Pediatric Bone Marrow Transplant
Discharge Navigator

Pediatric Blood and Bone Marrow Transplant Program
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This booklet reviews the transplant process from the point of admission to the hospital until your outpatient visit after discharge.
What should I expect during conditioning?

Before Transplant – the conditioning regimen
The first part of the stem cell transplant process is called “conditioning”. We refer to these days as “negative days”. The day you receive you transplant is day 0. The conditioning regimen consists of chemotherapy with or without radiation given for two reasons:

1. Making room for the new cells in the bone marrow space
2. Killing cancer cells

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

- **Radiation therapy:**
  - Performed in the Radiation Oncology Department
  - Usually takes 30-minutes per session

- **Chemotherapy:**
  - Schedule depends on your specific treatment plan (See below).

What is the purpose of radiation and chemotherapy?
The purpose of these therapies is to suppress your current immune system in preparation for transplant. Your immune system needs to be in suppression to prevent rejection of the new donor cells.

- Most commonly, higher dose chemotherapy regimens are used to destroy the bone marrow, so that new stem cells can take hold. This is called **myeloablative conditioning.**
- Some regimens use lower doses of chemotherapy to decrease but not completely destroy the bone marrow, which we call **non-myeloablative or reduced intensity** conditioning.
What are the side effects of conditioning?

- Certain side effects are expected from each of the medicines you receive during conditioning. These will be managed with various medications and supportive care measures. Commonly expected side effects include:
  - Nausea/vomiting
  - Diarrhea
  - Mucositis (mouth sores, throat pain, heart burn, abdominal pain)
  - Hair loss
  - Other side effects more specific to tailored regimen (see chemo handouts)

These side effects can remain throughout the transplant course but are not permanent.

Your therapy plan is:

- Day : __________________________
- Day : __________________________
- Day : __________________________
- Day : __________________________
- Day : __________________________
- Day : __________________________
- Day : __________________________
- Day : __________________________

Your nurse will check these boxes after each topic is reviewed:

- Review Side Effects
- Review Scheduled and PRN Medications for Side Effects
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 are obtained from one of three sources: bone marrow, umbilical cord blood, or normal (peripheral) blood. The day you receive your new cells is called “Day 0”.

Transplant date: _______________________
Transplant type: _______________________
Cell source: __________________________

What should I expect during the procedure?

1. Stem cells are delivered to your room in either a bag or a syringe.
2. You will receive medications and IV fluids before the infusion of stem cells to lessen your side effects.
3. Your nurse will infuse your stem cells through your central line similar to the way you receive blood products or IV medications.
   a. You may notice a smell during the infusion. Some people describe the smell as garlic, tomato juice, or creamed corn. This is normal, and is from the preservative used when cells are collected.
4. Depending on the volume, the entire process from start to finish can take a few minutes to a few hours.
5. A doctor, nurse practitioner, or physician assistant will be present to monitor you throughout the process.

What are the side effects?

Many patients tolerate transplant without any issues, however, some of the most common side effects include:

- High blood pressure
- Nausea, vomiting
- Fever
• Chills  
• Hives  
• Allergic reaction  
• Bloody or pink-tinged urine

Several of these side effects resolve when the infusion is over. However, we may need to take other measures to help your side effects such as medications and longer monitoring and care.

Your nurse will check these boxes after each topic is reviewed:

☐ Review Transplant Process
☐ Discuss Pre-medications
What can I expect during the transplant process?

Foundation of 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

What happens to my white blood cell levels?
We monitor labs closely and expect that the ANC and ALC will decrease (often as low as 0) during and after conditioning.

- The type and dose of chemotherapy determines when your neutrophil levels drop. They reach a low point about 7 to 14 days after treatment. This low point is called the nadir. At the nadir, you are at high risk of developing an infection. You will receive medications to try to prevent infection.
• This 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 occurs during this period when your counts are lowest. You will not be allowed to leave the unit while your counts are at this point.

Recovery
After your transplant, your new cells will start to grow.
• Neutrophils are the first cells to grow, followed by red blood cells, then platelets.
  o Engraftment occurs when you have neutrophil growth. This means your ANC level is rising. It typically occurs around days 10-20, depending on the type of transplant you receive.
• Peripheral blood stem cells grow back the fastest and umbilical blood cord cells take the longest.
• You will need blood and platelet transfusions and injections (Granix) to encourage neutrophil growth until your body is fully capable of producing them on its own.

Your nurse will check these boxes after each topic is reviewed:
☐ Review Daily Counts
☐ Emphasizing Infection Control and Hygiene
☐ Leave of Pass Restrictions
What can I expect during engraftment?

• After your conditioning regimen and transplant we will wait for 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 (ANC). Neutrophil engraftment is an ANC of 500 or greater over 3 days in a row.

When does it occur?

• 2 to 3 weeks following transplant, depending on the cell source:
  o Peripheral Stem Cells 10-28 Days
  o Bone Marrow 10-28 days
  o Cord Blood 14-42 days

What medications will I receive during this stage?

• G-CSF (Granix) injections
  o Speed up engraftment and reduces the length of time that blood cells are their lowest, which lowers the risk of infection
  o Started:
    ▪ Cords: Day +1
    ▪ Auto, Allo: Day +8
  o Stopped: Once stable engraftment occurs

It is rare, but sometimes engraftment does not happen. This is considered graft failure and occurs if the ANC has not met the goal after Day +28 for peripheral blood or bone marrow or Day +42 for cord blood cells.
What can I expect during recovery?

**Fluids, Electrolytes, Nutrition**
We will monitor you for the following (FEN):
- Fluids
- Electrolyte imbalance
- Nutrition

**Fluids (IV):**
- You will get these:
  1. As needed during your hospital stay
  2. Continuously before and for 1 day after your transplant
  3. When you are not able to drink enough fluid

**Fluid overload:**
- We monitor you weight once or twice a day to check for fluid overload.
- Medicines such as Lasix help your body remove excess fluid.

**Electrolyte imbalance:**
This means that one of more of the lab values we measure in the blood (such as sodium) is higher or lower than the normal values.
- Many causes: eating less, diarrhea, medication related (example: tacrolimus), IV fluids
- Most common imbalances: low magnesium levels and high or low potassium levels
- Treatment:
  - Oral and IV electrolyte replacement
  - Adjusting medications and Total Parenteral Nutrition (TPN) (See below)
  - Correcting the cause
**Nutrition**

You may experience appetite loss and eat less by mouth. The main causes are nausea, taste bud changes, and oral pain. Maintaining good nutrition is important for healing and overall health!

- A dietician will teach you about BMT diet specifics.
- **Treatment:**
  - Feeding through the gastrointestinal (GI) tract (stomach and intestines) as liquid (Enteral Nutrition):
    - Supplements
    - Tube Feeds: Medicines and liquids given through a small tube placed through the nose or mouth into the stomach or small intestine.
  - Feeding through an IV (Parenteral Nutrition)
    - Total Parenteral Nutrition (TPN): All of the protein, calories, vitamins and minerals a person needs delivered into a vein, it does not use the digestive system.
    - IV fluids

**Preventative medications:**

- Liver/biliary protection: Actigall
- Stomach ulcer prevention: Zantac, Pepcid, or Omeprazole
- Vitamin D deficiency: Cholecalciferol

Your nurse will check these boxes after each topic is reviewed:

- □ Educating on Accurate Reporting of I&Os
- □ Importance of Nutrition for Healing
**Medications to Prevent Infections**

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

<table>
<thead>
<tr>
<th>Type of Medication</th>
<th>Start</th>
<th>Stop</th>
<th>Medications</th>
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| **Bacterial:**     | Day +1      | • If you develop a fever antibiotics may be changed (usually to IV)  
                    |             | • Engraftment                              | Levaquin, Pen VK               |
|                    |             | • Day +100 (Cord Blood)                   |                              |
| **Viral:**         | Day 0       | • Herpes Simplex Virus (HSV+ patients): Day +30  
                    |             | • Varicella Zoster Virus (VZV+ patients): 1 year |                              |
|                    |             |                                          | Acyclovir                     |
| **Fungal**         | On admission| • Until Day +100, off immunosuppression   | • Fluconazole                 |
|                    |             | • Autos: Engraftment                      | • Voriconazole (Day +5)*      |
|                    |             |                                          | • Micafungin                  |
|                    |             |                                          |                              |

*Depending on your viral history and conditioning regimen, we may take weekly labs to monitor for viral infection after the transplant (CMV, EBV, Adeno).*
<table>
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<th>Start</th>
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| Pneumocystis jiroveci (PJP)                     | On day +30  | • When your platelet count is more than 50,000 and ANC is less than 1000 on Day +30. | • Pentamidine (inhaled, possibly IV)  
                                      |             |                                                                      | • Bactrim                                           |

Intravenous Immunoglobulin (IVIG)
This medicine is a boost of antibodies that can kill bacteria, fungi, or viruses.

* Trough levels will need to be monitored inpatient and outpatient.

Your nurse will check these boxes after each topic is reviewed:

☐ Review Prophylaxis Medication and Why
What side effects may occur during the transplant process?

Mucositis

Mucositis is a common side effect of the conditioning regimen. It is pain and swelling (inflammation) of the body’s mucous membranes. The mucous membrane is the soft layer of tissue lining of the body, particularly, the digestive system from the mouth to bottom. This can result in a break on the skin or on the surface of an organ (ulceration).

- Usually happens around 5-10 days after starting chemotherapy.

What are the symptoms?

- Sores or changes to lining of the mouth
- Change in taste buds and loss of appetite
- Pain/discomfort in mouth, esophagus, abdomen
- Nausea, vomiting, diarrhea
- Drooling
- Hoarse voice
- Infection due to skin/mucosal breakdown which can cause bacteria to spread

What is the treatment?

- Good oral care (brushing 4 times per day, lip balm use)
- Amino acid supplements (Glutasolve)
- Pain Medication, Magic Mouthwash
When will I start to heal?

Healing occurs when cells start to engraft, it starts with the mouth and progresses down through the digestive tract.

Your nurse will check these boxes after each topic is reviewed:

- [ ] Explain Mouth Care
- [ ] Discuss Symptom Management
Gastrointestinal (GI) Complications

Nausea and Vomiting:
This is the most common complication of transplant.

- **What is the prevention and treatment?**
  - Some medications are ordered both as scheduled around the clock.
    Others may be given as needed when feeling sick:
  - My regimen: ________________________________

Diarrhea:

- Diarrhea is usually caused by mucositis, although it may also be caused by a virus or bacteria.
- **What is the treatment?**
  - Hydration (IV fluids)
  - Time for GI tract to heal
  - May need antibiotics (if infectious)

Constipation:

- This is usually a result of not eating or side effects of pain medication use.
- **What is the treatment?**
  - Eating and drinking (when possible) to keep things moving
  - Medications to promote bowel movement: Senna, Colace, Miralax, Lactulose
Sinusoidal Obstructive Syndrome (SOS)/Veno Occlusive Disorder (VOD)

- This is a rare complication that is due to damage to lining of the blood vessels in the liver from chemotherapy.
- **What are the symptoms?**
  - weight gain
  - swelling due to extra water in body
  - abdominal tenderness
  - liver swelling
  - yellowing of skin or eyes
  - yellowing of skin or eyes

- Usually occurring within first 30 days after transplant
- Treatment: symptom management, including medications, blood transfusions, and careful monitoring of the liver and kidneys.
- May require transfer to the Intensive Care Unit (ICU)

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Your nurse will check these boxes after each topic is reviewed:
- Educating on Expected Complications
- Emphasizing Strict I&Os and Daily Weights
- Encouraging Use of PRNs
Fever and Neutropenia
While white blood cell counts are decreased, you are very likely to spike a fever. This may be due to an infection or inflammation from cells starting to engraft.

Inflammation
• Cell irritation likely from chemotherapy and the transplant
• Most likely reason for fever

Infection
• Most common sources:
  o Central line
  o GI tract
  o Respiratory

Testing
• Will need to be done to rule out an infection:
  o Blood cultures
  o Possible viral labs
  o Possible fungal labs
  o Possible x-rays or CT scans
  o Respiratory swabs
  o Stool cultures
  o Urine samples

Treatment for fever and neutropenia
• Will need to be started just in case the cause is an infection.
  o This may require use to change the antibiotics and antifungals that you were on as prophylaxis
  o Continue until infection ruled out
While a fever is present, some symptoms you might experience are:

- Tiredness
- Elevated heart rate
- Blood pressure changes
- Changes in breathing
- Chills and shaking

If infection is present, you may also have symptoms specific to site of infection (abdominal pain, pain with urination, diarrhea, runny nose, cough, etc.)

Your nurse will check these boxes after each topic is reviewed:

☐ Reinforce Common Occurrence of Fever
Need for transfusions

As your counts decline you will likely need blood products including packed red blood cells (pRBC) and platelets. You may experience some bleeding (nose bleeds, mouth bleeding) at this time. A blood transfusion may be required if your platelet count is less than 10,000 or your hemoglobin is less than 7 grams.

Pre-Medication before a transfusion

- If you’ve had a reaction in the past, you may get medicine such as Tylenol, Benadryl or steroids before the transfusion to try to prevent that reaction.

Your nurse will check these boxes after each topic is reviewed:

☐ Regularity of Transfusions
☐ Review of Transfusion Thresholds
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. GVHD usually occurs between engraftment and around Day +100.

Organs Involved:

- **Skin rash:**
  - Red
  - May be itchy
  - Often on palms, soles, ears, and face
  - Can be anywhere

- **Gastrointestinal (GI):**
  - Diarrhea:
    - Watery
    - Bloody
    - Green
    - Large volume
  - Abdominal pain/cramping
  - Nausea
  - Loss of appetite
  - Weight loss

- **Liver:**
  - Elevated bilirubin, a yellowish pigment found in bile, a fluid made by the liver. Your medical team will watch for this on labs.

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

- **Tacrolimus**
  - Taken twice daily, 12 hours apart. The timing of this medication is **really** important! We monitor the levels of this medicine in your blood to make sure you are taking the best dose for you.
    - Labs are drawn and the medicine should be taken at the same time every day
    - Goal level 8-12
    - Adjust doses often
  - Continue until at least Day 100, often times longer

- **Other medicines:**
  - _______________
  - _______________

Your nurse will check these boxes after each topic is reviewed:

- [ ] Reinforce the Timing of Tacro Doses & Importance of Compliance
- [ ] Review Additional GVHD Prophy Meds
What are my goals for discharge?
Before discharge, we expect:

- Engraftment with stable counts
- No active infections
- Controlled or no GVHD
- No fever for more than 24 hours
- Tolerating oral medications
- Adequate oral intake
- Transfusions required 2 or less days per week
- Limited nausea/vomiting or diarrhea
- You are able to move around and perform daily care
- Discharge medications are present at bedside
- Home infusions ordered and delivered
- Caregiver demonstration of care (lines, meds)
- Successful transition day
- Other:__________________________________________________________

What medications will I take at home?
You can pick up medications from the Cancer Center pharmacy before discharge. These will be checked at bedside for accuracy and you will receive education. You are expected to know what these medications are, when and why you are taking them.

After discharge, you must bring these medications to clinic with you. Some medications require lab monitoring to adjust doses such as: Voriconazole and Tacrolimus. You will not take these medications on clinic days until after your labs have been drawn.
You may go home with IV medications or IV fluids. These should be administered around the same time each day. You will be responsible for completing central line care and weekly dressing changes at home. You will learn and practice central line care during your hospital stay. Skilled nursing will assist you with this process at home, as well. Our case manager will work with you to set up home care before discharge.

Your nurse will check these boxes after each topic is reviewed:

- Reinforce DC Goals
- Education on Central Line Care and Other Home Med Infusions
- Discuss Upcoming Transition Day
- Provide Thermometer and Discuss Fever Guidelines at Home
- Provide Home Medication Cooler
What precautions should I take at home?
The following apply until you are off of immunosuppressant medication (steroids, tacrolimus, cyclosporine) or until cleared by your BMT doctor.

Personal Hygiene:
- Bathe daily (all family members)
- 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 it often. Cover your skin with cotton clothing and a protective hat.
- No new tattoos or piercings

Masks:
- Worn when coming to the clinic, hospital, or in large crowds

People:
- Avoid anyone ill (encourage guest to check their temperatures before coming over.)
- Avoid crowds
- Limit exposure to children younger than 12 who are not part of your immediate family.
- Call your doctor immediately if you or any other family member is exposed to chickenpox, shingles, measles, German measles (rubella), or any other contagious disease

Pets:
- No new pets
- Don't clean up after your pets. This includes changing a litter box or picking up waste
- Wash your hands following contact with pets
• No direct contact with birds or farm animals. No reptiles or amphibians in home

**Home:**
• No playing in the dirt, gardening, or caring for plants
• Avoid chores that involve dust exposure
• Do not use a bedside humidifier
• Do not have carpets cleaned or deep clean after discharge.

**School:**
• You may not return to school until cleared by your doctor
• You may continue your education at home via printed or computer material

**Outdoors:**
• 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. Do not swim if your central line is still in place.

**Sexual intercourse (see page 27)**

Your nurse will check these boxes after each topic is reviewed:

☐ Reinforce Appropriate Hygiene at Home
☐ Reinforce Using a Mask

__________
Sexuality after transplant
Due to the physical changes to your body following BMT, you may be affected physically and emotionally in regards to sex. It is normal to feel more self-conscious or nervous. The following are changes you may experience:

- trouble having an orgasm
- trouble maintaining an erection
- vaginal dryness, painful sex, increased bleeding

While fertility may be decreased post-transplant, it is possible to become pregnant. There are serious risks if you become pregnant as it may result in changes to your therapy plan which can have an effect on your outcome. Due to your medication regimen, birth defects are also possible.

How do I engage in sexual activity safely?
There will be times when sexual contact will need to be avoided including when your blood counts are low. The main reason is to prevent bleeding or major infections. This includes vaginal, oral, and anal sex or inserting fingers, vibrators, or other sex toys into your vagina or anus. Until your doctor tells you that your blood counts and immune system have recovered, follow these precautions

- Avoid when your ANC is under 1,000
- Avoid when your platelet count is under 50,000
- Use latex condoms each time you have vaginal, oral, or anal sex
- If using lubricant, use a water-soluble lubricant (i.e. K-Y Jelly). Do not use petroleum based products as they can increase chances of infection
- Abstain from any sexual activity that could expose your mouth to feces
- Avoid sex that involves contact with mucous membranes if a genital infection is suspected or present in either you or your partner
- Hugging, cuddling, gentle touching, and kissing are other ways you can be intimate with your partner during this time.
Kissing should be avoided if you have mouth sores or open lesions in your mouth or if your partner has mouth sores.

Speak with your healthcare provider if:

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

Your nurse will check these boxes after each topic is reviewed:

☐ Reinforce Appropriate Precautions
What should I expect in the BMT clinic for my post discharge visit?

- First visit will take at least 1 hour
- Lab appointments are scheduled before clinic appointment
  - Do not take Tacrolimus and Voriconazole prior to lab draw.

**Autologous Transplants:**
- You will have at least one post-discharge clinic visit at the University of Michigan before transfer of care to the referring doctor.
- Milestone visits at days 30, 100, (and day 180 for selected patients) and one year for restaging will take place for people not enrolled on clinical research studies. Afterwards, you will be followed by your referring doctor. People on clinical research studies will be seen in follow-up according to study specific guidelines.

**Allogeneic Transplants**
- After discharge, if there are no complications requiring closer follow-up, you will be seen in the BMT clinic at least weekly until day 100.
- You must remain in the Ann Arbor area, within a 90-mile driving distance of the University of Michigan Medical Center for the first 8-12 weeks post-transplant.
- Milestone visits at days 30, 100, (180 for selected patients), and one year for restaging and follow-up will take place for people not enrolled on clinical research studies. People on clinical research studies will be seen in follow-up according to study specific guidelines.

Your nurse will check these boxes after each topic is reviewed:
- ☐ Check Home Meds
- ☐ Remind Family to Hold Tacrolimus/Voriconazole for Levels