Navigating Allogeneic Transplant:

A Guide for Pediatric Bone Marrow Patients

Pediatric Blood and Bone Marrow Transplant Program

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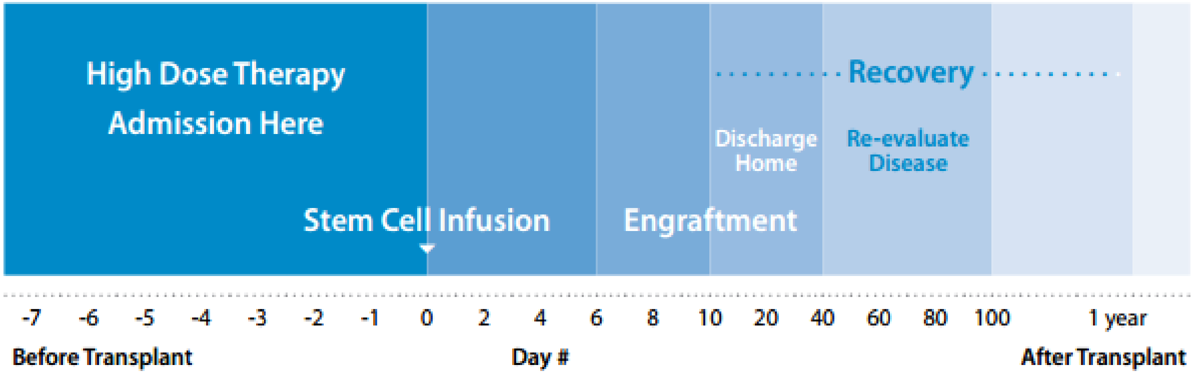
An Overview of the Allogeneic Transplant Process

What can I expect during the transplant process?

This diagram reflects a general overview of the transplant process:



The transplant process includes the following parts:

- **Conditioning:** a few days before your transplant, when you're admitted to the hospital and receive chemotherapy and possibly radiation to prepare your body for the transplant
- **Transplant:** the day of your stem cell infusion
- **After transplant:** the few days after your transplant
- **Engraftment:** when the transplanted cells start to grow and make new healthy blood cells (around 2-6 weeks)
- **Recovery:** your healing and wellness journey after you are discharged from the hospital

Read through this booklet to learn more about each part of the transplant process.

Part 1: Conditioning

What should I expect during conditioning?

The first part of the stem cell transplant process is called **conditioning**. We refer to these days as “negative days.” During this time, you will be admitted into the hospital. The day you receive your transplant is “Day 0.” Conditioning has 3 main goals (depending on the reason for your transplant):

- Making room for the new cells in your bone marrow space
- Killing cancer cells (for patients with cancer)
- Suppressing (weakening) your immune system

We will create a conditioning plan for you before transplant which will include chemotherapy with or without radiation therapy.

- **Chemotherapy**
  - Schedule depends on your specific treatment plan (see below)
- **Radiation therapy**
  - Performed in the Radiation Oncology department
  - Usually takes 30 minutes per session

What is the purpose of chemotherapy and radiation?

The purpose of these therapies is to suppress (weaken) your current immune system in preparation for transplant. Your immune system needs to be suppressed to prevent your body from rejecting the new donor cells.

- Most commonly, higher dose chemotherapy plans are used to destroy the bone marrow, so that new stem cells can start to grow there. This is called **myeloablative conditioning.**
- Some plans use lower doses of chemotherapy to decrease but not completely destroy the bone marrow, which we call **non-myeloablative** or **reduced intensity conditioning**.

Your conditioning plan:

- Day ( ): ________________________________
- Day ( ): ________________________________
- Day ( ): ________________________________
- Day ( ): ________________________________
- Day ( ): ________________________________
- Day ( ): ________________________________
- Day ( ): ________________________________

What are the side effects of conditioning?

You can expect certain side effects from each of the medicines you receive during conditioning. These will be managed with medications and other supportive care measures. Commonly expected side effects include:

- Nausea or vomiting
- Diarrhea
- Mucositis (mouth sores, throat pain, heart burn, stomach pain)
- Hair loss
- Bleeding
- Irritation to the liver
- Other side effects specific to your plan (see the chemo handouts in the binder we gave you)

These side effects can last throughout the transplant course, but they are usually not permanent.

What is a complete blood count (CBC)?

The **complete blood count (CBC)** is a test that measures your blood cell levels. This includes the following counts:

- White blood cells (WBC)
    - Absolute neutrophil count (ANC)
    - Absolute lymphocyte count (ALC)

    - Blast cells
- Red blood cells
    - Hemoglobin
    - Hematocrit
- Platelets

We will look at your counts for changes during conditioning, and later to see how your body is responding to your transplant.

What happens to my white blood cell levels during conditioning?

We monitor your labs (the results of your blood draws) closely and expect that your ANC and ALC levels will decrease (often as low as 0) during and after conditioning.

- The type and dose of chemotherapy you have will determine when your ANC drops. They reach a low point about 7-14 days after treatment. This low point is called the **nadir**. At the nadir, you are at high risk of developing an infection. We will give you medications to try to prevent infection.
- The nadir is also the time where you may lose your hair and feel general weakness. You likely will have mouth, throat, and abdominal (stomach) discomfort from conditioning to recovery, but the worst happens during this period when your counts are lowest.
- To reduce the risk of infection, you will not be allowed to leave the unit while your counts are at this low point.

Will I need blood transfusions?

In addition to your ANC declining, you will also notice a decline in your hemoglobin and platelet numbers. You will likely need a transfusion of blood products, including packed red blood cells (pRBC) and platelets. You may experience some bleeding (nose bleeds, mouth bleeding) at this time.

- You may need a blood transfusion if your platelet count is less than _____ or your hemoglobin is less than _____.
- If you've had a reaction to blood transfusions in the past, you may get medicine such as Tylenol®, Benadryl®, or steroids before the transfusion to try to prevent that reaction.

What do I need to know about central line care?

After transplant, most patients will go home with their **central line** (a long flexible tube that enters your body through a vein, which helps to give you treatments) in place. This line will stay in for months. We encourage you to become actively involved in the care of this line, starting from your admission (check-in) to the hospital, so that you have time to learn and feel comfortable caring for this line at discharge (when you leave the hospital). Care of your central line includes flushing the line, cap changes, and dressing changes. Your nurse will help teach you and oversee your care.

Part 2: The Transplant Procedure

What can I expect on the day of my stem cell transplant (Day 0)?

The **stem cell transplant** replaces the diseased or empty bone marrow with healthy donor stem cells. These donor cells come from 1 of 3 sources: bone marrow, umbilical cord blood, or normal (peripheral) blood. The day you receive your cells is called "Day 0."

Transplant date: ______________________________
Transplant type: Allogeneic
Cell source: __________________________________

What should I expect during the transplant infusion?

- We will deliver stem cells to your room in either a bag or a syringe. If they were frozen, they will be thawed at your bedside.
- You may receive medications and IV fluids to reduce your side effects before you get your infusion of stem cells.
- Your nurse will infuse (give you) the stem cells through your central line, similar to the way you receive blood or IV medications.
    - If your stem cells are frozen, you may notice a smell during the infusion. Some people describe the smell as garlic, tomato juice, or creamed corn. This is normal, and it is from the preservative used when the cells are collected and frozen.
- Depending on the fluid volume of your transplant, the entire process from start to finish can take a few minutes to a few hours.
- A doctor, nurse practitioner, or physician assistant will be there to monitor you (check on you) throughout the process.
    - We will monitor your vital signs (heart rate, etc.) more often during the infusion.

What are the side effects of the transplant infusion?

Many patients have no issues with their transplant. However, some of the most common side effects include:

- High blood pressure
- Nausea or vomiting
- Fever
- Chills
- Hives (small itchy bumps on your skin)
- Allergic reaction (rash, difficulty breathing, face swelling)
- Bloody or pink-colored urine (pee)

Many of these side effects typically go away when the stem cell infusion is over. However, we may need to do other things to help your side effects, such as giving you medications and longer monitoring and care.

What medications will I take to prevent infections?

During your admission and after your discharge, you will be taking several different medications to reduce your risk of viral, bacterial, and fungal infections.

Medication type: Anti-bacterial

In addition to taking this when your counts are low, this may be needed if you have **graft versus host disease (GVHD)** or if you are taking steroids.

Brand names:	**When you start taking it:**	**When you stop taking it:**
Levaquin® Vantin®	Day +1	• If you develop a fever, we will usually have you stop taking this and give you a stronger IV medication • Engraftment

Medication type: Anti-viral

Depending on your viral history and conditioning plan, we may take weekly labs to monitor you for viral infection after the transplant. We will watch for viral infections such as cytomegalovirus (CMV), Epstein-Barr virus (EBV), or adenovirus.

Brand names:	**When you start taking it:**	**When you stop taking it:**
Acyclovir®	Day 0	• Patients with herpes simplex virus (HSV+): Day +30 • Patients with varicella-zoster virus (VZV+): 1 year
Letermovir®	Day +10	• Until Day +100

Medication type: Anti-fungal

Brand names:	**When you start taking it:**	**When you stop taking it:**
Fluconazole® Micafungin® Voriconazole® Posaconazole® Isavuconazole®	On admission	• Day +100, as long as you're also off immunosuppressant medication

Medication type: Pneumocystis jiroveci pneumonia (PJP) treatment

Brand names:	**When you start taking it:**	**When you stop taking it:**
Pentamidine® Bactrim® Atovaquone®	Day +30	• 6 months after your transplant, as long as you're also off immunosuppressant medication

Medication type: Intravenous immunoglobulin (IVIG)

This medicine is a boost of antibodies that can kill bacteria, fungi, or viruses.

Brand names:	When you start taking it:	When you stop taking it:
---	You will be given this as needed based on your lab values	

Medication type: Encapsulated organisms infection prevention

You may receive these medications if you have had a splenectomy, you're functionally asplenic, you have chronic GVHD, or you are a cord blood transplant recipient.

Brand names:	When you start taking it:	When you stop taking it:
Penicillin-VK	After engraftment	• After you've been off immunosuppressant medication for 1 month and you're asymptomatic • If you have had a splenectomy or if you have extensive chronic GVHD, you will be on this for life

Part 3: After Your Transplant & Transplant Side Effects

What can I expect in the days after my transplant?

Fluids, electrolyte imbalance, and nutrition (FEN) monitoring

We will monitor you for the following:

- **F**luids
- **E**lectrolyte imbalance
- **N**utrition

Fluids:

You will get fluids through an IV:

- As needed during your hospital stay (including if you are not able to drink enough fluid)
- Continuously before, and for 1 day after, your transplant

Your daily fluid goal is: _____________ mL/day

- It is important that we closely monitor your fluid intake and output (how much fluid your body takes in and gets rid of).
- We monitor your weight once or twice a day to check for **fluid overload** (too much fluid in your body).
- We may give you medication such as Lasix® to help your body remove extra fluid.

Electrolyte imbalance:

If you have an **electrolyte imbalance**, this means that one or more of the lab values we measure in the blood (such as magnesium, potassium, phosphorus, or sodium) is higher or lower than normal.

- There are many causes of this, including eating less, diarrhea, medications (like tacrolimus), and IV fluids.
- The most common imbalances are low magnesium and high or low potassium.

Treatment for any electrolyte imbalance may include:

- Fixing the cause of the imbalance
- Oral (by mouth) or IV electrolyte replacement
- Adjusting your medications and total parenteral nutrition (TPN) (read the next section for details)
- It is likely that you will go home with an IV magnesium infusion, which will be slowly transitioned to oral magnesium (magnesium you take by mouth)

Nutrition:

You may feel less hungry (you "lose your appetite") and eat less after your transplant. The main causes are nausea, taste bud changes, and oral (mouth) pain. Getting good nutrition is important for your healing and overall health! A dietitian will teach you about a specific BMT (blood and marrow transplant) diet. Treatment for your nutritional needs may also include:

- Feeding through the gastrointestinal (GI) tract (stomach and intestines), called **enteral nutrition**
    - You may take supplements by mouth to get more calories and protein. There are many types and flavors of supplements.
    - You may have **tube feeds**, where you're given medication and liquid nutrition through a small tube placed through the nose into the stomach or small intestine.
- Feeding through an IV, called **parenteral nutrition**
    - You may have **total parenteral nutrition (TPN)**, where all of the protein, calories, vitamins, and minerals you need are given to you

through a vein. This type of feeding does not use your digestive system. It can irritate your liver and increases your risk of infection.

Your daily caloric goal is: ______________________kCal/day

You will get these medications to help prevent FEN-related issues:

- Glutasolve® (an amino acid which promotes healing of the GI tract)
- Liver/biliary protection: Actigall®, N-acetylcysteine
- Stomach ulcer prevention: Zantac®, Pepcid®, or Prilosec®
- Vitamin D deficiency: cholecalciferol

What side effects could I have during the transplant process?

Mucositis

Mucositis is a common side effect of conditioning, usually around 5-10 days after you start chemotherapy. It is pain and swelling (inflammation) of the body's mucous membranes. A **mucous membrane** is the soft layer of tissue lining parts of your body, particularly the digestive system from your mouth to your bottom. Mucositis can cause your skin or the surface of soft tissue to break down.

What are the symptoms?

- Mouth sores or changes to the inside of your mouth
- Change in taste buds and loss of appetite
- Pain or discomfort in your mouth, esophagus (the tube that food and liquid moves through from your throat to your stomach), or stomach
- Nausea, vomiting, or diarrhea
- Drooling thick or thin fluid
- Hoarse (rough or harsh) voice

How can I reduce these symptoms?

- Take good care of your mouth (brush 4 times a day, use lip balm)
- Take amino acid supplements (like Glutasolve®)

What is the treatment?

- Pain medication: you'll usually start taking pain medication for mucositis as a pill, but you may also need IV pain medication
- Magic mouthwash: this is a mouth rinse that we will give you during your hospital stay

When will I start to heal?

The sores and your mucositis will get better as your ANC starts to rise (during engraftment).

Gastrointestinal (GI) complications

Nausea and vomiting:

- This is the most common side effect of transplant.
- To prevent or treat nausea and vomiting, some medications will be given to you on a set schedule while others may be given to you as needed when you're feeling sick.
    - Commonly used medications include Zofran®, Kytril®, Zyprexa®, Ativan®, and Phenergan®.
    - Your medication plan: ____

Diarrhea:

- Diarrhea is usually caused by mucositis, although it may also be caused by a virus or bacteria.
- Diarrhea is treated with hydration (IV fluids) and giving time for the GI tract to heal. If you have infectious diarrhea, you may need antibiotics.

Constipation:

- Constipation (not being able to have bowel movements, or having hard bowel movements) is usually caused by not eating or by side effects of pain medication.
- Constipation can be treated by eating and drinking (when possible) to keep things moving in your GI tract. You may also take medications to help with bowel movements like Senna®, Colace®, Miralax®, or Lactulose®.

Sinusoidal obstructive syndrome (SOS), also called veno-occlusive disorder (VOD)

SOS/VOD is a rare side effect caused by damage to the lining of the blood vessels in your liver from chemotherapy. This usually occurs within the first 30 days after transplant. It is more common with the higher doses of chemotherapy used with transplant and some particular types of chemo.

What are the symptoms?

- Weight gain
- Swelling (because of extra water in your body)
- Stomach tenderness or pain
- Liver swelling
- Yellowing of your skin or eyes

How can I prevent SOS/VOD?

You can prevent SOS/VOD by closely monitoring your weight and fluids, measuring all fluid intake and output, and taking Actigall®.

What is the treatment?

- You can treat SOS/VOD by managing your symptoms, which may involve medications, blood transfusions, and careful monitoring of your liver and kidneys.

- We will pay close attention to how much fluid you take in and how much urine comes out. We often give medications (like Lasix®) to help increase urination.
- We may need to transfer you to the intensive care unit (ICU) for closer monitoring and aggressive diuresis (measures to increase urination).

Fever and neutropenia (low white blood cell count)

While your white blood cell counts are low, you are very likely to get a fever. This might be caused by an infection or inflammation from cells starting to engraft.

- Inflammation can be caused by cell irritation from chemotherapy and the transplant. This is the most likely reason for fever.
- The most common sources of infection are from your central line, your GI tract, or your respiratory system (your nose, mouth, throat, windpipe, and lungs).
- Fever may also be caused by a non-infectious inflammation response from your immune system called **haploidentical transplant-related cytokine release syndrome**. This can happen after your transplant until 4-5 days after your transplant. Symptoms include a long-lasting fever, changes in blood pressure, and low oxygen levels. You will receive Cytoxan® after your transplant, which will reduce this response.

What are the symptoms?

While you have a fever, some symptoms you might experience are:

- Tiredness
- Elevated (faster) heart rate
- Blood pressure changes
- Changes in your breathing
- Chills and shaking

If you have an infection, you may also have symptoms specific to the site of infection (like stomach pain, pain with urination, diarrhea, runny nose, cough, etc.).

What testing will I need?

If you have a fever or neutropenia, we will need to do these tests to rule out an infection:

- Blood cultures from all of your lines (if you have a fever, we will access your port)
- Possible viral labs
- Possible fungal labs
- Possible x-rays or CT scans
- Respiratory (nose) swabs
- Stool (poop) cultures
- Urine samples

What is the treatment?

We will need start treating you immediately, just in case the cause of your fever or neutropenia is an infection.

- As a safety measure, we may need to change the antibiotics and antifungals that you were on.
- We will continue to treat you as if you have an infection until we determine that you don’t have an infection.

Posterior reversible encephalopathy syndrome (PRES)

PRES is a rare side effect that medical experts think is related to severe high blood pressure, medications (like tacrolimus, cyclosporine, and Cytoxan®), and bone marrow transplant. It can happen at any time throughout the transplant process.

What are the symptoms?

- High blood pressure
- Headache (that is long-lasting and doesn't go away)
- Visual changes (difficulty seeing, blurred vision)
- Confusion
- Seizure

How can I prevent PRES?

Keep your blood pressure under control, and make sure that your magnesium and other medications are at appropriate levels.

How do you test for and diagnose PRES?

We will do a brain MRI (a scan that shows us pictures of your brain) and consult with the Neurology department.

What is the treatment?

- The medical staff may have you stop taking medications like tacrolimus or cyclosporine.
- You may need supportive care, including blood pressure management, seizure precautions, or anti-seizure medication.
- We may need to transfer you to the intensive care unit (ICU).

Transplant-associated thrombotic microangiopathy (TA-TMA)

TA-TMA is a syndrome defined by **hemolytic anemia** (destruction of red blood cells), low platelets, and organ damage. This is caused by the formation of very small blood clots in capillaries (tiny blood vessels) and small arteries, which can cause problems with your organs.

What are the symptoms?

- High blood pressure

- Low platelets and hemoglobin
- Kidney dysfunction (kidneys not working properly)
- Severe stomach pain
- Bloody diarrhea
- Other symptoms specific to the organs involved

How do you test for and diagnose TA-TMA?

We will do lab studies, urine tests, and a biopsy (if needed) to confirm if you have TA-TMA.

What is the treatment?

- Supportive care, including blood pressure management
- Changing your GVHD medications
- Reducing the number of transfusions you have
- If you have a severe case of TA-TMA, we may prescribe a medication called eculizumab

Part 4: Engraftment

What can I expect during engraftment?

After your transplant, your new cells will find their way to the bone marrow spaces and start to produce new blood cells. This is called **engraftment**.

- Engraftment means your new cells are growing and starting to rebuild your immune system.
- The first sign of engraftment is the production of neutrophils (measured by your ANC). **Neutrophil engraftment** is an ANC of 500 or greater for 3 days in a row.
- Neutrophils are the first cells to grow, followed by red blood cells, then platelets.

When does engraftment happen?

Your new cells will start to engraft 2-6 weeks after your transplant, depending on the cell source:

- Peripheral stem cells: 10-28 days
- Bone marrow: 10-28 days
- Cord blood: 14-42 days
- Haploidentical (haplo): 15-42 days

What medications will I receive during engraftment?

We will give you G-CSF (Granix®) injections. This will help speed up engraftment and reduce the length of time that your white blood cells are at their lowest count, which lowers your risk of infection.

- These injections are started on set days based on the transplant type. However, these days may change for a research protocol for a clinical trial.

- Your G-CSF will start on Day ____. We will stop giving you G-CSF once robust engraftment (engraftment with stable, solid counts) occurs.
- The most common side effects of G-CSF are body aches, bone pain, and discomfort with the injection.

What complications could I have during engraftment?

Engraftment syndrome

Engraftment syndrome is an inflammatory condition that happens around the time of engraftment. It is likely related to your body making too many inflammatory cells.

- Engraftment syndrome can be mild to severe.
- You may have a red rash, fevers, weight gain, or a need for oxygen.
- This condition is treated with steroid medications, Lasix®, and other supportive care activities.

Graft failure

It is rare, but sometimes engraftment does not happen. This is called graft failure. If your ANC has not met the goal after Day +28 for peripheral blood cells and bone marrow or Day +42 for haplo or cord blood cells, you have graft failure. If this happens, your medical team will talk with you.

Acute graft versus host disease (GVHD)

Acute GVHD is when the cells from your donor (the **graft**) see your body's cells (the **host**) as different and attack them. It can be mild to severe. GHVD usually happens between engraftment and around Day +100.

Depending on what parts of your body are involved, symptoms of acute GVHD may include:

- Skin rash

    - The rash may be red, flat, bumpy, or itchy.
    - It is often on the palms, soles (bottoms of your feet), ears, and face, but it can be anywhere.
- Nausea
- Not feeling hungry (loss of appetite)
- Weight loss
- Diarrhea that can be watery, bloody, green, or a large amount
- Stomach pain or cramping
- High levels of bilirubin in your liver
    - Your medical team will watch for this on your labs.

There may be other causes for these symptoms, which we will rule out first.

What medications will I take to prevent GVHD?

My GVHD prevention plan medications:

____

Calcineurin inhibitor: Tacrolimus (or "tacro")

Directions:	• In the early parts of your transplant, we will give this to you as an IV medicine that infuses around-the-clock (all day). • Once you can take it by mouth, you will take it 2 times a day, 12 hours apart. **The timing of this medication is really important!** o We take labs to monitor the levels of this medicine in your blood, and adjust your dose based on these labs, to make sure you are taking the best dose for you. The goal level is 8-12 nanograms per millileter (ng/ml) in most cases.

	• You will continue taking tacrolimus until at least Day +100 (often longer).
Side effects:	High blood pressure, low magnesium, high potassium, tremor (shaking), PRES, kidney injury
Things to avoid:	Do not drink grapefruit juice when taking tacrolimus.

Cyclosporine (CSA)

Directions:	• In the early parts of your transplant, we will give this to you as an IV medicine that infuses around-the-clock (all day). • Once you can take it by mouth, you will take it 2 times a day, 12 hours apart. **The timing of this medication is really important!** o We take labs to monitor the levels of this medicine in your blood, and adjust your dose based on these labs, to make sure you are taking the best dose for you. The goal level is typically 200-400 ng/ml.
Side effects:	High blood pressure, low magnesium, high potassium, tremor (shaking), increased hair growth, high triglycerides, PRES, kidney injury
Things to avoid:	Do not drink grapefruit juice when taking cyclosporine.

Mycophenolate mofetil (MMF or CellCept®)

Directions:	• Take this medication 2-3 times a day per instructions. • Usually you won't take this medication longer than Day +35.
Side effects:	Upset stomach, diarrhea

Sirolimus

Directions:	• This is a pill you will take once a day. • Follow your provider's instructions for how long you should take this.
Side effects:	High blood pressure, high triglycerides, swelling of your body's extremities (like your hands and feet), kidney injury

Post-transplant methotrexate

Directions:	• We will give this to you as an IV infusion in 4 separate doses, usually on Days +1, +3, +6, and +11.
Side effects:	Problems with liver and kidney function, mucositis (swelling of your mucous membranes)

Post-transplant Cytoxan®

Directions:	• We will give this to you as an IV infusion, usually on Days +3 and +4. • We may order EKGs before we give you the dose. • We will also give you IV fluids around this time to help protect your bladder.
Side effects:	Nausea, bladder irritation, problems with cardiac (heart) function

Restasis

Directions:	• These are eye drops for GVHD prevention. Use them as instructed 2 times a day.

What is the treatment for acute GVHD?

Mild cases of skin GVHD can often be treated with a steroid drug applied to the skin (topically) as an ointment, cream, or lotion. More serious cases of GVHD might need to be treated with a steroid drug taken by mouth (orally) or injected into a vein. If steroids aren’t effective, other drugs that affect the immune system can be used.

Part 5: Discharge and Recovery

What are my goals for discharge?

Before you are cleared to leave the hospital (called **discharge**), we expect that:

- You will have engraftment with stable counts (all blood counts)
- You need blood product transfusions 2 days or less per week
- You have not had a fever for more than 24 hours
- You have no active infections
- You have limited nausea, vomiting, or diarrhea
- You are able to take medications by mouth
- You're meeting your goals for calories and fluid intake
- You are able to move around and perform daily care activities (like bathing, taking medications, etc.)
- Your discharge medications have been delivered to your bedside so we can go over them with you
- Your caregiver has shown the hospital staff that they're able to care for your lines and medications
- Your home infusions have been ordered and delivered
- Other:____

What medications will I take at home?

- You will receive your medications from the Taubman Pharmacy before discharge. We will check these at your bedside to make sure you have the right medications, and we will teach you about them. You are expected to know what these medications are, as well as when and why you are taking them.
- After discharge, you must bring these medications to the clinic with you for your follow-up appointments. Some medications (such as voriconazole and tacrolimus) require lab monitoring to check and adjust

your doses. **On clinic days, you will not take these medications until after your labs have been drawn.**

What do I need to do to prevent sickness and stay healthy at home?

You must take the following **precautions** (actions to help you avoid getting sick) until you are off of immunosuppressant medication (steroids, tacrolimus, cyclosporine) or until you are cleared by your BMT doctor.

Personal hygiene (cleanliness)

- Shower or bathe every day. All your family members and people staying around you should also shower or bathe daily.
- Avoid direct sunlight. Your skin will be more sensitive after your transplant. Protect your skin with a sunscreen that has an SPF of at least 30. Reapply (put more on) often. Cover your skin with cotton clothing and a protective hat.
- Don't get any new tattoos or piercings.

Masking

- Wear a facemask when you're coming to the clinic or hospital, or when you'll be around large crowds of people.

Being around other people

- Avoid being around anyone who is sick. Ask your guests to take their temperatures before coming over and make sure they have not had colds, rashes, vomiting, or diarrhea.
- Avoid crowds of people.
- Try to limit your time around children younger than 12 years old who are not part of your immediate family.
- Call your doctor immediately if you, or any other friend or family member around you, is exposed to chickenpox, shingles, measles,

German measles (rubella), or any other contagious (easy to spread) disease.

Pets

- **Do not get any new pets.**
- Don't clean up after your pets. This includes changing a litter box or picking up poop.
- Wash your hands after any contact with pets.
- Do not touch any birds or farm animals.
- Do not keep any reptiles (lizards, snakes) or amphibians (frogs, toads) in your home.

Home safety and cleanliness

- Don’t play in the dirt or leaves. This includes avoiding gardening and caring for plants.
- Don’t do any chores where you’d come into contact with dust.
- Do not use a bedside humidifier.
- Do not have your carpets cleaned.
- Avoid lung irritants such as smoking, secondhand smoke (being around other people who are smoking), and aerosols (like spray paint).

School and work

- You can’t go back to school or work until your doctor says it’s okay.
- You may continue your education at home using printed or computer material through a virtual program.

Diet (food and drink)

- **Use the FDA Food Safety booklet you received from the dietary team.**

Substance use (including alcohol, nicotine, inhaled marijuana, vaping and illicit drug use)

- **To keep you safe, you should not use any of these substances after your transplant unless you've talked with your transplant doctor about it.** There are possible drug interactions (harmful or unsafe drug combinations) and risks of organ dysfunction with many of these substances.
- Smoking and vaping (tobacco or marijuana) can lead to lung injury, fungal infection, and secondary cancer risk.
- Drinking alcohol can harm your liver and interact with your medications.

Other activities

- You may not drive until your doctor says it's okay.
- You may not play contact sports (like football or hockey) until your doctor says it's okay.
- **Do not swim if your central line is still in place.** Once your central line is removed, you can swim in a private pool that isn't crowded. Make sure that the pool is chlorinated. You cannot swim in lakes, rivers, or crowded pools until your immune system has recovered.

What do I need to know about reproductive and sexual health after my transplant?

Because of the physical changes to your body after your transplant, you may be affected physically and emotionally with your sexual activity. It is normal to feel more self-conscious or nervous. Changes to your sexual health that you may experience after transplant include:

- Trouble having an orgasm
- Trouble keeping an erection
- Vaginal dryness, painful sex, or increased vaginal bleeding during menstruation (your period) or during sex

Will I be able to have children after transplant?

Your **fertility** (your ability to become pregnant or make someone else pregnant) may be decreased after your transplant. However, **it may still be possible to have children.** There are serious risks if you become pregnant, as it may require changes to your therapy plan which can have an effect on your health and transplant outcome. Because of the medications you are on, birth defects (where a baby's body develops differently than normal) are also possible.

How can I have sex safely?

There will be times when you'll need to avoid sexual activity, including when your blood counts are low. This includes vaginal, oral, and anal sex, or inserting fingers, vibrators, or other sex toys into your vagina or anus. This is to prevent bleeding or major infections. Until your doctor tells you that your blood counts and immune system have recovered, follow these precautions:

- Avoid sexual activity when your ANC is under 1000.
- Avoid sexual activity when your platelet count is under 50,000.
- Use condoms each time you have vaginal, oral, or anal sex.
- If using lubricant, use a water-based lubricant. Using other products can increase your risk of infection.
- Don't do any sexual activity where your mouth could come into contact with feces (poop).
- If you or your partner has a sexually-transmitted infection (STI), or if you think you might have an STI, avoid sex that involves contact with mucous membranes (including the vagina, mouth, or anus).
- Hugging, cuddling, gentle touching, and kissing are other ways you can be intimate with your partner during this time.
  - Avoid kissing if you have mouth sores or open wounds in your mouth, or if your partner has mouth sores.

Talk with your healthcare provider if:

- You have vaginal dryness or tightness that makes sexual activity painful
- You have difficulty getting or keeping an erection
- You have any other questions or concerns

What should I expect for my follow-up visits in the BMT clinic after discharge?

After discharge, if you don't have any complications requiring closer follow-up, you will be seen in the BMT clinic at least weekly until Day +100.

- You must stay in the Ann Arbor area, within 100 miles of the University of Michigan Medical Center, for the first 8-12 weeks after your transplant.
- People who are not enrolled in clinical research studies will have visits on Days +30, +100, +180 (for selected patients), and 1 year after transplant for follow-up. People in clinical research studies will be seen for follow-up based on their study's specific guidelines.
- Your first visit will take at least 1 hour.
- You may have an infusion appointment scheduled in case you need blood or platelets.
- Your lab appointments will be scheduled before your clinic appointment.
    - Do not take tacrolimus, posaconazole, or voriconazole before your lab draw. You make take these medications after getting your blood drawn.

What should I watch for, and when should I call 911 or go to the emergency room (ER)?

Call 911 immediately if:

- You or your child is having **trouble breathing**
- You or your child is **not responsive**
- You or your child has any other **issues that may be life-threatening**

Call the clinic and go to Mott Emergency Department, or go to your local ER (if you live more than 30 minutes away from the University of Michigan), if you notice these symptoms:

- **Fever**: We have given you a thermometer. You do not need to routinely check your temperature unless you are concerned about fever. If you need to check your temperature, do so orally (under the tongue). Rectal temperatures are not recommended for children with cancer. It's a good idea to keep a bag packed at home, just in case, as a fever usually means you will need to check into the hospital. **Call the clinic and go to the ER if your thermometer has these readings:**
    - 2 temperature readings (done 1 hour apart) of 100.4˚ Fahrenheit (38˚ Celsius) or higher
    - 1 temperature reading of 100.9˚ Fahrenheit (38.3˚ Celsius) or higher
    - Any temperature reading above 98.6˚ Fahrenheit (37 ˚ Celsius) with concerning symptoms such as cough, congestion, behavior changes, etc.
- **Bleeding**: This includes nosebleeds that last longer than 10 minutes, red or black bowel movements, red or dark brown vomiting, red urine, or an increase in bruising.
- **Cognitive symptoms:** This may include extreme sleepiness or drowsiness, changes in mental status or behavior, vision changes (such as double or blurred vision), or increased pain or headaches that last several hours or are not controlled by prescribed pain medication.
- **GI symptoms**: This includes constipation or vomiting that is not helped with prescribed medications, diarrhea or pain with bowel movements, pain with urination, not being able to eat or drink, or not being able to take oral (by mouth) medications.
- **Central line problems:** This may include any pain, redness, drainage (leaking fluid) or swollen areas around central lines or port sites, a break, crack, or tear in the central line, or issues with flushing or leaking from your catheter.

What is the contact information for my BMT team?

If you have any concerns or any of the symptoms listed above, please contact your BMT team:

- Monday through Friday from 8:00 AM – 5:00 PM: Call the BMT clinic and nurse line at (734) 936-9814
- After clinic hours and on weekends: Call (734) 936-9814 and ask for the BMT provider on-call

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