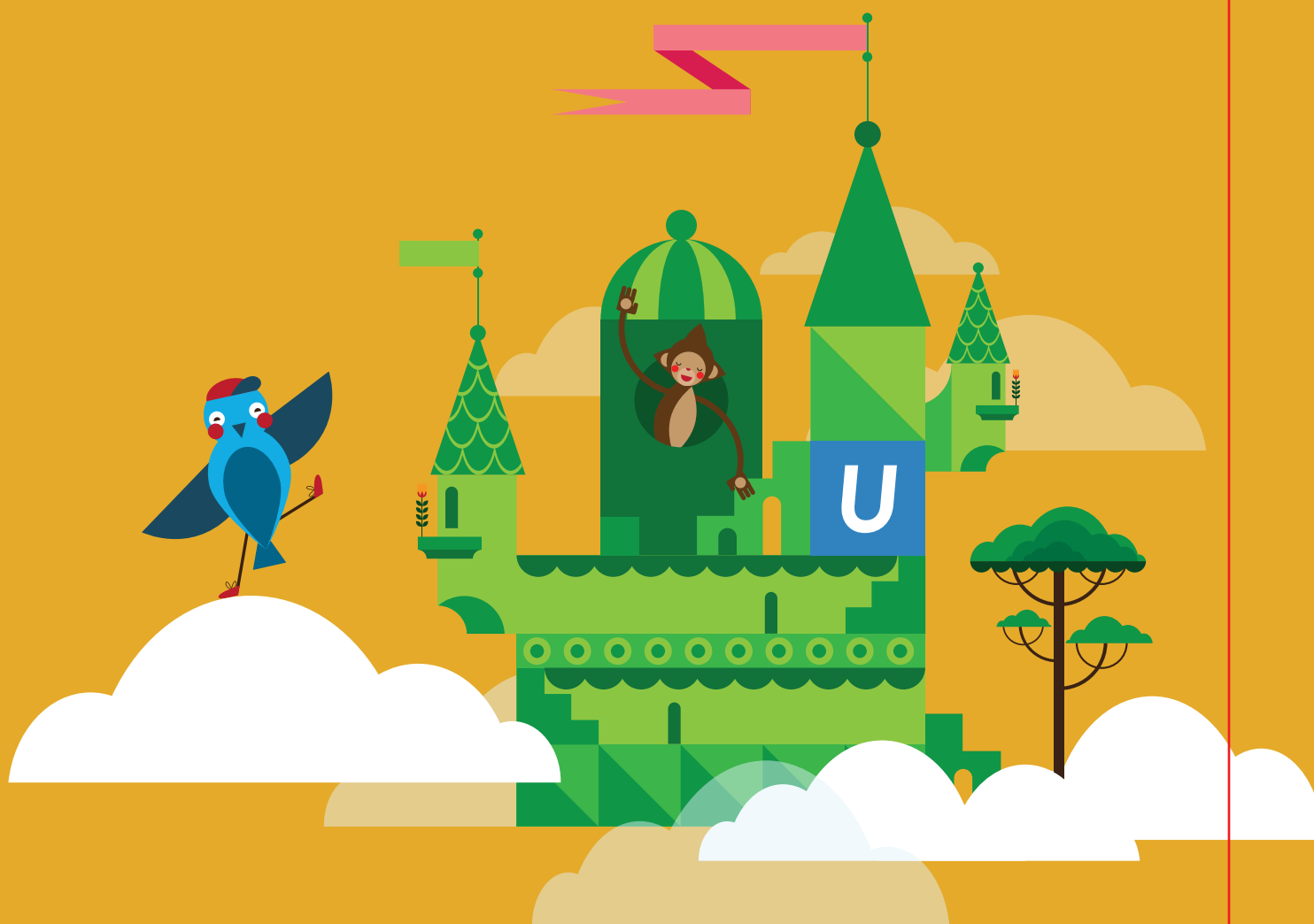
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“Why fit in when you were
born to stand out?”

— Dr. Seuss





UCLA Pediatric Bone Marrow Transplant Unit

What is bone marrow/stem cell transplantation?

Bone marrow — soft, spongy tissue found inside the bone — produces blood cells that make up the immune system. All blood made in the bone marrow starts out as stem cells. The transplant itself may be referred to as a “stem cell transplant” (SCT) or a “bone marrow transplant” (BMT); they are used interchangeably.

While patients in our BMT unit may be undergoing similar treatments, different patients have different care plans, and each patient’s body responds to treatments differently. So please keep in mind that even though other patients receiving bone marrow transplants may have a similar treatment plan to yours, you will most likely have different experiences. If at any point you have questions or concerns, please speak to your health care team.

There are two main types of bone marrow/stem cell transplants:

- **Autologous (self-donation):** This means you are receiving your own bone marrow, stem cells or cord blood. After you donate, it is frozen and stored for your infusion at a later date.
- **Allogeneic (someone else donates):** A donor, such as a parent, sibling or nonrelative selected from a national registry, provides the stem cells, bone marrow or cord blood for your transplant.



What are stem cells?

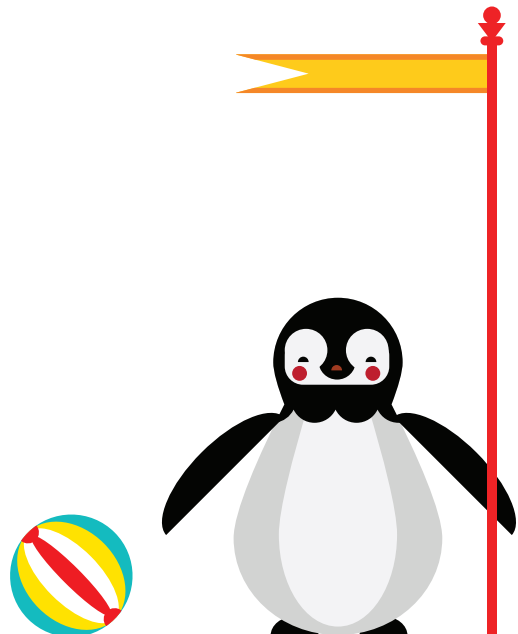
Stem cells are a special kind of cell that form in the bone marrow. As they mature, they develop into three different kinds of blood cells:

- **Red blood cells**, which carry oxygen throughout the body;
- **White blood cells**, which fight infections; and
- **Platelets**, which help your body form clots to stop bleeding.

Stem cells can be collected from a related donor, an unrelated donor or from you.

What is cord blood?

Cord blood is a source of stem cells for transplant; it is collected from the umbilical cord of a baby. After having a baby, parents can choose to donate their baby's cord. If the parents decide to donate, the blood is collected from the cord and then frozen and stored until it is matched to someone who needs it.



Pediatric BMT unit guidelines

Compliance with the transplant regimen plays a large role in the success of a pediatric bone marrow transplant. For the safety of our patients, the transplant team requests your cooperation with the guidelines below. When patients are admitted to the unit for their transplants, they will be required to initial and sign a contract, indicating that they understand the unit guidelines and agree to comply with the following requirements:

Visitation policies

- **Parents and caregivers may visit 24 hours a day.** However, no more than four people (two parents/caregivers and two visitors) are allowed in the patient's room at one time.
- **Two parents/caregivers (over age 18) are allowed to sleep in the patient's room overnight;** however, only one sleeper bed is provided in each room. A reclining chair may be available. Please check with your nurse if you have any questions about sleeping arrangements.
- **Visitors younger than 13 years old will not be allowed on the unit.** They are only permitted access to the lobby level (first floor).
- **Visitors between the ages of 13 and 17 years old must be supervised** by an adult family member at all times. No one under the age of 18 is permitted to spend the night at the hospital.
- **All visitors must be screened at the nursing station for symptoms of infection** (e.g., cough, runny nose, sore throat, fever) before entering the unit. To protect the patient's health, parents/caregivers and visitors with symptoms of infection will not be allowed to visit or stay.
- **Unvaccinated persons are not allowed on the unit.** This includes people who have not received the flu vaccine during the flu season. This policy protects our BMT patients' new immune systems.
- **Visitations from personal pets are not permitted.** Dogs within the hospital-sponsored visitation program will have some limited access to the hallways on the unit.



Infection control guidelines

- **Caregivers and visitors are required to wash their hands** with soap and water for 15 seconds when entering and leaving the patient's room. The alcohol hand rub provided in the room may also be used for 15 seconds.
- **Caregivers and patients are not allowed to visit other patients.** This is to protect all patients on the unit. The patient cannot walk the hallways until an attending physician has medically cleared them.
- **Parents and visitors may not use the patient's bathroom,** unless the patient receives bed baths and does not use the toilet/shower. Bathrooms for parents/visitors are located outside of the unit at the end of the main hallway. Showers for parents are available on the fifth floor. Your nurse will show you where they are located.
- **Food safety:** Food stored in the refrigerator must be discarded after 48 hours.
 - All food must be labeled with the date and time it is placed in the refrigerator.
 - Frozen foods must be transported frozen, may only be heated once, and must be eaten within four hours.
 - Once opened, nonfrozen, individually bagged items (e.g., chips, cereals, snacks) must be eaten within 24 hours.
 - Home-prepared foods will only be allowed with an attending physician's approval.
- **Keep your room clutter free.** If the room has clutter, you will be asked to take it home or it will be discarded. All toys should be able to be wiped down.
- **Home bedding (e.g., sheets, pillowcases) must be changed every day.** Home blankets must be washed weekly.
- **No home appliances are allowed on the unit.** All personal medical appliances are subject to facilities checks and approvals.



Your transplant team

Doctors

Attending physician: An attending physician who specializes in hematology-oncology will oversee your care. The attending physician will visit you at least once a day to do a physical exam and answer any questions you may have. As the leader and most senior-level member of your health care team, the attending physician is in charge of planning your treatment and coordinating your care with all members of the transplant team.

Fellow and resident: UCLA is a teaching institution. Therefore, the attending physician will be assisted by a hematology-oncology fellow and a pediatric resident. The fellow is a physician who has completed medical school, an internship and a residency as a pediatrician, and is now receiving specialized training in hematology-oncology and bone marrow transplantation. The resident, a medical trainee who has an MD, works closely with the fellow and will be responsible for writing your daily orders.

Surgeon: A surgeon is a physician who specializes in physical procedures and operations. For example, if you do not already have a central line (see section 2) when you come to the hospital for transplant, a pediatric surgeon will place one.

Radiation oncologist: If radiation is part of the treatment plan, a physician who specializes in radiation oncology will administer radiation therapy.

Dentist: A pediatric dentist cleans and examines your teeth before transplant.

Nursing team

Transplant coordinator: The transplant coordinator is a registered nurse who helps the attending physicians coordinate your pretransplant evaluation. The transplant coordinator will educate you and your family on the bone marrow transplant process and answer any questions you have before you are admitted to the hospital.

Nurse practitioner (NP): A nurse practitioner is a registered nurse who has completed advanced training and can perform physical exams, manage medications and devices, write prescriptions, order and check your labs, and provide education. You will meet the NP during your first visit to discuss transplant with your doctor. You will see the NP more often after transplant when you go to the clinic for your follow-up care.

Unit director: The unit director oversees all financial and administrative functions on the BMT unit. The unit director is responsible for the unit 24 hours a day and is always available if you have any questions, problems or concerns.

Registered nurse (RN): Your registered nurse is experienced in caring for children, teens and young adults who are receiving bone marrow transplants. They have specialized skills and knowledge about the transplant process. They are responsible for helping you with your daily routines (medications, dressing changes, etc.), answering questions about treatment, educating you and your family prior to discharge, and coordinating care with all of the transplant team members.

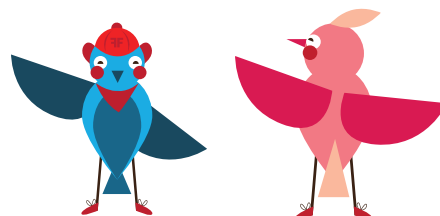
Clinical care partner (CCP): Clinical care partners are certified nurse assistants who help the registered nurse take care of you. They will measure your vital signs (blood pressure, heart rate, respiratory rate and temperature), and will help you with your meals, bathing, bedding changes and bathroom needs. They can also help get any supplies you may need.

Psychosocial team

We understand that illness and an upcoming bone marrow transplant can be a great source of stress for patients and their loved ones. Because bone marrow transplantation usually involves a lengthy stay at the hospital, the psychosocial team is an important part of your care team.

Social worker: A clinical social worker helps families minimize the disruption of “normal” life that long hospital stays can cause. Social workers also provide counseling for you and your family, as well as information about support groups or other cancer-related services. Other items your social worker can help you with include:

- Housing near UCLA
- Parking
- Disabled placards
- Transportation
- Co-pay assistance programs
- Psychosocial support
- Disability benefits
- Other resources



Child life specialist: UCLA child life specialists are trained in child development and work to promote coping and recovery through play and activities. They help you select games, books, toys, movies or other activities that you might want during your stay. If you are scheduled for a procedure (e.g., a bone marrow biopsy or lumbar puncture), the child life specialist will help get you ready for the procedure and can stay with you during the procedure. Volunteers are also present on the unit and are available to spend time playing or talking with you.

Psychiatrist/psychologist: A psychiatrist or psychologist will visit you and your family to see how you are doing emotionally throughout your hospital stay. They can teach relaxation techniques and are available to talk with you about your thoughts and feelings.

Case manager: Case managers work with you, your family and your health care team to coordinate your stay. They are also available to assist with the planning and coordination of your transition home or to other care facilities.

Consulting teams

Infectious disease: The infectious disease team comprises doctors who specialize in diagnosing and treating diseases caused by bacteria, fungi and viruses. Our infectious disease team closely follows all of our patients throughout the transplant process, as they are at higher risk for developing infections due to their weakened immune systems.

Pediatric pain and comfort care service: The pediatric pain and comfort care team includes medical, behavioral and spiritual care clinicians, who work closely with you, your family and the health care team to help alleviate pain and other symptoms experienced during transplant. The comfort care team provides recommendations for medical and nonmedical treatments to help with pain, nausea, anxiety and other discomforts associated with a bone marrow transplant.

Additional members of your care team

Administrative care partner (ACP): If you press your nurse “call button” during the day, an administrative care partner will answer over the intercom to ask how we can help you. The ACP sits at the first nurse’s station, answers the telephone and greets all visitors who come to the third floor, letting them in and out of the unit. At nighttime, hospital volunteers assist with ACP duties.

Physical therapist (PT): A physical therapist creates a specific exercise program to maintain your muscle strength and endurance while you are in the hospital.

Registered dietitian: The registered dietitian is a transplant nutrition expert who will explain the special low-bacteria diet that you will follow during and after your bone marrow transplant. The dietitian will help you make menu choices and may help monitor your nutritional needs by calculating calorie intake.

Nutrition ambassadors: Nutrition ambassadors bring the meals and snacks that you order and collect the trays later on.

Schoolteacher: A hospital-based schoolteacher will provide school-aged children with a study program during their hospital stay so they can keep up with their classwork. When patients are discharged home, the hospital teacher will help patients and families work with their schools to set up a home-school program.

School reintegration specialist: Following hospital discharge, the school reintegration specialist will help the patient transition back into the classroom and work with the patient's school to make sure they are progressing with their educational requirements.

Escort service: A member of our escort team will take you to any tests or procedures in other areas of the hospital. They will also help move your personal belongings to your caregiver's car when you are discharged.

Environmental services staff (EVS): Our environmental services staff will help keep your room clean, empty your trash and supply your room with hand soap, paper towels and toilet paper.





Know your care team

Use the blank team list below to fill in the names of the people on your care team. Your nurses and care partners will also update the whiteboard in your room every shift so you will know who is taking care of you.

Your care team	Name(s)
Staff nurses	
Care partners	
Environmental services staff	
Transplant coordinator	
Nurse practitioner	
Unit director	
Attending physician	
Fellow	
Resident	
Surgeon	
Psychiatrist/psychologist	
Infectious disease attending	
Comfort care attending	
Dietitian	
Physical therapist	
Clinical social worker	
Child life specialist	
School teacher	
Case manager	



“‘What day is it?’ asked Winnie the Pooh.
‘It’s today,’ squeaked Piglet.
‘My favorite day,’ said Pooh.”

— *The Adventures of Winnie the Pooh* by A. A. Milne







Preparing for transplant

Daily routines

Vital signs

Your temperature, heart rate, respiratory rate, oxygen saturation level and blood pressure are taken every four hours, or more often if necessary.

Weight

Your weight is usually measured once every evening, but more often if necessary.

Blood draws

A nurse will draw blood from your central line between 2 am and 4 am, or at 8 am if you have time-sensitive medication levels. Other lab draws may occur during the day if necessary.

Doctors rounds

Every morning, usually between 8 am and noon, your medical team will visit you and your family to check your condition and coordinate your care.



Bathing

To protect against infection, you will be bathed every day with a special solution called chlorhexidine (CHG). All patients must be cleaned with CHG, except those who are allergic, actively receiving total body irradiation (TBI), have a new lumbar puncture (LP) site, experience skin breakdown, or are younger than 2 months of age.

You will also use an antifungal powder called nystatin every day after your bath or shower. Nystatin powder is used on the dark, moist areas of the body that are prone to fungal growth, such as the armpits and groin (and neck folds for babies).

Central line care

The dressing (bandage) on your central line keeps it clean and dry. The dressing will be changed every two or seven days (or more often in some cases), depending on the type of central line dressing that is recommended by the treatment team. The dressing will be changed after your bath. The central line cap will be changed once a week, or more often if necessary.



Oral hygiene

It is important to maintain good oral hygiene and to continue it throughout your treatment. Mucositis (mouth sores) can be a side effect of conditioning treatments. Mucositis causes redness, tenderness, swelling and sores inside the mouth and on the tongue and throat. If severe, mucositis can cause pain and discomfort and place you at risk for an infection.

Proper mouth care can help decrease the risk of infections:

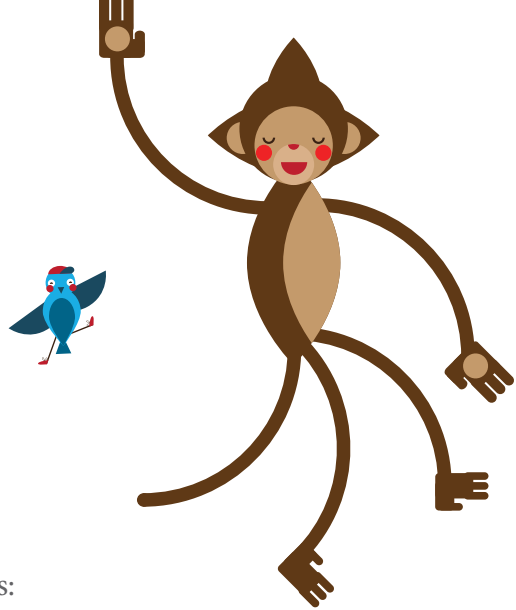
- **Brush your teeth:** Soft, sponge-like toothette swabs will be given to you. You should brush your teeth at least twice a day with the toothettes.
- **Clean your mouth with water and chlorhexidine mouthwash four times a day** — after breakfast, lunch and dinner, and at bedtime. Your nursing team will show you how. After using the mouthwash, wait at least 20 minutes before eating or drinking so it has time to coat your mouth.
- **Ask your nurse about the mouth care bundle.** Using the chlorhexidine mouthwash is mandatory, but we also have other options to soothe mouth discomfort, including “magic mouthwash,” baking soda and normal saline, and cryotherapy.
- **Let your health care team know right away if your mouth feels sensitive or sore.**

Meal hours

You may call extension 79218 or use the “Food Service” speed-dial button on your room telephone to order meals during the following times:

- Breakfast: 6:45 am – 10 am
- Lunch: 10 am – 3 pm
- Dinner: 3 pm – 7:30 pm

The call center can also schedule daily meal times per request. The pediatric BMT unit also has a microwave available. Ask your care partner or nurse if your food needs to be heated. If you do not eat your food right away, it must be refrigerated immediately and may be reheated only once. All precooked food should be thrown away after 24 hours (see section 3).



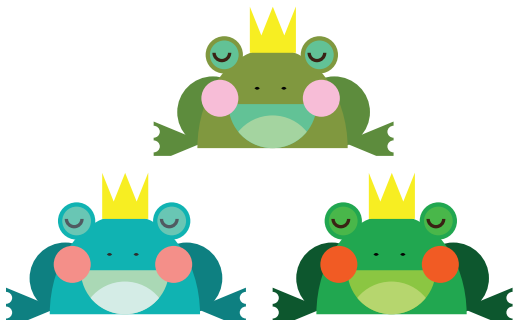
Pretransplant tests and evaluations

Before you undergo pretransplant “conditioning” (chemotherapy, immunotherapy and/or radiation therapy), you will need to complete a series of tests and evaluations. These tests, which examine your heart, lungs, kidneys, liver, brain, mouth and hearing, help the transplant team understand your overall medical condition so they can make sure that your body is able to tolerate the treatment plan.

These tests are usually completed before you are admitted and are conducted over the course of a few days. The types of tests needed will depend on your condition, previous test results and the type of therapy required.

General testing

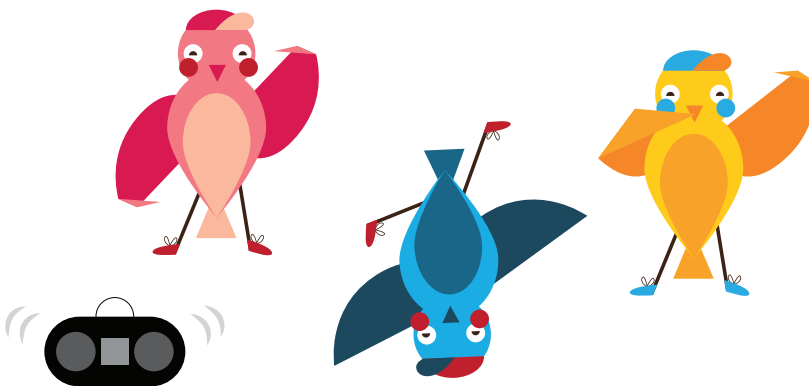
- **Blood tests:** We will try to draw most of these from your central line. These tests will tell us about your red blood cells, white blood cells, platelets, and liver and kidney function.
- **Urine sample:** Urine is collected in a cup and we run tests to see how your kidneys are working. It can also be tested for infection, which is called a urine culture.
- **Electrocardiogram (EKG):** An EKG checks your heart rhythm and shows how your heart is working.
- **Echocardiogram:** An “echo” is a detailed exam of how your heart is working.
- **Pulmonary function tests:** These tests how well your lungs are working by measuring how much air you can breathe in and out at one time.
- **Audiogram:** This is a hearing test that checks how well you can hear, as some chemotherapy drugs and antibiotics can affect hearing.
- **Dental exam:** A complete examination of your mouth and teeth helps prevent oral infections posttransplant.



Patient-specific testing

- **MRI:** This scan shows a detailed picture of normal and diseased tissue in the body. It is mostly used to look at soft tissue. There is no radiation, as a magnet is used.
- **MRV:** A detailed MRI picture of your veins shows if there are any problems with blood flow due to disease or obstruction (i.e., blood clots). The MRV focuses on the head and neck area.
- **MRA:** A detailed MRI picture of your arteries shows if there are any changes in blood flow due to disease or obstruction. As with the MRV, the MRA focuses on the head and neck area.
- **CT:** This scan shows detailed pictures of your organs and tissues. It produces better pictures of hard structures than soft tissues. CT scans use radiation.
- **PET/CT:** A radioactive material is injected into the body through your central line or peripheral IV. That material is then traced to form pictures in a PET scan. It shows the function of tissues and organs. Pictures from both PET and CT scans are combined to see more accurately how a specific area of the body is working.
- **Ultrasound:** A machine that uses sound waves to generate pictures of the inside of your body. Ultrasounds are often used to examine organs such as the kidneys, liver and bladder.
- **Bone marrow aspiration (collection):** A sample of your bone marrow is taken to confirm that you are in remission.

Before you are admitted to the hospital, your doctor will review any abnormal scan or lab results with you.

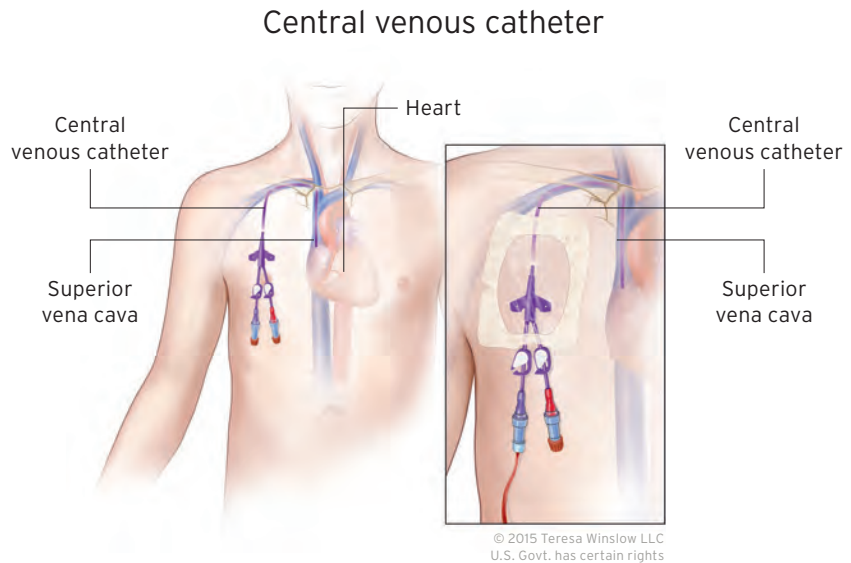


What is a central line?

A central line, also called a central venous catheter (CVC), is a plastic tube that is placed in a large vein that leads to the heart. Throughout the transplant process, the central line will be used for giving chemotherapy/immunotherapy, IV nutrition (if necessary) and other important medications. It is also used to draw blood so you will not have to be “poked” every day for IV initiation or blood draws (although this may be necessary on occasion).

If you do not already have a central line, one will be placed when you are admitted for your transplant.

It is very important to keep your central line and the area around your central line clean. A central line-associated bloodstream infection (CLABSI) can occur when germs (i.e., bacteria, fungi or viruses) enter the patient’s bloodstream through the central line.



To prevent infections, your health care team will:

- Keep your central line clear and free of blood clots by flushing it daily with saline and a medication called heparin.
- Clean their hands, wear gloves and scrub the central line opening with an antiseptic solution before using the catheter or changing the dressing.
- Carefully handle medications and fluids given through the catheter.
- Assess the central line’s dressing throughout each shift to ensure that it is clean, dry and intact; the dressing will be changed every two or seven days, depending on the type of dressing, or more often if necessary.

Your nurses will also teach you and your parents/caregivers the proper care routine, so that you will be able to take care of your central line once you go home.

What patients and families can do to prevent a central line infection:

- Wash your hands before touching your central line or handling your IV lines.
- Keep track of when the next dressing change is due to make sure dressings are changed at the right time (every two or seven days).
- Keep tubing clean and off the floor.
- Perform daily chlorhexidine (CHG) bath treatment to prevent infections.
- Inform your nurse immediately if:
 - The dressing becomes wet or dirty so it can be changed.
 - You feel as if you have a fever or notice swelling, soreness, pain, redness and/or fluid coming from the catheter site.



Tracking intake and output (“Is and Os”)

It is important for the health care team to closely monitor anything that goes in and out of your body, because certain medicines might affect the way your kidneys or bladder function.

- **Intake:** how much fluid you get through the central line, as well as what you eat and drink.
- **Output:** how much you release through your urine, stool and vomit.

You and your parents/caregivers can help us keep track of your “Is and Os” by writing down how much you eat and drink every day.

And please remember: never flush the toilet as your nurse or care partner must first measure and test your urine/stool.



Pretransplant conditioning

To prepare your body for transplant, you will undergo a “conditioning” regimen: a combination of chemotherapy, immunotherapy and/or radiation therapy. The conditioning regimen makes space in your bone marrow for the transplanted cells to grow. It also helps suppress your immune system so your body will accept the transplanted cells and, for those being treated for cancer, kills cancer cells if there are any left in your body. The type and amount of chemotherapy, immunotherapy and/or radiation therapy you receive depends on your diagnosis and will be decided by the hematology-oncology attending physician.

Chemotherapy and immunotherapy are usually given through the central line. Different therapies have different side effects. One of the most common side effects is nausea (i.e., having an uneasy feeling in the stomach, feeling queasy or feeling as if you are going to vomit). Prior to receiving these therapies, you will receive anti-nausea medicine. Your doctors and nurses will discuss the different types of therapies and their side effects with you in more detail.

Radiation therapy may also be part of your conditioning regimen. Before radiation, your nurses will give you medicine to help you relax and keep you from feeling nauseous. You will receive radiation therapy in a specific room that is in another part of the hospital. Your job during radiation is to hold very still. Parents/caregivers will not be able to be in the radiation room, but they can stand outside and watch through the window or on the closed-circuit television set. You can also talk to your parents during radiation therapy over a microphone.

We encourage you to ask your doctors and nurses any questions you may have about the conditioning regimen.



“So many of our dreams at first seem impossible, then they seem improbable, and then, when we summon the will, they soon become inevitable.”

— Christopher Reeve

3







Protecting your health

Protective isolation: a germ-free environment

Because conditioning regimens weaken the immune system and affect the body's white blood cells, BMT patients are at higher risk of infection. To protect our patients from infections caused by bacteria, fungi or viruses, we place them on protective isolation the day they are admitted to the bone marrow transplant unit. After the patient is discharged, they will still need to follow protective isolation guidelines (e.g., avoid crowds, sick visitors and animals) until your immune system starts to recover, which takes about six months.

While you are in our hospital, protective isolation means:

- You must stay in your room until your new bone marrow is able to make white blood cells, which protect the body from infection. This usually takes two to six weeks after transplant, but can take longer.
- The only time you will leave your room is for radiation (if it is part of your conditioning regimen) or tests that cannot be done in your room.
- A sign will be put on the outside of your door to remind those entering of the isolation rules.
- All who visit must wash their hands every time they enter and exit your room.
- Anyone who is ill (colds, flu, chicken pox, etc.) is not allowed to visit or stay the night.
- Any equipment brought into your room (e.g., scales, X-ray machines, stethoscopes) must also be cleaned.
- Live flowers, plants and animals are not permitted on the unit, as they can have bacteria and fungi on them.



To help pass the time and make your isolation room more comfortable, we encourage you to:

- Bring some of your favorite things from home (e.g., books, movies, puzzles, audiobooks, toys and games, pictures, blankets, arts and crafts). The room will have a TV and a DVD player.
- Bring your cellphones or laptops from home, as you and your family will have access to WiFi in your room. An iPad is also provided in each room for patient and family use.
- Ask for the UCLA Chase Child Life Program's collection of DVDs, toys, games and crafts, which include Nintendo and PlayStation 2 game stations (available by reservation).
- Keep the window shades up and the room lights on during the day to help your body maintain a normal day and night schedule.

Your health and safety is our top priority. For this reason, you are not allowed to bring any home electrical appliances (air mattresses, electric blankets, rice cookers, toaster ovens, etc.) with you to the hospital. We apologize for any inconvenience.

Exercising

While you are on protective isolation, it is very important that you stay as active as possible in your room. Physical activity keeps the heart, lungs and muscles in good shape. Regular activity also supports a normal sleep schedule (i.e., staying awake during the day and sleeping at night).

A physical therapist can show you safe exercises that you can do while in the hospital to help keep your muscles strong. Exercise equipment, such as a stationary or arm bike, is available for our teenage and young adult patients to use if their physical therapist and doctor approve.



Common transplant medications

One of the most important jobs you have is to take your medication. Sometimes this is the hardest job because there are many medicines to take, but they are all very important to ensure a successful transplant process. Here are a list of some of the common medications you may take during transplant and why they are important:

Acetaminophen helps reduce fevers and prevent side effects from certain medicines. It may be given before you get blood transfusions, as well as before your bone marrow infusion. It comes in pill and liquid forms and, in special cases, can be given through an IV.

Chlorhexidine is an alcohol-free mouthwash that helps get rid of germs that cause dental plaque and cavities. It is a liquid that you swish around in your mouth then spit out. For younger patients, it is used with toothettes. This mouthwash should not be swallowed.

Diphenhydramine is mainly given to prevent nausea, as well as reactions to certain medications and blood product transfusions (including the bone marrow infusion). It comes in pill and liquid forms or can be given through an IV.

Fluconazole is an antifungal medicine. It comes in pill and liquid forms and can be given through an IV. You will take fluconazole once a day starting the day after your transplant and for at least 100 days thereafter.

Granisetron is a medication used to prevent nausea. It comes in pill and liquid forms and can be given through an IV. Granisetron is given during conditioning and may continue after transplant if needed. Granisetron can be used instead of ondansetron (see following page) for the prevention of nausea, but they cannot be given together.

Granulocyte-colony stimulating factor (G-CSF) helps the body produce white blood cells faster following transplant. It can be given as a shot or through an IV. Not everyone will receive this medication, as it is only used for patients with certain diagnoses and transplant types. Your doctor will let you know if G-CSF is part of your treatment plan.



Intravenous immunoglobulin (IVIG) boosts the immune system and helps the body fight off infections while recovering after transplant. It is usually given every other week through an IV while the patient is in the hospital. IVIG therapy will start two days before transplant and continue for at least 100 days after transplant. At that point, IVIG will be given once a month. Your transplant doctor will let you know when it is no longer needed. Not everyone will receive this medication. Your doctor will let you know if IVIG is part of your treatment plan.

Methylprednisolone and prednisone are two types of steroids that help prevent graft-versus-host disease (GVHD), which occurs when the donor's transplanted cells think the recipient's cells are harmful and start attacking them. Methylprednisolone comes in pill and liquid forms, or can be given through an IV; prednisone comes in pill and liquid forms. The patient will start receiving a steroid three days after transplant and will continue receiving it twice a day for at least 30 days. Not everyone will receive this medication, as it is only used for patients with certain transplant types. Your doctor will let you know if steroids are a part of your treatment plan.

Metoclopramide helps prevent nausea. It comes in pill and liquid forms or can be given through an IV. One side effect of metoclopramide is dystonic reactions, or difficulty controlling body movements. To prevent this side effect, diphenhydramine is always given prior to metoclopramide.

Nystatin powder helps prevent yeast (fungal) infections. The powder is applied under the arms and in the groin area. For babies, nystatin powder is also applied between their neck folds.

Ondansetron is a common medication used to prevent nausea. It comes in pill and liquid forms or can be given through an IV. Ondansetron is given during conditioning and may continue after transplant if needed. If your nausea does not improve while on this medication, please let your health care team know so they can change or add medications.

Phytonadione (vitamin K) helps the blood clot. Certain "good" bacteria in the gut produce it naturally. Some of the medications used during transplant will kill or decrease the amount of these bacteria. You will receive vitamin K once a week until your body is able to produce it on its own again. Vitamin K is given as a pill or through an IV.

Sulfamethoxazole-trimethoprim helps prevent a specific kind of pneumonia called *Pneumocystis jiroveci*. You start taking this medicine shortly after you are admitted to the hospital and will take it until two days before transplant. Once your new bone marrow is making healthy new cells, you will start taking it twice a day on Saturdays and Sundays for approximately one year. Sulfamethoxazole-trimethoprim comes in pill and liquid forms or, in special circumstances, can be given through an IV. Some patients are unable to tolerate sulfamethoxazole-trimethoprim. In these cases, an alternative medication will be given.

Tacrolimus also helps prevent graft-versus-host disease (GVHD), which occurs when the donor's transplanted cells think the recipient's cells are harmful and start attacking them. It comes in pill and liquid forms or can be given through an IV. The patient will usually start receiving tacrolimus two days before transplant through an IV. When the patient is nearing discharge from the hospital, they will start receiving tacrolimus in pill or liquid form twice a day. Every day, the health care team will check the patient's blood levels to make sure the tacrolimus dosage is right. They may change the dosage depending on the blood-level results. It is very important that patients take this medicine at the same times every day. Not everyone will receive this medication, as it is only used for patients with certain transplant types. Your doctor will let you know if tacrolimus is part of your treatment plan.

Ursodiol helps prevent problems with liver function. It comes in pill and liquid forms. On the day you are admitted to the hospital for transplant, you will start taking ursodiol twice a day and will continue to take it for at least 100 days after transplant.

Antiviral medications

Some viruses cannot be killed once they are in the body. They may be inactive (showing no symptoms) when the immune system is working well, but they can be reactivated when the patient's number of infection-fighting white blood cells are low (neutropenia). Patients who carry these viruses prior to transplant may be given antiviral medications, such as acyclovir and ganciclovir, as a precaution.

Acyclovir is given to patients who test positive for the herpes simplex virus (HSV) prior to transplant. It comes in pill and liquid forms or can be given through an IV. Patients usually start taking acyclovir two days before transplant (or earlier in some cases) and will continue to take it for at least 100 days after transplant.

Ganciclovir is given to patients who test positive for a cytomegalovirus (CMV) prior to transplant. Ganciclovir treatment, given through an IV, will start the day the patient is admitted to the hospital for transplant and will continue until two days before transplant. Ganciclovir is stopped at this time because it can further suppress the body's white blood cells. After transplant, once the patient's bone marrow is making healthy new cells, ganciclovir may be restarted if the virus is detected. Until that time, acyclovir will be given to help keep the virus under control. Your doctor will order a weekly CMV blood test to monitor the virus.

While the list above includes some of the most common medicines that patients get during transplant, there may be others during the transplant process. Your doctors and nurses will always keep you informed about any new medicines they may need to give you. Please do not hesitate to ask them any questions you may have.

Nutrition and diet

Good nutrition is very important to help the body recover after transplant. Once you are admitted to the hospital, you will meet with a dietitian to discuss what foods you like, your eating habits, your usual weight and any recent changes in weight, and if you take any supplements at home. This information will help the dietitian create a personal nutrition plan for you. In addition to providing you with specific food guidelines, your dietitian will also discuss food preparation and storage.

Low-bacteria diet

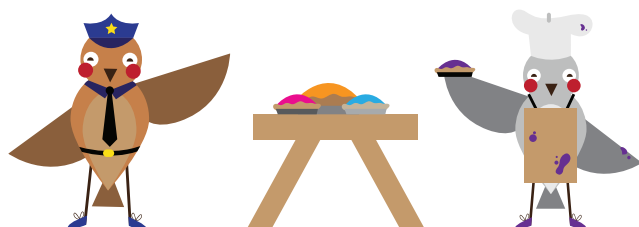
While you are recovering from transplant, your immune systems will be weaker than usual, placing you at high risk for infections. For this reason, you will need to follow a diet that excludes foods known to be high in bacteria. The diet consists of cooked, canned, frozen and prepackaged foods.

Modified low-bacteria diet

If your absolute neutrophil count (ANC) — a measure of infection-fighting white blood cells — is above 1,000 for three consecutive days, your diet will be changed to a modified low-bacteria diet, which includes thick-skinned fruits (e.g., oranges, unripened bananas and melon). The modified low-bacteria diet will continue for at least 100 days after transplant. Duration can vary depending on each patient's needs, so we encourage you and your family to discuss your nutrition plan with your health care team. Also, ask your doctor when outside food is allowed.

General food and beverage guidelines

The table on the following pages is a sample of common foods and drinks that are safe for transplant patients, as well as foods and drinks that should be avoided. If you have any questions, or there are foods and drinks that you like that are not listed on the following pages, please write them down and ask your dietitian about them when you meet.



Food group	Allowed	Avoid
Beverages	<ul style="list-style-type: none"> • Hot coffee and tea brewed in boiling water. • Carbonated drinks in cans or bottles. • Individually packaged nutritional supplements. • Bottled, canned or individual packet powdered drinks (Kool-Aid, lemonade mix, hot cocoa mix, instant breakfast mix). • Pasteurized or UHT-processed* vegetable and fruit juice individually packaged. • Pasteurized or UHT processed soy milk. • Ice filtered through a filter with an absolute pore size of 1 micron or smaller (NSF Standard #53 for cyst removal). • Distilled or bottled water. 	<ul style="list-style-type: none"> • Tap water. • Ice from ice machines (except the ice machine in the third floor kitchen of the UCLA Pediatric Bone Marrow Transplant Unit). • Ice made from tap water. • Beverages from soda fountains. • Fresh squeezed or unpasteurized fruit or vegetable juice. • Unpasteurized eggnog or apple cider. • Tea made from loose leaves.
Milk and dairy	<ul style="list-style-type: none"> • Pasteurized or UHT-processed* milk and dairy products in single-serve containers. • Lactaid milk from a large container, but consume within two hours of pouring out. • Plain single-serve ice cream, sherbet and ice cream bars (without dried fruits or nuts). • Sour cream, cream cheese and cottage cheese, preferably in individual containers. Commercially packaged hard and semisoft cheeses, such as American, mild cheddars, pasteurized mozzarella, Monterey jack, Swiss and shelf stable pregrated parmesan; cooked goat cheese; and brick pasteurized cheeses sliced from the hospital nutrition department. 	<ul style="list-style-type: none"> • Unpasteurized (raw) milk and dairy products. • Restaurant milkshakes and malts. • Homemade ice cream, soft-serve ice cream and yogurts. • Ice creams or ice cream bars containing dried fruits or nuts. • Deli cheeses, mold-ripened cheeses, such as Brie or Camembert; blue-veined cheese, such as Stilton and Gorgonzola (the blue veins are mold); soft cheese, such as fresh feta and goat cheese; Mexican-style soft cheeses, such as queso fresco and queso blanco; and cheeses with chili peppers.

* UHT stands for ultra-high temperature. This is another form of acceptable sterilization other than pasteurization.



Food group	Allowed	Avoid
Meat, fish, proteins and meat substitutes	<ul style="list-style-type: none">• Well-cooked meats, fish, shellfish, poultry and eggs.• Meat and poultry should be cooked to 165°F, fish to 145°F and egg dishes to 160°F.• Cooked tofu (cut into 1-inch cubes and boiled for at least five minutes).• Hot dogs and commercially packaged luncheon meats reheated until steaming hot or 165°F.• Individually canned meats and fish products: tuna, seafood, chicken, pâtés or meat spreads. Cooked dried beans, peas and refried beans.• Individual packages of peanut butter.	<ul style="list-style-type: none">• Processed meats (luncheon meats).• Deli meats.• Raw eggs and foods containing uncooked eggs (e.g., cookie dough).• Raw fish or shellfish, including caviar, sashimi or cerviche.• Raw or cooked mollusks (e.g., clams, mussels, oysters).• Smoked seafood, such as salmon or trout labeled as “nova style,” “lox,” “kippered” or “smoked” unless cooked to 165°F or contained in a cooked dish or casserole.• Hard cured salami or beef jerky.• Tempeh.• Unpasteurized, refrigerated pâtés.
Cereals	<ul style="list-style-type: none">• All dry and cooked cereals without nuts, seeds or dried fruit.	<ul style="list-style-type: none">• Raisin Bran or other cereals containing nuts, seeds or dried fruit.• Large (communal) boxes of cereals.
Breads and other starches	<ul style="list-style-type: none">• Bread, bagels, rolls, muffins, tortillas or crackers (they may only contain dried fruits or nuts if they were baked into them).• Pancakes, waffles and French toast may contain dried fruits or nuts that are cooked into them.• Rice, barley, pasta and other cooked grains.• Cooked potatoes (can contain skin if scrubbed clean and cooked), French fries and hash browns.• Single servings of potato chips, tortilla chips and pretzels (served unopened).	<ul style="list-style-type: none">• Bread products and crackers with seeds or nuts added after the cooking process.• Cold salads, including commercial potato salad and all macaroni/pasta salads.

Food group	Allowed	Avoid
Vegetables	<ul style="list-style-type: none"> • Fresh, frozen or canned vegetables that are washed and cooked well. • Pasteurized vegetable juices. 	<ul style="list-style-type: none"> • Raw or undercooked vegetables. • Coleslaw. • Unpasteurized vegetable juices.
Fruits	<ul style="list-style-type: none"> • Single servings of all canned fruits (served unopened). • Well-washed frozen fruits. • Pasteurized fruit juices. 	<ul style="list-style-type: none"> • Fresh, unwashed frozen or dried fruits. • Unpasteurized fruit juices.
Fats and oils	<ul style="list-style-type: none"> • Butter, margarine, oil, shortening, whipped cream and non-dairy creamer. • Gravy and cream sauces brought to a boil. 	<ul style="list-style-type: none"> • Hollandaise sauce.
Soups	<ul style="list-style-type: none"> • Any homemade, canned, frozen or dehydrated cooked soup. 	<ul style="list-style-type: none"> • Uncooked and cold soups (e.g., gazpacho)
Desserts and sweets	<ul style="list-style-type: none"> • Commercially packaged, single-serve ice cream, sherbet and ice cream bars (without dried fruits or nuts). • Jell-O made with sterile water. • Sugar, jam, jelly, syrup, molasses, pudding, candy and plain chocolate wrapped and sealed individually. • Individually packaged, pasteurized or UHT-processed honey. 	<ul style="list-style-type: none"> • Cream pies, cream-filled pastries and desserts that contain nuts or fruits (dried or fresh) added after the baking process. • Candy made with dried fruits and nuts. • Unsealed candy. • Raw or unpasteurized honey.
Snacks	<ul style="list-style-type: none"> • Crackers, commercially packaged cheese and crackers, fresh popped popcorn. • Vacuum-packed roasted nuts. 	<ul style="list-style-type: none"> • Raw or fresh roasted nuts (shelled or unshelled).



Food group	Allowed	Avoid
Miscellaneous	<ul style="list-style-type: none"> • Salt, pepper, herbs, spices and seasonings used during cooking. • Ketchup, soy sauce, mustard and mayonnaise in individual packages. Individual servings of pickles, relishes and olives. • Dry flavored milk powders. 	<ul style="list-style-type: none"> • Pepper, spices, herbs, seasonings and salt substitutes added to foods after cooking. • Seaweed.



Loss of appetite

There are many reasons why you may not feel like eating during your hospital stay. Some of the most common reasons include nausea, temporary loss of taste or change in taste related to chemotherapy or radiation, or painful mouth sores. If you are not able to eat enough and are not receiving the nutrients your body needs to recover, you will be given your daily nutritional requirements through an IV (this is called total parenteral nutrition, or TPN).

You will be weighed daily to monitor for weight loss or gain, and your dietitian will help the medical team calculate the amount of IV nutrition you need to maintain a healthy weight.



Food preparation, serving and storage guidelines

- **Wash your hands often** to prevent foodborne illness, especially before preparing food. Wash hands in warm, soapy water for at least 15 seconds.
- **All ingredients for cooking should be cleaned well.** The person preparing the food should not be sick.
- **Wash all kitchen items** in hot soapy water or use a dishwasher. Launder rags and hand towels daily in hot water. Bacteria can spread from cutting boards to colanders, sinks, utensils, sponges and hands.
- **Do not reheat food more than one time.** Food that has been cooked for you to eat later needs to be sealed or wrapped and put in the refrigerator immediately.
- **Do not leave cooked foods out at room temperature** for more than one hour (it will no longer be considered low bacteria).
- **Room-temperature snacks** (e.g., chips and crackers) should be purchased in single-serving packages and eaten within 24 hours of opening them.
- **If you consume homemade foods**, please follow these food safety guidelines:
 - Meat and poultry should be cooked to a temperature of 165°F, fish to 145°F and egg dishes to 160°F.
 - It must be brought to you frozen. We recommend homemade foods be divided into single-serving portions and frozen individually. Once a serving is thawed, it cannot be refrozen.
 - Cold foods should be kept below 40°F and hot foods should be kept above 140°F.
 - Perishable foods should not be out of the refrigerator for more than two hours.
 - Egg dishes or foods that contain mayonnaise should not be out of the refrigerator for more than one hour.
 - Food should be cooked and consumed within 24 hours.
- **Do not consume any “fast foods” or restaurant foods** even after you are discharged home. Wait until your doctor tells you it is OK.
- **Posttransplant food safety** is very important once you are home as well. The dietitian will go over this information with you when you are closer to going home.

Fevers

A normal body temperature is 98.6°F (37°C). A temperature of 100.4°F (38°C) or higher is considered a fever while you are in the hospital. Most transplant patients have fevers during their hospital stay. The most common cause of fever is infection. Infections can happen when your white blood cell count is very low for a long period of time.

If you have a fever, your nurse will draw blood from your central line to check for bacteria or fungus in your blood. These are called blood cultures. Your nurse may also ask you for a urine sample to check for bacteria or fungus in your urine. This is called a urine culture. After the cultures are collected, antibiotics will be given to you through your central line.

Your nurse will give you acetaminophen to help lower your temperature and make you feel better. Taking off your blankets and putting cold washcloths or cold packs on your forehead and chest can also help cool you down.





“A person’s a person,
no matter how small.”

— Dr. Seuss





Transplant day: what to expect

For autologous transplant patients: The stem cells, cord blood or bone marrow that you donated and we stored for your procedure will be defrosted and given to you through your central line (this is called an “infusion”).

For allogeneic transplant patients: The bone marrow, stem cells or cord blood that was donated by someone else (a donor) will be infused through your central line. The process will start with your donor being taken to the operating room, where bone marrow will be removed from their pelvis or hipbone. Next, the bone marrow is filtered and put into an IV bag, then taken to the bone marrow processing laboratory to have the quality verified. It is then brought up to your room and given to you through your central line. If your donor is unrelated to you (e.g., someone from the bone marrow registry), their donation will be collected and filtered at another hospital, then delivered to our hospital to be given to you.

Whether you have an autologous or an allogeneic transplant, some things will be the same:

- **Before the bone marrow comes to your room, we will give you two medications** through your central line: diphenhydramine and hydrocortisone. These medicines help prevent allergic reactions.
- **You will get acetaminophen to prevent a fever.**
- **We will put you on a heart monitor** to watch your heart beat during the transplant and for two to four hours after the transplant (or longer if necessary).
- **A pulse oximeter** — a sticker with a red light that is placed on your finger or toe — will also be used to tell us the oxygen level in your body.
- **While your bone marrow is infusing, a nurse will stay in your room** to check your blood pressure, pulse and temperature, and watch you closely for any infusion-related reactions.
- **After the infusion, you may notice an odor on your breath and body.** Your urine may also be a little pink for up to 48 hours. This is normal, as there are broken red blood cells that do not survive the freezing process and leave your body through your urine.



“Counts”: understanding your lab results

To measure the level of white blood cells, red bloods and platelets in your blood, your health care team will frequently take blood samples. The results are referred to as your “blood counts.” Blood counts are important because they let us know when you need transfusions of red blood cells and platelets, and they can give us an idea of your new bone marrow’s progress after transplant.

What does a “low blood count” mean?

Before transplant, you will receive conditioning therapies (chemotherapy, immunotherapy and/or radiation therapy) that will destroy your existing bone marrow cells in order to make room for your newly transplanted cells. Because most blood-forming cells (red blood cells, white blood cells and platelets) are made in the bone marrow, which is being destroyed by conditioning therapies, the number of these cells will be very low during transplant. This is referred to as having “low blood counts,” and is an expected part of the transplant process.

Eventually, the transplanted stem cells will start to grow and form new healthy cells; but, in the meantime, you will require transfusions to increase your red blood cell and platelet counts. White blood cells cannot always be given through infusion, so you may receive medications (e.g., antibiotics, antivirals and antifungals) to help fight off infections. In some cases, patients will receive a medication called G-CSF to help their white blood cells grow more rapidly. Your doctor will let you know if G-CSF is a part of your treatment plan.

What are my blood counts measuring?

Because “counts” are such an important part of a transplant, you may want to understand the parts of a blood count a little better:

Red blood count: Red blood cells carry oxygen from the lungs to all areas of the body. Your red blood cell count looks at two things: hemoglobin and hematocrit.

- **Hemoglobin** is the part of the red blood cell that carries oxygen. A low hemoglobin level is called “anemia.” Symptoms of anemia include shortness of breath, weakness, lack of energy, paleness, dizziness, increased heart rate, irritability and feeling cold (especially in the arms and legs). If your hemoglobin level is below 7 grams per deciliter, you will probably require a packed red blood cell (PRBC) transfusion.
- **Hematocrit** shows what percentage of the blood is made up of red blood cells. When the hemoglobin is low, the hematocrit is also low.

When your red blood cell count is low, you may feel tired. Receiving a PRBC transfusion will help give you more energy.

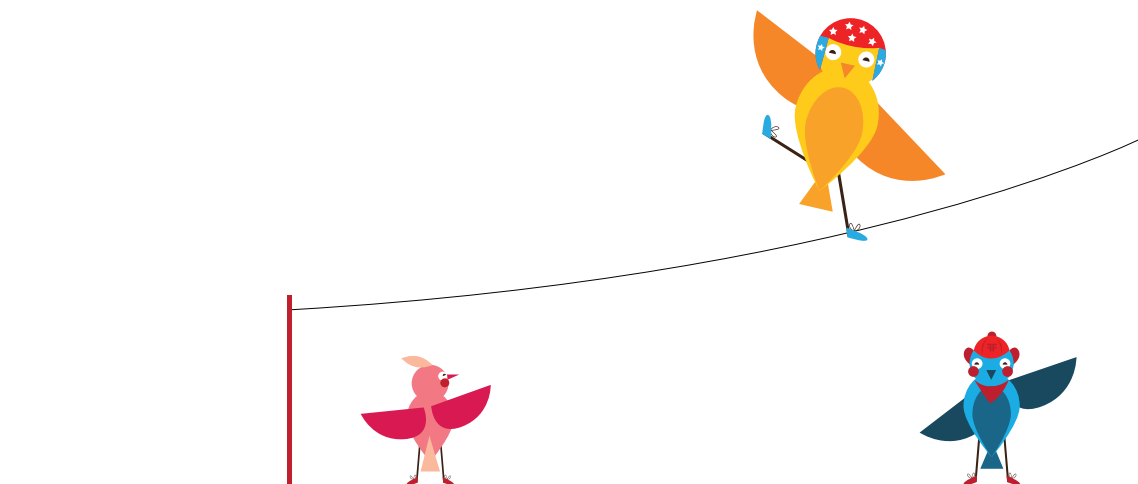
Platelet count: Platelets are disk-shaped cells that help prevent bleeding by helping your blood form clots. A low platelet count increases the risk of bleeding. Signs of a low platelet count include:

- Bruising
- Nose bleeds
- Bleeding from the mouth
- Bleeding around puncture sites, cuts or scrapes
- Blood in urine
- Blood in stool (stool may be very dark)
- Small red dots on the skin, a condition called petechiae

For most patients, a platelet transfusion will be given if their platelet count is below 20,000.

White blood count: White blood cells are part of the body's immune system. They work to destroy any foreign virus, fungus or bacteria that enter your body and threaten to make you sick. We know that your bone marrow is starting to grow back when your white blood cell count starts to increase after your transplant.

One type of white blood cell is a neutrophil, which works as the body's first line of defense against infections. To measure your neutrophil count, your health care team will conduct an absolute neutrophil count (ANC). If it shows that your neutrophil count is below 1,000, you are considered neutropenic and at higher risk for infection.



A few more important tests

Basic metabolic panel (BMP): A BMP is a blood test that measures your body's fluid balance (electrolytes) and blood glucose (sugar) level, as well as how your kidneys are working. Some transplant medications and therapies can affect your blood sugar level and kidney function, so your health care team will use the BMP to monitor them closely. "Normal" results depend on your age. Your doctors and nurses will be able to tell you what the normal ranges are for you.

Liver function tests (LFTs): This group of tests checks how your liver is functioning, as some transplant medications can have side effects on your liver. Your health care team will closely monitor how your liver is working. "Normal" results depend on your age. Your doctors and nurses will be able to tell you what the normal ranges are for you.

Tacrolimus levels: Tacrolimus is a medicine given to help prevent graft-versus-host disease (GVHD). Your health care team will monitor your blood levels every day to make sure the tacrolimus dosage is right. Your doctor may change the dosage depending on the blood-level results and how well controlled the GVHD is after the first two months.



Family and friends: how to donate blood

Almost all BMT patients will need some type of blood transfusion during their hospital stay. Red blood cell and platelet transfusions are the two most common types of transfusions.

There are two ways to donate blood products:

- Designated (directed) donation: donating blood products for a specific recipient.
- General donation: donating blood products for anyone who needs it.

Donors will need to complete a screening questionnaire as well as a blood draw to check blood type, hemoglobin level and for the presence of any infections or diseases. This process is repeated every 56 days for blood donation and every three days for platelet donation. That means that a person must wait at least 56 days before donating blood again; and for platelets, they must wait at least three days after their last donation (it takes the body longer to make red blood cells than platelets).

Donating red blood cells: A needle is inserted in the arm and tubing connects it to the collection bag. It takes 15 to 30 minutes to fill the collection bag. It is important to hydrate and eat a good meal before donating.

Donating platelets: A needle is inserted into the arm and connected to an apheresis machine with tubing. The apheresis machine collects whole blood from the donor's arm, separates out the platelets and returns the remaining whole blood to the donor through the same needle in his or her arm. This procedure takes two to two-and-a-half hours, so the donor can bring something to read, watch a movie or take a nap while the procedure is taking place. Platelets are good for up to five days after they are donated.

Although platelets are quickly replenished in healthy people, it is a good idea for donors to get a good night's sleep, eat a good meal and take calcium supplements before they come to UCLA for their appointment. Donors must be in good health and cannot be taking certain medications, as some medications can interfere with platelet production. Donors cannot take any aspirin or ibuprofen for at least five days before donation.

Please ask your hematology-oncology doctors or nurses any questions you may have about these types of blood donations. Call 310-825-0888 and follow the directory to reach general blood and platelet donation, designated donation or a UCLA representative for information. To donate platelets, please call 310-206-6187. You can also email gotblood@ucla.edu for more information.

“You have been my friend.
That in itself is a tremendous thing.”

— *Charlotte’s Web* by E.B. White





Getting ready to go home


After your bone marrow starts growing and producing enough white blood cells, your doctor may allow you to walk outside your room while wearing a mask. You should stay out of crowded areas, including the cafeteria and playroom. Talk to our UCLA Chase Child Life specialists about arranging private sessions in the playroom.

Your nurses will teach you what you need to know in order to go home, such as what medicines you will be taking, how to prevent infections and how to care for your central line.

You will probably have many questions and, as always, it is very important to ask your doctors and nurses any questions you have. We will give you a copy of all of your discharge instructions to take home with you, as there will be some special things you have to do at home to help protect your new immune system.

We will miss you after you go home, but we hope that you will keep in touch! We enjoy it when you stop by to visit before or after your clinic appointments. We want to know how things are going for you, so please feel free to stop by and let us know how you are doing.



The illustration is set against a solid teal background. At the top, a red and orange striped kite with a long red tail is flying. To its right, a sailboat with a multi-colored sail (yellow, blue, red) is visible behind a white cloud. In the center, a green diamond-shaped kite with yellow circles is flying. To its right, a yellow and red kite is also flying. A white cloud is positioned below the green kite. In the bottom left, a boy with dark hair, wearing red shorts, stands on a sandy beach. He is holding two strings that lead up to the green and yellow/red kites. To his right is a blue bucket and a red shovel. In the bottom right, a walrus with a red headband is lying on a blue lounge chair under a large red and orange striped beach umbrella. The quote is centered in the upper half of the image.

“When I let go of what I am,
I become what I might be.”

— Lao Tzu





Additional resources

Resources for patients and families

Blood & Marrow Transplant Information Network

Provides patients and their families with information on the transplant process, from preparing for transplant to life after transplant.

847-433-3313 or 888-597-7674

help@bmtinfonet.org

bmtinfonet.org

Children's Oncology Group

Provides information for patients and their families to help them through the phases of a child's cancer experience.

HelpDesk@childrensoncologygroup.org

childrensoncologygroup.org



CureSearch for Children's Cancer

Provides information on the different types of childhood cancer, what to expect during and after treatment, and resources on how patients and their families can cope with childhood cancer.

800-458-6223

info@curesearch.org

curesearch.org

Leukemia & Lymphoma Society

Provides disease information, support resources and educational resources for patients with leukemia/lymphoma and their caregivers.

800-955-4572 or 914-949-5213

lls.org



LIVESTRONG Fertility

Provides information on fertility risks and options for patients undergoing cancer treatment.
liverstrong.org/we-can-help/liverstrong-fertility

UCLA Mildred E. Mathias Botanical Garden and the Franklin Murphy Sculpture Garden

For caregivers and family members in need of a place to relax, the botanical and sculpture gardens are ideal for quiet reflection or as a nice place to have lunch or a picnic.

Directions and parking

For maps and directions, please visit uclahealth.org/reagan/maps-and-directions.
The Information Desk in the hospital also has maps available.

If your family has a car, be sure to apply for a reduced parking permit. Your social worker can help you with this process. It will allow you to make multiple entries in and out of the parking garage without having to pay each time. For more information, visit uclahealth.org/security-and-parking/parking-information.





“Love recognizes no barriers. It jumps hurdles,
leaps fences, penetrates walls to arrive at
its destination full of hope.”

— Maya Angelou





Glossary of medical terms

Medical term	Definition
Cardiac monitor	A machine that continuously measures your heart rate, breathing rate and oxygen level.
Central line	A small plastic tube placed into a large vein leading to your heart. The line is usually placed a few days after you are admitted to the hospital and remains in place until after you go home.
Chemotherapy	Medicines given to prepare you for transplant. Some of these medicines may cause side effects such as nausea, vomiting, hair loss and mouth sores.
Clean catch urine	A sterile urine sample collected to check for infection.
Conditioning	A term used for therapies (chemotherapy, immunotherapy and/or radiation) that prepare the body for transplant. Conditioning lasts several days before the transplant.
Counts	A term used to describe the number of white blood cells, red blood cells and platelets seen on a blood smear under the microscope.
EKG (electrocardiogram)	A test that checks the electrical activity in the heart.
Engraftment	The process in which transplanted donor stem cells migrate to the recipient's marrow and then produce blood cells of all types. This result is first seen when new white cells, red cells and platelets begin to appear in the recipient's blood following transplantation.
Febrile	Another term for fever, which is a temperature greater than 100.4°F (38°C).

Medical term	Definition
Graft-versus-host disease (GVHD)	This condition can be acute or chronic. It is caused by the transplanted bone marrow (graft) attacking certain cells and tissues of the transplant recipient (host) by mistake. It is an expected side effect of transplant. It can affect the skin (rash, redness, blisters, itching), the liver (swelling of the liver, inflammation of the liver cells), and the gastrointestinal tract (diarrhea, belly pain, inability to absorb food or medications properly).
Hemorrhagic cystitis	A possible complication after transplant caused by chemotherapy or a viral infection that affects the bladder. Symptoms include painful and frequent urination, as well as blood in the urine.
Immunosuppressed	A decreased defense system against infection, which can be caused by chemotherapy or other medications used during the transplant process (e.g., steroids).
“Is and Os” (intake and output)	A careful measurement of everything you eat and drink (either through your IV or by mouth) and put out (urine, stool or vomit).
Mucositis	Irritation and inflammation of the lining of the gastrointestinal tract, which can go from the mouth to the anus. It can range from redness and white patches to open sores.
NPO (nothing by mouth)	Fasting; not eating or drinking.
Oncology	The study of cancer.
Peripheral IV (PIV)	An IV most commonly placed in the hand or arm.
Sepsis	A possible complication after transplant in which a very serious bacterial or fungal infection spreads from the skin, gut or urinary tract into the bloodstream. Symptoms include fever, chills, cold sweats and a high heart rate. Sepsis is more likely to happen when white blood cell counts are very low.

Medical term

Definition

TPN

(total parenteral nutrition)

An IV solution that provides all of the nutrients and calories needed when patients are unable to eat. This solution is given through a central line.

Typhlitis

A possible complication after transplant in which bacteria invades a part of the intestine called the cecum. Symptoms include fever, severe pain on the right-lower side of the stomach, bloating, nausea, vomiting and diarrhea. Typhlitis is more likely to happen when white blood cell counts are very low.

VOD

(veno-occlusive disease)

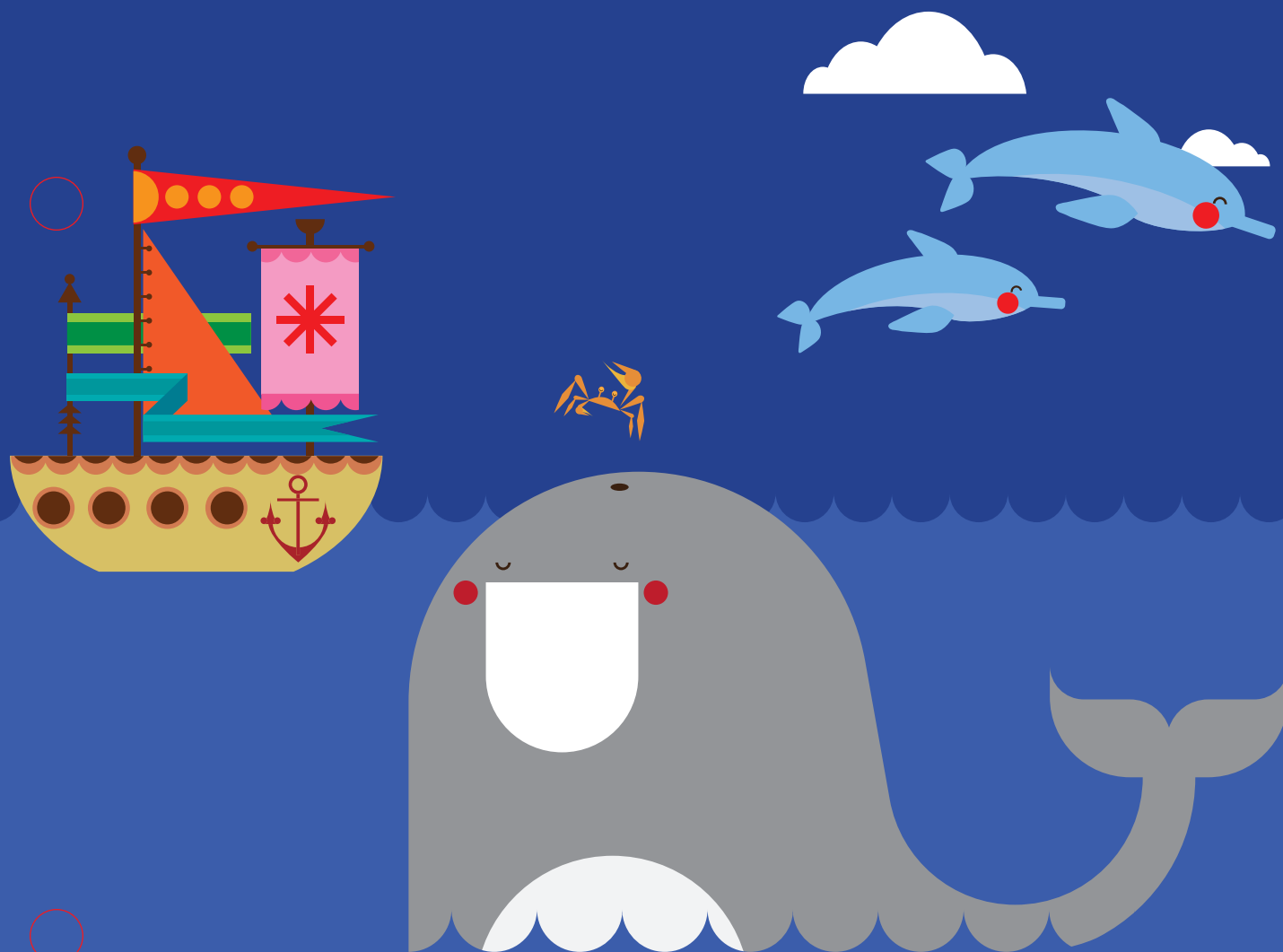
or SOS (sinusoidal
obstruction syndrome)

A possible complication after transplant that affects the liver. Symptoms include weight gain, enlarged liver and stomach pain. VOD or SOS most often occurs during the first three weeks after transplant.



“Children are likely to live up to
what you believe of them.”

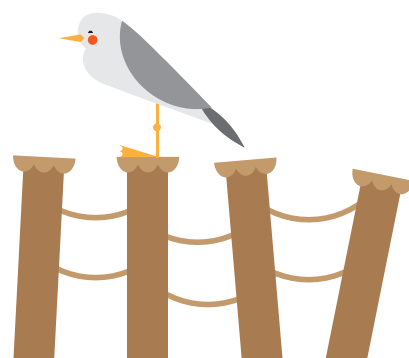
— Lady Bird Johnson, *Former First Lady of the United States*





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