

Health Facts for You



**Stem cell transplant – Day 0
through day 100**

UWHealth



**Carbone
Cancer Center**

Table of Contents	
The Hospital Unit • Your room • What to bring • Housekeeping • Internet access • Lounges and patios • Privacy • Visitor Guidelines	2-4
Hospital Routines • Infection risk • Skin care and mouth care • Intake and output • Central line care • Therapy • Activity • Exercises • Nutrition • Commonly drawn lab values • Transplant day • Engraftment • Discharge day	4-10
Transplant Day • Engraftment	11
Discharge Day	12
Coming to Clinic • Cognitive changes after cancer treatment • Watch for signs of infection • Hand hygiene • Activity • Diet	12-15
Symptom Tracking After Transplant	15-16
Medicines	16-17
Acute Graft vs Host Disease (GVHD) (Allogeneic patients only) • Acute GVHD Prevention (prophylaxis) • Acute GVHD Monitoring • What happens if I get GVHD? • Steroids • Steroid side effects	17-20
Infection Measures	21
Who to Call	22
2-Week Symptom Logs	23

Welcome to the UW Health Stem Cell Transplant and Cellular Therapy program. Our team takes pride in building a care plan tailored to your needs and your success.

It can be overwhelming to learn about stem cell transplant. Transplant is a process, and your transplant team is here to help you learn along the way.

The names used to refer to a transplant have changed over the years. The names you might hear include bone marrow transplant, stem cell transplant, hemopoietic stem cell transplant, peripheral blood stem cell transplant, and cellular therapy. Cellular therapy is an umbrella term that includes stem cell transplant (SCT) and CAR-T therapy.

You have completed the pre-transplant process, and you are nearing your transplant.

Some people receive their prep regimen and transplant in their hospital room and stay in the hospital until blood counts recover. Other people may receive their prep regimen and transplant in the Cancer Center with frequent visits to the clinic. Your team will decide which is right for you. If you are not admitted to the hospital, skip to 'Transplant Day' section.

The Hospital Unit

The stem cell transplant and cellular therapy unit is part of B6/6, on the 6th floor. You could be here as little as a few days or as long as a month or more.

Your Room

The hospital rooms are small, but all are private with their own bathroom.

- There is a call light attached to the wall that you can use to call the nurse or nursing assistant. This will

also control the television and room lights.

- Each room has its own thermostat so you can adjust your room temperature.
- Phones are in each patient room that are free to use. Your room has a direct phone number which is printed on the white board on the wall.
- If you chose to wear your own clothes (instead of hospital supplied clothing), make a laundry plan with your caregiver. We do not have washing machines on the unit.

What to Bring

Since rooms are small, keep your room free of clutter so nurses can safely care for you and housekeeping can clean. You should bring:

- ☐ Loose fitting, comfortable clothes
- ☐ Shoes for walking in the halls
- ☐ Snacks and nutrition supplements that can be kept in your room and will not spoil
 - If items need to be put in the fridge, they can be kept in the unit fridge. Opened items will be discarded after 3 days.
- ☐ Home bi-pap/c-pap machine, if you use one
- ☐ Pictures or other small items to make your room cozy
- ☐ Bring something to do, such as:
 - Laptop and charger
 - Book
 - Cell phone and charger
 - Tablet and charger

Do not bring:

- Do not wear jewelry—you will need to remove any earrings, nose rings, or other body jewelry
- Personal care items. You will be given a toothbrush, toothpaste,

shampoo, soap and skin moisturizer for your hospital stay

- Straight blade razors
- Pillows, blanket or stuffed animals (if you bring these items, they must be thrown away at discharge or easily washed so you don't bring germs home)
- Plants (real or fake)

Housekeeping

Our housekeeping staff will clean your room often. If you can:

- Try to leave the room during cleaning and not return for at least 30 minutes after it is completed. This allows time for any fungal spores to be removed by the air filters.
- Help to decrease clutter in your room to make it easier for the staff to clean.

Free Wifi

We provide free internet access during your stay. Connect your smartphone, tablet or laptop to the wifi network "UW Health Guest."

iPads

Each patient will receive an iPad to use during their inpatient stay. The iPad will have MyChart Bedside and allows you to:

- See your care team each day
- See what medicines you are getting
- View your lab results and vital signs
- Order 3 meals from food service
- Access entertainment apps to watch movies, play games, and listen to music

Lounges and Patios

There are small lounges at the end of the hallways on B6/6. In the lounges, you may find a TV, DVD player and exercise bike. You may use this space and these items. You can bring DVDs from home or borrow them from the nursing unit. Access to these areas may vary depending on the state of infection spread in the area.

During warmer months, UW Health's outdoor rooftop gardens and patios are open daily from 7 am – 8 pm. Furniture has been placed to ensure social distancing. For your safety, talk to your nurse if you wish to visit outdoor gardens or patios as badge access is required for most areas.

- **1st floor:** Atrium Patio, located at J3/1
- **1st floor:** Health Sciences Learning Center patio, located past the K elevators
- **3rd floor:** Patio, located at C4/3
- **4th floor:** Hilary Grace Healing Garden, located at E4/4

Privacy

We take your health privacy seriously, but also know that it is important to keep your support people updated. If you have signed paperwork giving permission to share your health information, staff will be able to provide updates to the people you listed on the form.

Visitor Guidelines	
Visiting hours	8:00 am – 9:00 pm Check with the information desk or B6/6 as visitor guidelines may change due to infection concerns.
Illnesses	All visitors must be healthy. Visitors with illnesses are not allowed. Even colds and minor illnesses can be very harmful for transplant patients.
Children	• Children under 16: They must have an adult with them and cannot be left alone on the unit. • Vaccines: They must be up to date on vaccines. They cannot visit if they just had a live vaccine or have been exposed to chicken pox.
Hand washing	All visitors must wash hands at the sinks in the B6/6 hallway before visiting the patient.
Bathroom	Visitors cannot use the patient's bathroom or sit on the patient's bed.
Flowers and gifts	No flowers are allowed or gifts/items that cannot be cleaned.

Patient Letters: Address to

Patient's name

B6/6

University of Wisconsin Hospital & Clinics

600 Highland Avenue

Madison, WI 53792-6718

Parking

One visitor can get their parking validated each day. Other visitors can park in the ramp and will need to pay the hourly parking fee.

Hospital Routines

The transplant team will come to your room each day to see how you are feeling. Your nurse and nursing assistant will be monitoring and caring for you throughout the day and night. You will have blood draws done most days and vital signs will be taken throughout the day and night.

Every day you should:

- Take a shower
- Work with the physical therapist or exercise on your own
- Do mouth care every hour when you're awake
- Eat multiple meals, snacks or shakes to help meet your increased nutritional needs

Your safety is very important to us. Every time there is a change of shift, the off-going nurse will update your on-coming nurse on your condition. There will be a safety check which is a review of all lines, drains, tubes, and equipment. We will try not to disturb you unless necessary. The most common times for change of shift are 7 am, 3 pm, 7 pm, 11 pm.

Infection Risk

You will be at high risk of infection from your conditioning chemotherapy. Your risk of infection from bacteria decreases after engraftment but your immune system will still be weak. A few days before your transplant, you will have a sign placed outside your door listing guidelines for visitors. These guidelines help protect you when your immune system is weakened.

Masking

You will have to wear a mask each time you exit your room to protect you from things in the air that may harm you. The mask should fit snug to your face. There should **not be any gaps** between the mask and your face.

1. There are two elastic bands to hold the mask in place. Put one on the base of the skull and other near the top of your head.



2. Pinch the nosepiece to fit snugly on the bridge of your nose.
3. Replace the mask if it has been worn longer than 8 hours or it is moist, as it won't keep its shape. Masks can be reused if kept in a dry, clean space.

Air Filtration

Your room has a special air filter so you will not have to wear a mask in the room. Because of this filter, your door needs to remain closed.

Handwashing

Good handwashing is one of the **best ways** to reduce the risk of infection.

Soap and water:

1. Clean all parts of your hands, fingers, thumbs, nails, and wrists.
2. Use liquid soap if possible. Bar soap can spread skin infections.
3. Wash for at least 15 seconds.
4. Rinse and dry your hands with paper towels or a dry clean towel.
5. Use a towel or your elbow to turn off the faucet.
6. Use moisturizer after washing and drying your hands. Dry, cracked skin can be a way for infection to get into your body.

Alcohol hand gels: Use **only** when your hands are not visibly dirty:

1. Put the alcohol hand gel in the palm of one hand.
2. Rub your hands together. Clean all parts of your hands, fingers, thumbs, nails, and wrists.
3. Rub your hands until they are dry, about 25-30 seconds.

While you are in the hospital, we will take steps to protect you from infections. You will be given antibiotics and closely watched for signs of infection. If you get a fever, we will take some blood, a urine sample and get a chest x-ray to look for infection. Then, you will be treated with antibiotics through your IV.

Skin Care and Mouth Care

Keeping your body and mouth clean are **critical to prevent infection** while you're in the hospital. You must shower every day and perform your mouth care often, even on days you don't feel well.

Skin care: You **must shower every day** to reduce the number of bacteria on your skin. Showering and changing your clothing are important to prevent infection.

- You will need to use a special soap that will help protect you from infection – the staff will teach you how to use it.
- Your central line must be covered properly before showering. The staff will help you with this each day.
- Apply a moisturizing lotion after you shower to prevent skin cracking.
 - You will need to use the lotion that is given to you. It works with the special soap.

Mouth care: You will likely get some mouth sores. Frequent mouth care will help prevent bacteria from getting into your bloodstream through those sores.

- **Saline rinses:** Rinse with saline often throughout the day (your nurse will provide this). This will help decrease germs in your mouth in between brushing.
- **Brushing teeth:** Brush your teeth (and tongue) twice a day. This helps keep your mouth healthy by reducing levels of harmful germs.
 - Use an **extra-soft, compact head toothbrush** (these will be given to you while you are in the hospital).
 - **Replace your toothbrush weekly** to prevent germ buildup. Make it a part of your weekly routine.
 - Staff can help you brush your teeth while sitting at the edge of your bed instead of standing if needed.

Intake and Output

The staff will measure and document what you eat and drink. They will also keep track of your output by measuring your urine and number of bowel movements. There may be times where your stool volume also needs to be measured. Keeping track of your intake and output is important for decisions on medicines, IV fluids, or diet changes.

Central Line Care

The nurse will take care of flushing the lines every day if it is not hooked up to an IV line. If you are hooked up to an IV line, the staff will limit the times you are unhooked from the tubing. This will decrease your risk of infection. The central line dressing will be changed every 7 days or sooner if the dressing is soiled or comes loose. In most cases, the catheter is removed before you go

home. Rarely, some people go home with their central line. If this happens, you and your caregiver will learn how to take care of your catheter before you are discharged.

Therapy

You will see physical and occupational therapists while you are inpatient.

- **Physical therapists** work on walking, balance, lower body strength and other movements. They decide if you will need any tools to help you with walking or moving.
- **Occupational therapists** work with arm function and strength, self-care skills and cognitive functions for daily life tasks. They will help you find ways to conserve energy and adapt your daily tasks to allow you to be as independent as possible with your daily routine.

Activity

It is important to stay active while in the hospital. Doing this is crucial to reduce risk of infection and maintain your current strength. You can start to decline and lose strength within just two days of being in the hospital. Staying active can help prevent this, reduce complications, decrease length of stay and reduce your risk of falling.

If you become very weak, you may need help walking to the bathroom. If you are feeling unsteady, ask for an escort. In some cases, the staff may use alarms that will alert the staff if you are out of bed. This is done to keep you safe and prevent you from falling.

Activity guidelines:

- Spend 6 or more hours out of bed daily. Sitting up in a chair or at the side of the bed is better than lying in bed.
- You will meet with PT and OT during your hospital admission. They will teach you exercises to help keep your strength.
 - Try to do at least 4 exercises, 3 times a day. It is important to perform some exercise every day, even if you feel weak or tired.
 - You will have to make some activity changes if your platelets or red cells are very low. Your therapists will help figure out the right level of activity for your blood counts.
- Leave your room and walk on the unit at least **3 times per day**. You must wear a “duck bill” mask when you leave your room and keep it on throughout your walk. Wash your

hands when you return. Taking a walk when your room is being cleaned every day is a good idea.

- Use an assistive device (walker, cane, etc) when walking if needed. If you are hooked up to an IV, you may need someone to walk with you to push the IV pole.
- Exercise for at least 30 minutes each day. It’s ok to spread this throughout the day.
- Exercise at a light to moderate level. You should be able to talk during exercise.
- Avoid any position which puts your head below your heart.
- If you feel pain, stop the exercise and tell your team.
-

It is important to keep your mind active too. Read, do crossword puzzles, or games you enjoy.

Nutrition

You need good nutrition for your recovery. We offer room service for patients for meal ordering. You may order your meals from a menu during specific times. Order extra snacks with your meals to keep at your bedside. You can also get nutrition supplements, such as Ensure or Boost®.

You will meet with a registered dietitian soon after your admission. They will discuss your nutrition needs and they will keep helping you during your stay. You can also request to see them at any time if you have food or nutrition concerns.

Proper nutrition helps to reduce length of hospital stay, treatment side effects, improve treatment outcomes, and may help reduce the risk of graft-versus-host-disease of the gut.

During and after your stem cell transplant, you will be at risk of getting sick from foods and drinks with bacteria, viruses, and mold. You need to follow special diet guidelines during and after your transplant. Click this link or scan the QR code to learn about food safety:

<https://patient.uwhealth.org/healthfacts/476>



In the days to weeks after transplant, you may find it hard to eat. You may have side effects like nausea, vomiting, diarrhea, poor appetite, taste changes and sore mouth or throat. It's important to work with your nursing staff to use the available medicines as needed to try and control your symptoms like nausea. If you are not able to meet your nutrient needs with oral intake (eating and drinking) we may recommend a feeding tube to help you.

Commonly Drawn Lab Values

You will have blood drawn most days you are inpatient and at every clinic visit. The table on the next page lists the most common labs that you will have drawn during transplant. If your results are outside of the normal range, you may need blood or platelet transfusions for a short time. This is common.

Complete Blood Count with differential is a blood panel that gives many different results for each cell type. Often, we focus most on 4 parts of the CBC – the hemoglobin (red cells), WBC (white blood cells), platelets and absolute neutrophil count (one type of white blood cell).

Test	Normal range	What it is	What might be done if abnormal results
White Blood Cells (WBC)	3.8-10.5 (same as 3,800-10,500)	These are the cells that fight germs. There are 5 types of WBCs. Neutrophils are the most common type.	Low WBC/ANC – this is called neutropenia. Chemotherapy will lower your blood counts and it is expected that your WBCs will be low for a time after transplant. During this time, you will be at a higher risk of getting an infection.
Absolute Neutrophil Count (ANC)	1500-7500	Neutrophils are the ‘first defenders’ against bacteria and are the most common type of the 5 WBCs (usually >70% of your WBCs are neutrophils)	High WBC/ANC – there are many reasons why your WBCs might be high, including infection, disease and being on steroids (prednisone or dexamethasone)
Hemoglobin (Hgb)	13.6-17.2	This test is one way to measure red blood cells (RBCs). These are the cells that help carry oxygen to body tissues.	Low hemoglobin – this is called anemia. You will likely get a blood transfusion when your hemoglobin is below 8. You may feel more tired, get winded more easily with activity and feel dizzy if you’re hemoglobin is low.
Platelets (Plt)	160,000-370,000 (same as 160-370)	These are the cells that help clot blood.	Low platelets – this is called thrombocytopenia. You might notice that you bleed more easily or for a longer time when your platelets are low. We usually transfuse when platelets are below 10 (10,000).

Comprehensive Metabolic Panel is a number of tests that look at your kidneys, liver and electrolytes.

Test	What it is	What might be done if abnormal results
Creatinine and BUN	Creatinine and BUN are tests that tells us how your kidneys are doing. Your kidneys do many things, such as: • Balance fluid levels in the body by making urine • Filter and balance minerals in the blood • Control blood pressure • Help to make red blood cells • Release hormones to keep bones strong.	High blood pressure, medicines and dehydration are some reasons that your kidneys might get stressed. Some medicines that are used to prevent graft vs host disease can be hard on the kidneys. To try and prevent this stress, your team will monitor the levels of these medicines and make sure you are not getting too much medicine, and that your kidneys are working.
Liver Function tests (LFTs)	Liver Function Tests (LFTs) are several tests that measure different enzymes, proteins, and other substances made by the liver. These tests check the overall health of your liver. LFTs are made up of these tests: • Alkaline phosphatase (AlkPhos) • Alanine aminotransferase (ALT) • Aspartate aminotransferase (AST) • Bilirubin, total (TBIL)	By looking at your LFTs, we're monitoring for liver GVHD or other complications that can occur after transplant, like VOD. Many things can impact LFTs including medicines and infection. We start to worry about liver GVHD if the ALT or AP is over three times the upper limit of normal or if your T.bili is above 2.
Electrolytes	Electrolytes are different minerals in your blood. They help balance body fluids, control blood pressure, and are important in heart, nerve and muscle function. Electrolytes include: • Sodium • Potassium • Calcium • Chloride • Magnesium • Phosphate	An electrolyte imbalance may be a sign of a heart, lung or kidney problem. Dehydration also causes electrolyte imbalances. Some medicines, like tacrolimus can cause your potassium and magnesium to be low. If low, you may be given pills or IV infusions or different electrolytes to help raise your levels.

Transplant Day

The day you receive your stem cell infusion is often called Day '0.' Each day after will be day +1, +2, and so on. Some patients feel anxious or nervous on day '0'. For others, it is a happy day. These are normal feelings. Your family and friends can be with you if you want them to, check with your nurse on current visitor guidelines before making plans.

The stem cells arrive in either an IV bag or syringes. The stem cells will be infused through your central line, much like a blood transfusion. The cells will float through the blood stream and settle into the bone marrow space inside your bones. These new cells will begin to grow and produce new red blood cells, white blood cells and platelets.

The stem cell infusion can take a few minutes to a few hours. The time will depend on the type and volume of stem cells. A nurse will watch your blood pressure and pulse for any reactions.

Some symptoms you may have during the infusion are listed below. Not all patients have these symptoms. You may receive medicine before the transplant to help prevent these side effects. If you do have any symptoms during or shortly after the infusion, it is often due to the preservative used to keep the cells, not due to the cells themselves. Symptoms include:

- Feeling short of breath
- Chest pain or chest heaviness
- Nausea and vomiting

It will take time for the infused stem cells to start making new blood cells. Your blood counts will be low during this time and it's common for people to get blood and platelet transfusions. You will likely feel the side effects of the chemotherapy which can cause

nausea, vomiting, diarrhea, mouth sores, pain and fatigue. It's important to let your team know what side effects you're having. Your team will work to find the right treatment to control your symptoms.

You will start to feel better when the new stem cells start making new blood cells, which can take up to 30 days.

Stem cell transplant is treatment for aggressive life-threatening diseases. Side effects are common and can vary in severity. Every person's experience with transplant is different. Talk to the team if you are worried about what your symptoms mean. Most symptoms are a normal part of the transplant process.

Engraftment

This is when the stem cells begin to grow in your body and start making blood cells. It is an important milestone in your progress. This will likely occur 1-3 weeks after the transplant day.

White blood cells will recover first. Platelets and red blood cells take longer to recover. You may also receive growth factor injections to help cells engraft more quickly. Your counts may vary at first. You may start to show signs of healing, such as healing of mouth sores. You will also gain more energy.

Discharge Day

Hospital discharge day is both exciting and a little overwhelming. You will get a lot of information from pharmacy and nursing about safety measures you need to follow while at home.

Most patients can leave the hospital after transplant when they have met these goals:

- Free of fever and active infection
- Able to take medicine by mouth (off any IV medicines)
- Able to eat and drink enough
- Able to walk and care for basic needs (toileting, showering, dressing)

Be sure that your caregiver is present for discharge day to ask questions and take notes.

Once your doctor says that you can go home, several things need to take place before you can leave. Please speak with your nurse before arranging transportation so you have a time frame for going home. A nurse will update you on when the discharge orders have been written. At that time, you can begin to expect the things listed below. It may be a few hours after the discharge orders have been written before you can leave.

- A pharmacist will talk to you about the medicines you will go home with. They will review all the details for your medicines and their schedules.
- Your nurse will take out your central line or IV, provide written discharge instructions, review your future visits and important phone numbers.
- If you do not live near Madison, you may be asked to stay in a hotel nearby for the first few weeks after discharge. This will allow you to access help more quickly. Based on

your recovery, you may be allowed to return home shortly after transplant.

Post transplant

- ☐ Watch for fevers – call if over 100.4°F
- ☐ Log your symptoms and bring the log to each clinic visit
- ☐ Use SPF to avoid sunburns when outside to help prevent skin GVHD (allogeneic patients)
- ☐ Help prevent getting infections by good hand washing and taking your prescribed medicines
- ☐ Stay active, slowly increase your activity levels to build back stamina and strength

Coming to Clinic

Most patients come to the stem cell transplant clinic 1-3 times a week for the first 1-3 months after transplant. You should wear a mask each time you come to clinic.

If you have complications after transplant, your clinic visits may become more frequent. If you have a fever after transplant, you will be re-admitted to the hospital for a short time. This is common.

If you do not have complications, your clinic visits will start to space out as you recover. How often you see your SCT team in clinic will depend on several factors and may change over time.

You will have labs drawn one or more times weekly. We are looking to see if you need any blood products, IV fluids, or adjustments to your medicine. We will ask you how you are eating and drinking, if you are having regular bowel movements, and if you are sleeping well. We will check your skin for any rashes. Please bring a list of your current medicines with you. The best

way to manage your health is to attend your clinic visits.

Although you will have frequent visits to the SCT clinic, you may have questions or changes that happen in between visits. Please do not wait until your next visit if you have concerns, such as shortness of breath, bleeding, rash, diarrhea or if you're unable to take your medicines. **Always call 911 for emergencies.** If you have urgent concerns or changes that are not an emergency, call the SCT clinic during business hours and the SCT doctor on call after hours.

Allogeneic patients only: You and your caregiver should watch for a skin rash or GI symptoms as these could be signs of GVHD. If you notice a skin rash or are having diarrhea, call the clinic to let the team know as these could be signs of GVHD. Keep caring for your skin and teeth carefully.

Cognitive Changes After Cancer Treatment

Some patients will notice a change in their ability to concentrate and process information. Some people may have memory lapses, poor concentration, or trouble multi-tasking. There are many things that affect how the brain works such as, chemotherapy, medicines, low blood counts, trouble sleeping, infection, hormone changes, nutrition, depression and anxiety. Feeling like you have “chemo brain” can last long after your last chemotherapy treatment.

Not everyone will have these changes, but if you do it's good to know that there are ways to help manage these issues.

- Do one thing at a time
- Make lists, checklists or daily reminders
- Get plenty of rest and sleep

- Exercise your brain: take a class, do crossword puzzles, Sudoku, number or word games, or electronic games
- Get regular exercise and eat a balanced diet
- Set up and follow routines

Let your team know if it gets worse. Often this will slowly improve over the months and years after transplant. Speech-language pathologists and health psychologists can offer tips for improving thinking, self-expression, and memory.

Watch for Signs of Infection

Even when your white blood cells return to normal levels after transplant, you are still at high risk for infection. Transplant patients are at risk for bacterial, fungal, viral, and parasitic infections. Most transplant patients have a weakened immune system for 6-12 months after transplant (or longer if you are on steroids or have GVHD). During the first 6-12 months it is very important to follow safety precautions.

Signs of infection include:

- Fever at or above 100.4°F
- Redness
- Swelling
- Tenderness

Infections can occur throughout the body, sometimes a fever is the only sign that you have an infection.

Hand Hygiene

Use good hand hygiene. **It's the best way to prevent infection!**

Using soap and water:

1. Clean all parts of your hands, fingers, thumbs, nails, and wrists. Wash for at least 15 seconds.
2. Use liquid soap if you can. Bar soap can spread skin infections.
3. Rinse and dry your hands with paper towels or a dry clean towel.
4. Use a towel or your elbow to turn off the faucet.
5. Use moisturizer after washing and drying your hands. Dry, cracked skin can be a way for infection to get into your body.

Using alcohol hand gels (only when your hands are not visibly dirty):

1. Put the alcohol hand gel in the palm of one hand.
2. Rub your hands together. Clean all parts of your hands, fingers, thumbs, nails, and wrists.
3. Rub your hands until they are dry, usually 25-30 seconds.

Wash your hands often, especially:

- After using the restroom
- Before and after eating or preparing food
- After touching door handles, pets, shaking or holding hands
- After coughing, sneezing, or blowing your nose
- After holding infants or young children
- Have towels that only you use, change them every 2 days

Mouth Care

Keep doing frequent mouth **care** as you will have a higher risk for bacterial, fungal, and viral infections in your mouth. If you have dry mouth, let the transplant team and your dentist know. Constant dry mouth increases your risk of getting cavities. Ask your dentist about fluoride treatments or other ways to keep your teeth healthy.

We suggest most patients go back to the dentist 6 months to 1-year post-transplant for routine dental care. Talk to your transplant doctor about when it's right to return to the dentist.

Avoid anything that is high risk for infections.

Reduce being exposed to bacteria, viruses, and other micro-organisms.

- Avoid people who are sick
- Always wear a mask:
 - When around people you don't live with
 - When you come to any hospital or clinic
- Avoid construction areas

Sometimes people will get an infection despite doing all the right things. This is because your immune system is still weakened from the transplant.

Activity

Fatigue is common after transplant. You may need to adjust your activities for a while, but don't stop being active. Keep doing the exercises that occupational and physical therapy gave you to keep your strength up. Be active. We know that exercise can help you feel less tired and improve your sleep and mood. Try going for a short walk.

Eating and drinking enough will also help you feel less fatigued. You may not have enough energy to do everything you want to do in a day. While you have energy, do the things you want to do and ask someone to help you with the others (such as, cleaning, grocery shopping, cooking meals). Know your limits and don't be too hard on yourself. If you are having trouble sleeping at night, limit daytime naps to 10-15 minutes. Longer naps can make it hard to sleep at night.

If your platelet count is less than 20 K/ μ l (20,000): Do **not** push, pull, lift, or perform resistance exercise but keep doing your range of motion exercises, walk and use the stationary bike without resistance.

If your red cells (hemoglobin) are low: You may get tired and out of breath more quickly. Your resting heart rate may be higher, and you may need to adjust your level of activity. A physical therapist can suggest a program that is right for you.

Diet

During and after your stem cell transplant, you will be at risk of getting sick from foods and drinks with bacteria, viruses, and mold. You need to follow special diet guidelines during and after your transplant. Click this link or scan the QR code to learn about food safety:

<https://patient.uwhealth.org/healthfacts/476>



Follow these guidelines until your immune system is no longer suppressed.

Keep trying to consume enough calories and proteins to help you keep your strength and energy up, maintain your weight and muscle

mass, help you heal, and support your immune system. Include a protein source at each meal and snack (see information about High Protein Food Sources: *Health Facts for You* #275).

After discharge a registered dietitian can help. Ask clinic staff to schedule a visit for you or call **(608) 915-0100** to request an appointment.

Symptom Tracking After Transplant

For at least the first 2 months after your transplant, take notes about how you're feeling throughout the day. This information will help your team manage any symptoms and better understand how things are going for you at home.

Track the symptoms listed and bring to your clinic visits. There is a template on the next page to help with tracking your symptoms.

Eating

- Write down how much you're eating and drinking throughout the day.
- Getting enough food and fluids are important for keeping your organs healthy and helping your body heal.

Nausea, Vomiting and Bowel Movements

- Keep track of how many times you have bowel movements each day (Use log on last page of booklet) and what number they are based on the Bristol stool chart. Scan the QR code to see the Bristol stool chart.
- If you have any vomiting, track how many times you vomit.
- If you take medicine for your nausea or diarrhea, write down how much you take each day.



Sleep

- Changes in sleep pattern are common due to medicine and hospital stays. If it is an ongoing problem, talk to your doctor.

Allogeneic patients only:

Watch for GVHD symptoms, call if you have any rash, nausea or diarrhea.

Skin

- Look at your skin **before** you shower or bathe. Your skin will flush more easily so it may look red after a hot shower. When your temperature goes down, the flushing will go away.
- Tell your team about changes in your skin, especially redness that doesn't go away. A rash may be splotchy and bumpy or smooth and red (similar to a sunburn).
- If your skin tone is dark, a rash may be hard to see. A rash may be red, brown, purple, or gray. Let the team know if the skin is swollen, itchy, bumpy or very sensitive in areas.
- If you develop a skin rash, please attempt to take a picture on your phone or tablet when you first notice the rash. This will help you see if the rash is getting better or worse each day. Send these pictures to the team in a MyChart message.
 - Put notes in the 'other' column on when the rash starts, worsens or improves.

Medicines

Managing all the new medicines after transplant can be confusing and overwhelming. At first, you may rely on your caregiver to help you manage your medicine. There are many medicines that you will need to take during transplant and for several months (or more) after. As time

goes on after transplant, your medicine needs will start to decrease.

Understand your medicine routine. Make sure you know these details:

- The dose and timing of each medicine.
- Which medicines you need to take on an empty stomach or with food.
- If there are medicines that you need to hold before a blood draw.

Never stop taking a medicine on your own. Always talk with your SCT team before making any changes to your medicines. Some medicines must be stopped slowly to avoid complications. If the medicine is causing side effects, tell your team so that they can make the right adjustments for you. If you're having trouble paying for your medicines, let your team know so they can research lower cost options or medicine assistance programs.

Make a plan that works for you and is easy to update.

- Place your daily medicine routine on a calendar or chart.
- Use a pill organizer with compartments for each day of the week — and for morning, noon and night. Keep a chart that details your medicine schedule and carefully consult this chart when you fill the boxes each week.
- There are also medicine tracking apps for the iPhone, iPad or Android phones. Two examples are Medisafe and Dosecast.

Tips to keep your medicines on track:

- Keep your schedule in an obvious place or an area you see often, like the door of your refrigerator or of a kitchen cabinet.

- Make your medicines a part of your daily routine. It can be helpful to link your medicines with daily tasks (for example, taking your pills right after you brush your teeth).
- Set a timer on your phone, watch or alarm clock.
- Put a sticky note on your mirror or kitchen cupboard to remind yourself to take your medicines.
- Keep a calendar in a visible place and mark the days off in a brightly colored marker each time you take your pills.

Other important tips:

- Medicine should always be stored safely in a dry, cool place. Avoid keeping prescriptions in the bathroom.
- Keep medicine in a childproof place. Keep medicine containers out of reach for children, especially those without childproof caps.
- Never take medicine in the dark or when you are tired or distracted. You might take the wrong medicine or too much. Ask for help, if needed, to find and take the correct medicine.
- There are times when we may call the patient or caregiver to adjust the dose of a medicine. A tip to ensure you understand the phone instructions is to write down the information. Then repeat the change in dose back to the health care professional.

Many people will have disease assessments occur at different points after transplant. When and how often will depend on the disease you were transplanted for and other factors that are specific to you. Your provider will come up with a plan specific to you.

Allogeneic Patients Only

Acute Graft vs Host Disease (GVHD)

Before talking about graft vs host disease (GVHD), it's important to first talk about the immune system. Your immune system is complex, made of up many cells and organs. They all work together to protect you from germs and help you get better when you're sick.

Your immune system's job is to keep germs, like bacteria and viruses, out of your body. It does this by knowing which cells are yours and which are 'foreign,' or different, to your body. If something looks foreign, the immune system attacks and destroys it.

After an allogeneic transplant, your donor's immune cells will become your new immune system. Because the donor's cells are in a different body, there is a chance that GVHD will occur. GVHD happens when the donor's immune system sees your body as foreign and attacks your tissues or organs. It is a reaction of the donor's immune system (the graft) versus you (the new host).

Acute GVHD Prevention

Some people will get acute GVHD. We don't know all the factors that impact why some people get it and others won't. We have listed some guidelines you should follow to help prevent GVHD. Even those who follow these guidelines can still get GVHD.

Medicines: You will be given medicines that help prevent GVHD by calming, or suppressing, the immune system. Make sure you know which medicines you take to prevent GVHD. Even with these medicines, some people will still get acute GVHD.

Below are common medicines to prevent GVHD:

Cyclophosphamide – this is an IV infusion given on day +3 and day +4.

Tacrolimus – this can be given in a pill or IV. It starts shortly after your transplant and will continue for 2 to 6 months.

Take tacrolimus consistently either with or without food. This is because an empty or full stomach absorbs the medicine differently.

Blood levels of tacrolimus will be checked to see if your dose needs to be adjusted. You will need to hold your dose of tacrolimus before your lab draw. Bring the pill with you and take it after your blood is drawn.

Mycophenolate – this can be given in a pill or IV. It continues until about day + 35.

Preventing infections: Preventing infections can help reduce the risk of GVHD.

- **Take all of your medicines.** Some of these are to help prevent infection.
- **Get your post-transplant vaccines** (starting about 3-6 months after transplant). These are important for preventing infection.

Limit sun exposure: UV rays in sunlight can trigger a reaction in the skin that causes GVHD. Your skin will be more sensitive to sun after transplant, making it easier to burn. You also may be on medicines that will make you burn more quickly and easily.

- When you are outside, wear a sunscreen with an SPF of at least 30. Reapply it as directed.
- Wear clothes that protect your skin from sunlight such as hats and long-sleeve shirts.

- Do not use tanning beds.

Acute GVHD Monitoring

Watch for signs of GVHD. Log your symptoms for at least the first two months after transplant. Acute GVHD can affect the skin, gut or liver. Symptoms range from mild to severe or even untreatable.

Skin: Watch for any skin rash (it may be itchy or painful). The skin may look pink or red. If you have a darker skin tone, the skin may look darker, purple or grey. Skin GVHD can start anywhere on your body, even on the palms of the hands or soles of the feet.

- Tell your team about any skin changes.
- If you notice skin changes between visits, take a picture and send it to your team via MyChart.

Gut: Acute GVHD can affect the stomach and intestines. It can cause cramps, diarrhea, and nausea. In severe cases, there can be large amounts of diarrhea which can become bloody. There are many other causes of nausea and diarrhea after transplant, like the effects of the chemotherapy, which can last for weeks after transplant.

- **Nausea/Poor appetite:** Use anti-nausea medicines. Keep track of when you take these medicines, how much you're eating and if you've vomited. Bring these notes to your clinic visits.
- **Diarrhea:** Record each time you have a bowel movement and what the stool looks like based on the Bristol stool chart. You can access this chart by scanning the QR code. Call if you have more than 3 bowel movements of watery diarrhea in a day. See symptom log on pages 23.



Liver: Liver GVHD can cause your liver to not function as it should. Your team will see a change in your lab test results if this happens. You could also have yellow skin and eyes. In severe cases, liver failure can occur.

You will have labs drawn at your clinic visits to watch for changes that could be liver GVHD.

Acute GVHD often occurs in the first several months after SCT or donor lymphocyte infusion. Chronic GVHD is similar to acute GVHD, but it affects different areas of your body in different ways. Acute and chronic GVHD are caused by different immune system reactions and respond differently to treatment.

What happens if I get GVHD?

Where your GVHD occurs (skin, gut or liver) and how bad it is will help your team decide what treatment you need.

The medicines used to treat GVHD calm and weaken the immune system. You will be at a higher risk of developing an infection. Treatment for GVHD starts with steroids for most people. Non-steroid medicines to treat GVHD work more slowly to show results than steroids.

At first, you will need to be seen in clinic more often to make sure the treatment is working, or you may have to stay in the hospital if your symptoms are severe.

Sometimes, acute GVHD can be so hard to control that none of the treatments work. Sometimes we'll need to increase the doses or change medicines. GVHD can come back if treatment is stopped too soon. Severe, acute GVHD that does not respond to treatment can result in death.

Steroids

Steroids, also called corticosteroids, are a type of anti-inflammatory drug. Some common steroid medicines are **prednisone** and **dexamethasone**. Steroid medicines are very similar to cortisol, a hormone that your body produce naturally. These steroids are different from the male hormone-related steroids that some athletes abuse.

Depending on where and how bad your GVHD is, the steroids might be:

- **Topical or local** (like a skin cream or eye drops)
- **Systemic** (a pill that treats your whole body)

Steroids work by decreasing inflammation and reducing the activity of the immune system. Your immune system's white blood cells cause inflammation when it tries to protect you against infection and foreign substances such as bacteria and viruses. In GVHD, the donor's immune system doesn't recognize your body. The donor's white blood cells then cause inflammation to your body's tissues and cause damage. Steroids reduce inflammation to reduce tissue damage as much as possible. Steroids also reduce the activity of the immune system by affecting the way white blood cells work.

Steroid Side Effects

You are more likely to have side effects with higher doses of steroids and the longer you take them. Not everyone will have side effects. Even though there are side effects, you need these to control GVHD. Your team will monitor you closely. Your steroid dose will be slowly decreased over time in a way that allows the new immune system to adjust at its own pace. You should not stop your steroids unless your team tells you to.

We've listed the most common steroid side effects and things you can do to help prevent or decrease the side effects. Most of the side effects will decrease or go away as you decrease or stop steroids.

Muscle weakness and thinning of your muscle mass: This can happen very quickly, especially when on high doses. To prevent muscle loss:

- **Remain as active as possible.** Maintain a regular exercise routine. This will help slow muscle weakening and help you to keep the strength that you have. **If you feel weak let your team know.** Often the first signs are trouble getting up from a seated position or trouble going up stairs. You may need physical therapy to prevent the weakness from getting worse.
- Eat a protein-rich diet along with exercise.

Mood swings, trouble sleeping, changes in mood, nervousness or restlessness can be common on high doses of steroids. You may also notice changes in your memory.

Increased appetite and weight gain: Steroids make it easier to gain weight and retain fluid. To reduce the risk of weight gain:

- Eat well-balanced, healthy meals.
- Avoid salty foods such as canned, instant, and frozen soups or entrees and cured meats. Processed foods contain too much salt. A high salt intake can worsen fluid retention caused by steroids.

Increased risk of infection: Because the steroids decrease the activity of the immune system, you are at higher risk of getting an infection. To reduce your risk of infection:

- Avoid anyone who might be sick.
- Report any signs or symptoms of infection to your team.
- If you feel unwell or have shaking chills without a fever, call your team. Steroids will delay a fever from starting.

Skin changes like acne, easy bruising, thinning of the skin, stretch marks and increased sensitivity to the sun are common.

Changes in body fat distribution may happen if you are on steroids for more than 3 months. You may notice your face becomes full or cheeks become rounded ("moon face"). You may also notice more weight gain to the abdomen.

These are not all the possible side effects of steroids. Most of the side effects will improve as you decrease your steroid dose. Side effects should go away in the weeks to months after stopping steroids. Talk to your team if you are concerned about any of the steroid side effects.

What to do	All Patients Conditioning start to 6 months post- transplant	Allogeneic patients 6 - 12 months post- transplant	Allogeneic patients 1 year + after transplant (if no GVHD and off GVHD prevention medicines)	Allogeneic patients Anytime while on GVHD treatment
Frequent thorough handwashing	✓	(Always a good idea)		✓
Daily Shower	✓	(Always a good idea)		✓
Frequent oral care	✓	(Always a good idea)		
Avoid people who are ill	✓	✓	(Always a good idea)	✓
Avoid dust or airborne particles (like those at construction area or around farms)	✓	✓		✓
Don't care for dogs and cats	✓			✓
No gardening or mowing the lawn	✓	✓		✓
Avoid swimming	✓			
Avoid fishing	✓	✓		✓
Avoid being in ponds or lakes	✓	✓		✓
Extended travel or vacationing	✓	✓		Discuss with your team
Attend large social gatherings	✓	Discuss with your team		Discuss with your team
Wear a mask when outside your home	✓	✓		Wear mask when coming to clinic

Who to Call	
UW Health Carbone Cancer Clinic Nursing Triage An answering service covers this line after hours and on weekends or holidays. Ask to speak with a Stem Cell Transplant (SCT) doctor on call.	608-915-0100 or 1-800-323-8942
Stem Cell Transplant Nurse Navigators	
Lauren Racki, Program Director	608-263-7673
Nicki Bates-Czyzewski	608-262-0455
Courtney Botteron	608-890-5934
Bethaney Campbell	608-263-0501
Karen Kranz	608-890-5923
Mandy Swiecichowski	608-890-5922
Brett Welhouse	608-263-8628
Clinic Social Worker	
Kristin Studer	608-262-7894
Clinic Pharmacist	
	608-263-1284
Infusion Center	
	608-263-8369
Inpatient Case Managers	
Mary Lynn Kessenich	608-262-0857
Bonnie Nelson	608-267-8105
Inpatient Nurses Station (B6/6)	
	608-263-8196
Nutrition	
Clinic Nutritionists	608-915-0100
Inpatient Nutritionist	608-263-8230
Spiritual Care Services	
	608-263-8574
Guest Services/Lodging	
UW Health patients and visitors can reserve a local hotel room at a discount through Guest Services by calling or stopping at the information desk at the hospital entrance. Restoring Hope Transplant House (RHTH) in Middleton, offers an affordable housing option for transplant patients and their families. RHTH has sleeping rooms and common areas including a kitchen and living area. Learn more at https://www.restoringhope.org . To reserve a room, call Guest Services and tell them know that you or your family member will be having transplant-related care at UW Health, and that you would like to stay at the Restoring Hope Transplant House.	608-263-0315

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 8/2025 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8408.

2 Week Symptom Log						
	Breakfast	Lunch	Dinner	Snacks and Fluids	Bowel Movement, Vomiting	Other
Mon						
Tues						
Wed						
Thurs						
Fri						
Sat						
Sun						
Mon						
Tues						
Wed						
Thurs						
Fri						
Sat						
Sun						