PATIENT & CAREGIVER EDUCATION

About Your Stem Cell Transplant: Information for Pediatric Patients

Welcome to the Claire Tow Pediatric Inpatient Unit (M9) at MSK. This guide has information about your hospital stay and what to do after discharge. In this guide, the word “you” mean you or your child.

When you’re admitted to the hospital, a countdown period will start. During the countdown period, you’ll get cytoreductive therapy, including chemotherapy, radiation therapy, or both. These treatments will get your body ready for your transplant.

Day 0 is the day of your transplant. The days after your stem cell transplant are then counted up (Day +1 is the first day after your transplant).

Your care team is here to give care and emotional support to both you and your family throughout your treatment. Don’t be afraid to ask the same question more than once. Transplant information is hard to understand. Most people need to hear things a few times before they understand completely. We know your journey will be difficult, but we'll be by your side every step of the way.

Your transplant team

A medical team specializing in pediatric cancers, blood disorders, immune disorders, and bone marrow failure syndromes will care for you throughout your treatment. Having a team working together to care for you helps make sure all parts of your care are addressed. Here is a description of our team members.

Physicians (doctors)

Attending physicians are experts in pediatrics, hematology-oncology, immunotherapy, and stem cell transplantation. The doctor you see in the Pediatric Ambulatory Care Center may not be the same one who takes care of you while you're inpatient. Transplant doctors take turns working in the inpatient unit. They usually work in the inpatient unit for 1 or 2 weeks at a time. During that time, they manage all the transplant patients 24 hours a day. While you're inpatient, the inpatient attending physician will be in charge of your day-to-day care. If any major problems come up while you're in the hospital, the inpatient attending physician will discuss them with your primary transplant doctor. Once a week, all the attending physicians meet to discuss your progress.

Fellows are pediatricians doing training in pediatric hematology-oncology. They work closely with the attending physician to manage your care. The inpatient fellow changes every 3 to 5 weeks.

Advanced practice providers (APPs)

APPs are a group of medical providers that include **physician assistants (PAs)** and **nurse practitioners (NPs)**. They work with the attending physicians to manage your care. This includes doing physical exams, prescribing medicine, and following your test results and progress. You’ll see them often, both in the Pediatric Ambulatory Care Center before and after your stem cell transplant and in the inpatient unit.

Pediatric bone marrow transplant (BMT) nurse coordinators

These are registered nurses who coordinate the evaluation and preparation of all pediatric stem cell transplant patients before you come to the hospital. They work very closely with you and the entire BMT team to make sure you have all your pre-transplant blood work, tests, and procedures done.

They’re also responsible for teaching you about your stem cell transplant. They’ll help make sure you understand the reasons for your treatment and details about your treatment before and during your hospital stay. They will also work with your care team to make sure you have the support, resources, and supplies you need as you recover from your transplant and leave the hospital.

Registered nurses (RNs)
RNs provide essential, critical bedside care. They work closely with the physicians and support team to address various aspects of your treatment, healing, and recovery. Throughout your treatment, your nurse will teach you about many topics, including what medicine you’re taking, why you’re taking them, how to care for your central line, and much more. The same primary nursing team will care for you during your whole hospital stay. Your primary nurses build a close relationship with you and are able to notice small changes in your condition.

Research nurses and research APPs
These are registered nurses and APPs who work closely with the clinical team on various research studies that pediatric patients can participate in.

Nursing assistants
Nursing assistants support the registered nurses with basic bedside care, such as checking your weight and vital signs (temperature, heart rate, and blood pressure) every day. They can help you with bathing every day.

Psychology services

The psychology team is made up of psychiatrists and psychologists. They're here to help you and your family deal with the stresses of treatment. They are an essential part of the transplant team. We ask them to meet with all patients and families during their inpatient stay.

Rehabilitation medicine team

The Rehabilitation Medicine team includes both Physical Therapists (PTs) and Occupational Therapists (OTs). They're a huge part of your inpatient stay. They will work with you and evaluate your needs to help you stay as active as possible.

Nutrition services

The nutrition services team has both outpatient and inpatient clinical dietician nutritionists. They'll keep track of your weight and help make sure you get enough nutrition before, during, and after your stem cell transplant.

A **room service associate** will explain how room service works, including the hours of operation, the specific menus that have your medical and cultural dietary needs, and how to order. They'll make sure you get the meals, snacks, and supplements that you need throughout the day.

Pediatric gastrointestinal (GI) service

The pediatric GI service includes healthcare providers who specialize in caring for children with GI problems. If you had GI problems before your stem cell transplant or develop new ones after your transplant, a healthcare provider from the pediatric GI team will work closely with other members of your care team to diagnose and treat your GI condition.

Pediatric pain and palliative care team

The Pediatric Pain and Palliative Care Team (PACT) is a team of doctors and APPs who support children and families facing serious illnesses at MSK Kids. The goal of palliative care is to anticipate, prevent, and manage physical, psychological, social, and spiritual distress while helping patients and their families throughout their treatment. Palliative care is important and helpful no matter how old a patient is, what stage of illness they’re experiencing, or whether their treatment is inpatient or outpatient.

The PACT is focused on improving the quality of life of our young patients by treating pain and other symptoms. They are available to guide our team regarding new medicine and innovative procedures, particularly for pain.

The PACT respects your preferences, values, and cultural beliefs and encourages you and your family to be active in making decisions about your goals and plans of care. The PACT will work together with all members of your care team to ensure that you and your family have the support needed to live as well as possible.

Pharmacist

A clinical pharmacist who specializes in the care of people having stem cell transplants will review your medicine with you. They will teach you how to take them and tell you about any side effects they might cause. They will create and provide your medicine schedule for home and make sure your medicine is delivered to your room before you leave the hospital. They are available on the inpatient floor as well as in the outpatient clinic to review any medicine that is new or if there are any changes to your doses and medicine schedule.

Fertility service

Your transplant team may recommend you meet with our fertility service. The fertility service will discuss how your treatment may affect your ability to have children in the future, and the steps you can take to preserve your fertility. The social workers can also help you navigate the costs of fertility treatments if you're interested and eligible.

Supportive services are also available and include social work, child life, psychology, teachers, spiritual care, and integrative medicine.

Environmental services

Members of the environmental service staff play an important role in lowering your risk of infection by disinfecting surfaces, cleaning the floors, bathroom, and air vents, and getting rid of trash. They'll come to your room at least 2 times a day and when needed to keep your room clean.

Your hospital room

When you're admitted to the inpatient unit, you'll be in a private room. This is called protective isolation.

You can wear your own pajamas or comfortable clothing, or you can wear a hospital gown. Please wear non-skid footwear when you're out of bed. Your nurse can give you hospital non-skid socks, or you can bring a pair of slippers from home.

Protective isolation precautions

When you're admitted to the hospital, you'll be placed on **protective isolation precautions** to protect you from germs. This means that anyone in the room, other than you, must wash their hands and wear a mask and gloves. It also means you can't leave the room unless it's to go to a test or procedure. You're welcome to decorate your room, but you can’t have fresh flowers or plants while you’re in the hospital. They’re a source of bacteria and fungus.

If you get an infection such as *C. difficile,* you’ll be placed on **special contact isolation precautions.** If you get a respiratory infection, you will be placed on **droplet isolation precautions.**

Your daily routine

Rounds

Your health care team will meet every day to discuss your blood test results, fluid intake and output, vital signs, medicine, and how you’re responding to treatment. They’ll also determine your plan of care. This meeting is called rounds.

Early each morning, the APP caring for you will come in and examine you so they can update the team on your physical assessment during rounds. After your team has discussed your plan of care for the day, they’ll come into your room and examine you. Getting up and dressed before morning rounds is helpful so you’re ready to talk with the team when they arrive.

At times, the transplant process can be overwhelming. You and your caregivers can use the space in the back of this guide to write down questions you have before rounds to help you remember what to ask.

Weight

You'll be weighed 1 to 2 times a day. Your care team needs to know how much you weigh before they do morning rounds. This is usually between 12 a.m. and 9 a.m. They'll use this information to make important decisions about your treatment. Most weight changes during a stem cell transplant hospitalization are due to fluid (water) gain or loss.

Vital signs

Your care team will check your vital signs (blood pressure, temperature, pulse, breathing rate, and blood oxygen level) at least every 4 hours both during the day and overnight. No one likes being woken up, but these measurements are important. If your vital signs change, you may need to be evaluated by your care team.

Intake and output

Your care team will keep track of how much food and liquid you take in each day (both by mouth and through your IV line). They'll also measure your urine, stool (poop), and vomit (throw up). **Do not flush your urine (pee), stool (poop), or vomit (throw up) down the toilet.** Your nurse or nursing assistant will measure and flush them for you.

Your caregiver should always wear gloves when handling your urine, vomit, or stool. Some chemotherapy medicine is carried out of your body in your urine. Viruses and bacteria can be in urine and stool (poop).

Blood tests

You'll have blood drawn for testing at least once a day and sometimes more often. Your blood will be drawn from your central venous catheter (CVC). Usually, your blood will be drawn at night so your test results are ready when your doctors round in the morning.

The blood tests that are done most often are:

- **Complete Blood Count (CBC)**. This test measures the cells that make up your blood: white blood cells, red blood cells, and platelets.
- **Basic Metabolic Panel**. This test measures your electrolyte levels, kidney function, and glucose (sugar) levels.
- **Hepatic function**. This test measures levels of total protein, albumin, bilirubin, and liver enzymes.
- **Epstein-Barr virus (EBV)**, **cytomegalovirus (CMV)**, and **adenovirus** are viral infections that we check for at least weekly because they're sometimes seen in patients after a stem cell transplant.

Transfusions

Based on the results of your blood tests, your team will decide if you need a red blood cell or platelet transfusion.

Your results will be below normal until the stem cells start to grow in your bone marrow. After you get your stem cell transplant, your family members may be asked to donate red blood cells, platelets, or both.

Your blood carries oxygen and nutrients to all the cells in your body. Blood cells also fight infection and control bleeding. Blood is made up of 4 parts: red cells, white cells, platelets, and plasma.

- **Red blood cells** carry oxygen from your lungs to your cells. They also bring the waste product, carbon dioxide, back to your lungs where it's exhaled. Hemoglobin shows how much oxygen red blood cells can carry and is the value we look at to see if you need a red blood cell transfusion.
- **White blood cells** fight infection and help you develop immunity. There are 3 types of white blood cells: granulocytes, monocytes, and lymphocytes. Each type has their own way of helping your body fight infection. You'll hear the term **ANC,** which stands for Absolute Neutrophil Count. Your ANC is the total number of neutrophils in your white blood cell count. The lower the

ANC, the higher the risk of infection.

- **Platelets** are colorless cells whose main job is to control bleeding. When your platelet count is low, you’re at risk for bleeding. Depending on your platelet level or symptoms, you’ll be given a transfusion.
- **Plasma** is the liquid part of blood. It carries water, nutrients, minerals, and hormones throughout your body. It carries various waste products to your kidneys so they can be removed from your body. Plasma also has proteins that help your blood clot. If these proteins are low, you may get a transfusion of fresh frozen plasma or an infusion of albumin to replace them.

Caring for yourself during transplant

Showering

Keeping your body clean is very important. Shower every day using a 4% chlorhexidine gluconate (CHG) solution antiseptic skin cleanser, such as Hibiclens®. 4% CHG solution is a skin cleanser that kills germs for up to 24 hours after you use it. Showering with 4% CHG helps lower your risk of infection. Your care team will tell you if there’s a reason you shouldn’t bathe with 4% CHG.

Your care team will teach you how to use 4% CHG. You should only use it on certain areas of your body. Do not use it on your face, head, mouth, genitals, or deep wounds.

You can wash the rest of your body with alcohol-free, fragrance-free soap. You can bring soap from home, or you can get it from your care team. Let your care team know if you have any skin reaction after washing with 4% CHG.

Your care team will show you how to put a waterproof dressing (such as Aquaguard®) over your CVC dressing to keep it dry. Do not spray water directly on your dressing. Do not submerge any catheters in water. If your dressing becomes wet or starts to loosen, tell your nurse.

Washing your hands

Germs are often carried on your hands or on objects that you touch. Wash your hands well with soap after you use the bathroom and before you eat.

Caring for your mouth

Mouth care is an important part of your daily routine. It must be done at least 4 times a day, or more often if you have mouth sores. Good mouth care can help prevent infections and other problems in your mouth.

Follow the guidelines below.

- Only use the mouthwash your nurse gives you. Don’t use a store-bought mouthwash. Store-bough mouthwashes irritate and dry out your mouth and throat.

- Your nurse will also give you toothpaste. Only use it if it doesn't irritate your mouth.
- When your platelet count is low, you may bleed easily. Be very careful when you're brushing your teeth Always use an **ultra-soft toothbrush**.
- Some people prefer to use small green sponges for mouth care. A member of your healthcare team can give these to you.
- Don't use dental floss.
- To keep your lips moist, apply a lubricant such as Aquaphor® or A&D® ointment.
- If your mouth becomes sensitive, avoid hot, spicy, acidic, or coarse foods. You may prefer soft or liquid food served chilled or at room temperature.
- Tell your nurse if you have any tenderness, discomfort, or pain in your mouth. If this happens, your doctor can prescribe medicine to help manage the pain.
- Your doctor may give you a prescription for an oral antifungal antibiotic to keep you from getting and infection in your mouth. Follow the instructions it comes with.

Nutrition

Chemotherapy and radiation therapy damage the lining of your stomach. This may make it hard for you to eat and drink during your hospital stay. You may need to have a nasogastric (NG) tube placed or get nutrition through your IV called TPN (total parenteral nutrition) to keep you from losing weight.

About your NG tube

An NG tube goes through your nose into your stomach. It can be placed by the nurse at your bedside. Your care team can use your tube to:

- Give you medicine when you can’t swallow.
- Give you liquid food when you can’t eat enough by mouth.
- Relieve gas or air pressure from your stomach.

Getting liquid food through your NG tube can help keep your gastrointestinal tract active. Your care team will take out your NG tube once you can eat, drink, and take medicine by mouth. Your clinical dietitian nutritionist will give you more information about the types of tube feedings you will need and how often you will need them.

About your TPN

The TPN mixture gives you all the nutrients your body needs through your IV. You will get your nutrition through TPN if you cannot eat or drink on your own and you aren’t able to have an NG tube. Your care team will check your nutrition levels every day and will make changes to your TPN mixture as needed.

Even if you’re getting NG tube feeds or TPN, you can try to eat and drink on your own if you feel well enough. Do not force yourself to eat or drink if you don’t feel well. Your clinical dietitian nutritionist and nurse will talk with you about the diet you’ll follow. They will also tell you which foods you should eat during your treatments.

Exercise and physical activity

Physical activity is very important. Get out of bed at least 2 times a day. Try to walk in your room every day to keep your muscle tone and strength. Sit up in your chair as often and for as long as you can each day.

You can bring things to do, such as a laptop, books, and games. If you’re a student, you can bring your books and assignments to keep up with schoolwork. The hospital teacher will come to your room and help you with your lessons.

The physical therapists (PTs) and occupational therapists

(OTs) will also check your needs. They will help you keep your muscle tone and strength as much as possible throughout your stem cell transplant.

What to expect between hospital admission and the day of your transplant

Supportive care

Supportive care medicine is used to prevent or treat the symptoms of a disease or side effects caused by treatment as early as possible. You'll get several supportive care medicines throughout your transplant admission. These include:

- **Ondansetron**: This helps reduce nausea (feeling like you're going to throw up) and vomiting (throwing up).
- **Ursodiol**: This protects your liver from the side effects of chemotherapy.
- **Antibiotics and antivirals**: These prevent or treat infections.
- **Pain medicine:** This will help with any pain or discomfort you have as part of the side effects of your treatment. Pain medicine may include narcotics, such as opioids. You may also get a patient-controlled analgesia (PCA) pump. A PCA pump helps you control your pain by letting you give yourself pain medicine at the dosage prescribed to you.

You’ll also get **red blood cell, platelet, and plasma transfusions** to correct anemia and prevent bleeding.

Cytoreductive therapy

Cytoreductive therapy is either chemotherapy alone or chemotherapy and radiation. Cytoreductive therapy will help destroy any cancer cells in your body and eliminate your immune system so it doesn’t reject the new blood stem cells.

You’ll get chemotherapy for several days. Your team will review your treatment plan with you. You can also refer to a copy of your roadmap in the front of this guide. Depending on your treatment, you’ll have 1 to 2 days of rest after your cytoreductive therapy before you get your blood stem cell transplant.

If you’re getting radiation therapy as part of your cytoreductive therapy, you’ll get written information about Total Body Irradiation (TBI). You’ll also get a schedule with the timing of each session that week. You’ll get the treatments 2 to 3 times per day. Each session lasts 20 to 40 minutes. A patient escort will take you to and from each session.

Types of stem cell transplants

The type of transplant you have depends on the underlying disease or diagnosis and:

- The type of donor.
- The level of HLA (tissue typing) match between you and your donor.
- The source of the donation (marrow, peripheral blood, or cord blood).
- How the stem cells are processed in the laboratory before you get them.

You can read more about these things below. Your doctor will talk with you about the type of transplant you're scheduled to have.

Type of donor

- **Autologous donor**: This is when your own stem cells are collected in the donor room and frozen. They can be thawed either in the laboratory or at your bedside. The attending physician will infuse the stem cells into your CVC.
- **Allogeneic donor**: This is when stem cells are donated by someone other than yourself. An allogeneic donor can be a family member or a volunteer unrelated donor.

Tissue typing

If you're having an allogeneic stem cell transplant, your donor can be:

- **HLA matched** (identical)
- **HLA mismatched** (not identical)

Source of stem cells

Blood stem cells can come from:

- **Bone marrow**: Marrow is taken from the donor's hip bones during a procedure in the operating room. The donor will get general anesthesia (medicine to make them sleep) before the procedure.
- **Peripheral blood**: Blood stem cells are taken from the donor's veins. The donor will take G-CSF (Neupogen®) for 4 to 5 days before the donation. They'll then donate the stem cells in the blood donor room while they're awake.
- **Cord blood**: Blood stem cells are taken from umbilical cord blood donated by a mother after her baby is born. The cord blood cells are frozen and thawed when they're needed. Cord blood can come from a family member, but it usually comes from a public cord blood bank.

Type of processing

- **None/minimal**: Red cells or plasma may be removed from the donor marrow or peripheral blood, but no other changes are made. This is called unmodified or T replete marrow or peripheral blood.
- **T cell reduced**: The donor marrow or peripheral blood is treated in the laboratory to reduce the number of T cells. This helps lower the chance that you get Graft versus Host Disease (GVHD). This type of stem cell transplant used to be called "T cell depleted."

What to expect on the day of your transplant

One to 3 days after you finish your cytoreductive therapy treatments, you'll get the donor's stem cells. The stem cells will be given to you through your CVC from a syringe or a bag, like a blood transfusion. The nurse will check your temperature, blood pressure, pulse, and oxygen level during and after the infusion. You'll also get diphenhydramine (Benadryl®) and acetaminophen (Tylenol ®) before your transplant. This is to help lower side effects you may have during your infusion.

Even though side effects are rare, a nurse will watch closely for any side effects during your bone marrow or peripheral stem cell infusion. If you're getting a cord blood transplant, you may experience high blood pressure.

Some other side effects you may have include:

- Nausea
- Vomiting
- A tickle in your throat
- A cough

Other less common side effects include:

- A fever
- Chills
- Low blood pressure

Tell your care team and your caregiver if you have any of these side effects. They will help you manage them.

Depending on the type of transplant you get, you may notice a strong, garlic-like taste in your mouth during and after your transplant. Your urine, sweat, and skin may also have a garlic-like smell. You may not notice the smell but people around you may. This smell is caused by the preservative used to store your stem cells. It will gradually go away over 1 to 2 days. You can use gum, hard candies, or drinks to help with the taste.

Once infused, the blood stem cells will travel through your bloodstream to your bone marrow space. There, they will grow, making healthy blood cells in your body. You'll stay in the hospital until your new stem cells can make enough white cells, red cells, and platelets. This usually takes about 4 to 6 weeks from the day of your stem cell transplant.

What to expect after your transplant

Engraftment

Engraftment of the stem cells occurs when the donated cells go to your marrow and make healthy new donor blood cells.

Depending on the type of stem cell transplant you have and your disease, engraftment can occur anytime between 2 and 4 weeks after your stem cell transplant. The first sign of engraftment is the gradual rise of your white blood cell count. When your ANC (absolute neutrophil count) is 0.5 or greater for 3 days in a row, we consider you to be to be engrafted. Platelets are generally the last blood cell type to recover. Engraftment can be delayed because of infection, medicines, low donated stem cell count, or graft failure.

The new bone marrow may start making cells in the first month after a stem cell transplant, but it may take several months for your whole immune system to fully recover. Your care team will check your blood to see how your immune system is recovering.

Graft rejection and graft failure

Sometimes, the transplanted cells don’t engraft as well as we want them to. Graft rejection means your immune system rejects the new stem cells. The cytoreductive treatments you get before your stem cell transplant are meant to help prevent graft rejection.

If your care team sees any signs of graft rejection or failure, they’ll do special tests on your blood and bone marrow. The results of the tests will guide your treatment. Your doctor will talk with you about your treatment options.

Possible issues after your transplant

Some issues are possible while you’re waiting for your blood counts to return to normal. Examples include infections, mouth sores, diarrhea (loose or watery bowel movements), bleeding, and anemia. Your care team will also watch you for any signs of organ toxicity (heart, lung, kidney and liver) and for GVHD. There are usually steps that you and your care team can take to prevent, manage, and treat these issues.

Review the consent form you signed with your doctor to learn more.

Everyone’s experience is unique. Not everyone will develop the symptoms or problems listed below. As a team, we’ll be observing you closely 24 hours a day. Please don’t hesitate to ask questions or express your concerns throughout your transplant journey!

Mucositis and diarrhea

Mucositis is inflammation in your mouth, inside your cheeks and lips, and down your digestive tract. Certain chemotherapy drugs and radiation therapy can cause this inflammation. The inflammation can cause painful sores, difficulty swallowing, and diarrhea.

Mucositis and diarrhea usually start 3 to 10 days after treatment starts. They usually heal 2 to 4 weeks after transplant as engraftment occurs. Your care team will give you pain medicine as needed to keep you comfortable.

Infection

You’ll be at risk for bacterial, fungal, and viral infections for several months after your stem cell transplant. This is because your immune system isn’t fully functioning. These infections are a major risk to your well-being, especially in the early recovery period until your new marrow grows and makes white blood cells to fight infection. Neutrophils recover first and fight bacterial infections, but T lymphocytes (T cells) that fight viral and some fungal infections can take several months to recover.

Fever is an important sign of infection. If you develop a fever, tests (such as blood cultures) will be done to find the cause of the fever. You'll get antibiotics to help your body fight the infection.

Nearly everyone develops a fever during the first 2 weeks after transplantation. Your team may change the antibiotics you're taking to fight the infection causing the fever. Most infections are treated successfully with antibiotics. If your care team thinks you have a central line infection, a doctor can take out your line and place peripheral IVs to give you your medicine. Sometimes we can take out your central line while you're in your hospital room.

Other tests that may be done when you have fever include:

- Blood tests to look for specific infections.
- X-Rays.
- Computed tomography (CT) scans or a positron emission tomography (PET) scan to look for infection in your internal organs.

You'll get medicine to treat and prevent infections. You'll also get anti-viral medicine to help keep any viral infections you had in the past from coming back after your stem cell transplant. These infections can include:

- Cold sores
- Shingles
- Pneumocystis jirovecii pneumonia (PCP)
- Cytomegalovirus (CMV)
- Other infections affecting the lungs or intestine

People whose immune systems aren't working well can get infections that healthy people don't usually get. These infections are called opportunistic infections. You may need medicine to help protect you from opportunistic infections. You're at risk for opportunistic infections until your white blood cell count and immune system return to normal.

Bleeding

Platelets are colorless cells that are a part of your blood. They're made in your bone marrow. The main job of platelets is to stop bleeding.

When your platelet count drops below a certain level set by your doctor, you'll get a platelet transfusion to prevent bleeding. If you have bleeding, you may get more platelets or fresh frozen plasma (FFP) to replace proteins needed for your blood to clot.

To avoid bleeding:

- Don’t use sharp objects (such as a straightedge razor, scissors, and nail clippers).
- Use a soft toothbrush and avoid flossing.
- Blow your nose gently, if needed.
- Avoid falling.

Anemia

When your red blood cell count is low, you may have weakness and fatigue (feeling more tired than usual). Your hemoglobin (a measure of your red blood cell count) will be checked every day. If your hemoglobin is low, you’ll get a red blood cell transfusion.

Organ problems

You may have damage to your kidneys, bladder, liver, lungs, heart, or central nervous system. You’ll be examined often and have daily lab tests to check for organ damage. Your treatment will be adjusted as needed to reduce this damage. Examples of adjustments include changing a medicine you’re taking or lowering the dose of a medicine you’re taking.

Kidneys

Your kidneys filter your blood and make urine to carry waste products out of your body. Chemotherapy and other medicines can affect how well your kidneys work.

Your medical team will know how well your kidneys are working by monitoring your daily blood tests (BUN and creatinine) and knowing how well your kidneys are making urine to get rid of toxins in your body. This is why it’s important that your nurse knows and records exactly how much you drink and how much urine you make. It’s also why you must be weighed at least once a day. If your weight increases, you may need a medicine to help your kidneys get rid of fluid and toxins in your body.

Additional tests that may be done to check how well your kidneys are working are:

- 24-hour urine collection for a creatinine clearance test.
- Glomerular Filtration Rate (GFR) done in the radiology department.

Damage to your kidneys may cause hypertension (high blood pressure) that needs to be treated. Your care team will determine if you need treatment by looking at the recordings of your vital signs. Your vital signs will be checked every 4 hours or more often depending on your needs.

Bladder (hemorrhagic cystitis)

Certain medicine, such as cyclophosphamide (Cytoxan®), and certain viruses, such as BK virus, can irritate the lining of your bladder. This may cause blood in your urine and make it painful to urinate (pee). This is called hemorrhagic cystitis.

To help prevent or treat this complication, you'll get large amounts of IV fluids. This will make you urinate often. Treatment for BK virus may include pain medicine and antibiotics. Sometimes, a urinary (Foley or straight) catheter can be placed in your bladder to help you urinate more easily.

Liver

Your liver takes harmful substances out from your blood, absorbs nutrients, and makes important proteins to help your blood clot. It also makes bile to help digest fatty foods. Damage to your liver can cause many problems.

After transplant, we're particularly concerned if small blood vessels in your liver are injured. The blood vessels can become blocked, making it difficult for blood to flow properly. This type of injury is called veno-occlusive disease (VOD) or sinusoidal obstructive syndrome (SOS).

VOD/SOS can cause your liver to get bigger and damage your liver cells. Swelling of your liver can also cause pain in your right upper abdomen (belly) under your rib bones. Because fluid can't pass through your liver, fluid may build up in your abdomen. This is called ascites. VOD/SOS can be mild or severe depending on the amount of fluid that your liver can't handle.

To check how your liver is working, you may have:

- Blood lab work (bilirubin, AST, ALT, and blood clotting proteins).
- An ultrasound scan to look at the size of your liver, how much ascites you have, and how well blood can flow through your liver.

If you develop VOD/SOS, you may get treatment with methylprednisolone, defibrotide, or both medicines. Your doctor will discuss treatment options with you.

Lungs

Your lungs control your breathing. You may breathe faster or develop a low oxygen level if there's a problem with your lungs. Problems with your lungs that can happen after a stem cell transplant include:

- Damage to your lungs from chemotherapy or radiation that causes inflammation and scarring (interstitial

pneumonitis). If this happens, it usually shows up later after transplantation.
- Pneumonia caused by an infection in your lungs.

Lung infections happen most often in the first few weeks after a stem cell transplant. Your care team will watch you closely for any sign of pneumonia. Tell them if you notice any change in your breathing or if you get a cough. Treatment of pneumonia depends on what bacteria, virus, or fungus causes the pneumonia.

To help find a lung infection, you may have a:

- Chest x-ray
- CT scan
- Bronchoscopy (a procedure to take some fluid from your lungs so it can be tested for infection).

To help prevent and treat pneumonia, it’s important for you to exercise your lungs. Your nurse will show you how to use an incentive spirometer (a device that you breathe into that helps your lungs expand). Regular, deep breathing exercises can also help.

Heart

Your heart pumps blood throughout your body. Certain chemotherapy medicines may have side effects that damage your heart. Your doctors will watch your heart function carefully while you're in the hospital.

Your heart function can be checked using:

- Lab tests
- An electrocardiogram (EKG)
- An echocardiogram (ECHO)

Graft versus host disease (GVHD)

T cells are white blood cells that attack foreign materials such as viruses and fungus. T cells also attack foreign grafts (tissue transplants), such as marrow, kidney, lung, or heart transplants. This is called graft rejection. T cells in the donor tissue also attack foreign material. The donor T-cells (graft) see the patient (host) as foreign and attack the patient's tissues. This is called graft versus host disease.

GVHD can develop when the new stem cells start to engraft (grow). The risk for GVHD is lower, but not gone, in people who get a closely HLA matched graft or a T cell reduced (depleted) stem cell transplant.

Anyone whose donor isn't an identical twin gets some type of prevention for GVHD. This prevention includes either removing the T cells from the transplant or taking medicine (such as Mycophenolate mofetil (MMF), tacrolimus, or cyclosporine). Your doctor will talk with you about these options before you’re admitted to the hospital.

There are 2 types of GVHD:

- **Acute** (early, usually within 3 months of transplant).
- **Chronic** (late and longer acting). Chronic GVHD usually develops after the first 100 days, and within the first year of transplant.

Common signs of acute GVHD include:

- Skin rash, often starting on the palms of your hands or soles of your feet
- Diarrhea
- Jaundice (a yellow skin color)
- Abnormal liver function tests

Common signs of chronic GVHD include:

- Skin rash or dry or thickened skin
- Loss of energy
- Loss of appetite and weight
- Diarrhea
- Dry mouth and mouth sores
- Dry eyes
- Hair loss

- Liver inflammation

GVHD may be mild or severe. Your medical team will be constantly watching you for any of these signs and will recommend tests for evaluation and treatment options.

Tests that might be done to evaluate for GVHD are:

- Lab tests
- Skin biopsy
- Colonoscopy or endoscopy to take biopsies (tissue samples) of the lining of your intestines

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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