

Navigating Autologous Transplant:

A Guide for Pediatric Bone Marrow Patients

**Pediatric Blood and Bone Marrow
Transplant Program**



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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 your transplant is day 0. The conditioning regimen consists of chemotherapy given at higher doses with the purpose of killing cancer cells.

Chemotherapy:

Your therapy plan is:

- Day : _____
- Day : _____
- Day : _____
- Day : _____
- Day : _____
- Day : _____
- Day : _____

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
 - Bleeding
 - Elevation in liver enzymes due to irritation to liver
 - Other side effects more specific to tailored regimen (see chemo handouts)

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

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

- Review Side Effects
- Review Scheduled and PRN Medications for Side Effects
- Start to Encourage Participation in Line Care

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. **Autologous** means that the stem cells come from yourself. These donor cells are obtained from your normal (peripheral) blood before coming in. The day you receive your new cells is called “Day 0”.

Transplant date: _____

Transplant type: Autologous

Cell source: Peripheral Blood

What should I expect during the procedure?

1. Stem cells are delivered to your room in either a bag or a syringe and thawed at bedside.
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 and frozen.
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

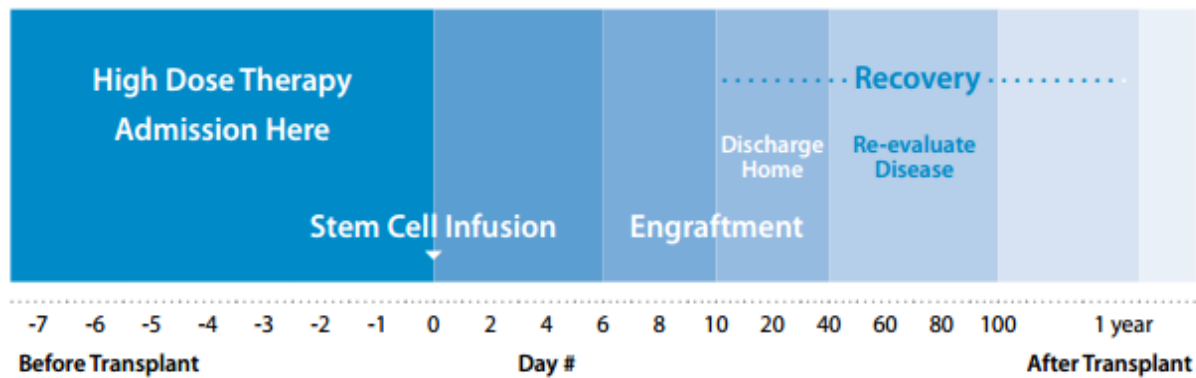
Several of these side effects resolve when the infusion is over. However, we may need to take other measures to help your side effects such as medications and longer monitoring and care.

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?

This diagram reflects a general overview of 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.

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 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 your weight once or twice a day to check for fluid overload.
- Medicines such as Lasix may be given to help your body remove excess fluid.

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 the normal values.

- Many causes: eating less, diarrhea, medication related (example: lasix), IV fluids
- Most common imbalances: low magnesium and high or low potassium
- Treatment:
 - Correcting the cause
 - Oral and IV electrolyte replacement
 - Adjusting medications and Total Parenteral Nutrition (TPN) (See below)

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 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.
 - Can irritate the liver
 - IV fluids

Preventative medications:

- Liver/biliary protection: Actigall
- Stomach ulcer prevention: Zantac, Pepcid, or Prilosec
- 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.

Purpose of Medication	Medications	Start	Stop
Bacterial:	<ul style="list-style-type: none"> • Levaquin • Vantin 	Day +1	<ul style="list-style-type: none"> • If you develop a fever (usually changes to IV medication) • Engraftment
Viral: <i>Depending on your viral history</i>	Acyclovir	Day 0	<ul style="list-style-type: none"> • Herpes Simplex Virus (HSV+ patients): Day +30 • Varicella Zoster Virus (VZV+ patients): 1 year
Fungal	<ul style="list-style-type: none"> • Fluconazole • Micafungin 	On admission	<ul style="list-style-type: none"> • Engraftment
Pneumocystis jiroveci (PJP)	<ul style="list-style-type: none"> • Pentamidine (inhaled, possibly IV) • Bactrim • Mepron 	On day +30	<ul style="list-style-type: none"> • 3-6 months or until therapy is completed or no longer immunosuppressed
Intravenous Immunoglobulin (IVIG) This medicine is a boost of antibodies that can kill bacteria, fungi, or viruses.		It is given as needed based on lab values	

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 breakdown on the skin or on the surface of soft tissue.

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

What are the symptoms?

- Sores or changes to the inside 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

How can I minimize this?

- Amino acid supplements (Glutasolve)
- Good oral care (brushing 4 times per day, lip balm use)

What is the treatment?

- Pain Medication, Magic Mouthwash

When will I start to heal?

The sores/mucositis improve as your counts start to rise (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 the 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/pain
 - liver swelling
 - yellowing of skin or eyes

- Usually occurring within first 30 days after transplant. More common with each exposure to chemotherapy and the higher doses used with transplant.
- Prevention: close monitoring of weight and fluids, measuring all intake and output, taking actigall
- Treatment: symptom management, including medications, blood transfusions, and careful monitoring of the liver and kidneys. We pay close attention to how much fluid goes in and urine comes out. We often give medications to help increase urination.
- May require transfer to the Intensive Care Unit (ICU)

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**:
 - Central line
 - GI tract
 - Respiratory

Testing

- Will need to be done to rule out an infection:
 - Blood cultures obtained from **all** lines
 - Possible viral labs
 - Possible fungal labs
 - Possible x-rays or CT scans
 - Respiratory swabs
 - Stool cultures
 - Urine samples

Treatment for fever and neutropenia

- Will need to be started just in case the cause is an infection.
 - This may require us to change the antibiotics and antifungals that you were on as prophylaxis
 - 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 the 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 product transfusion may be required if your platelet count is less than _____ or your hemoglobin is less than _____.

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
-

What can I expect during engraftment?

After your transplant, your new cells will find their way to the bone marrow spaces in the center of the large bones of the body. Only then can the transplanted stem cells begin to produce new blood cells.

- Neutrophils are the first cells to grow, followed by red blood cells, then platelets.
 - Engraftment occurs when you have neutrophil growth. This means your ANC level is rising. It typically occurs around week 2.
- 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.
- 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 for 3 days in a row.

When does it occur?

- 2 to 6 weeks following transplant, depending on the cell source:
 - Peripheral Stem Cells 10-28 Days

Engraftment Syndrome

An inflammatory condition that occurs around the time of engraftment.

- Mild to severe
- May have a red rash, fevers, weight gain, a need for oxygen
- Treatment: Steroids

What medications will I receive during this stage?

- G-CSF (Granix) injections

- Speed up engraftment and reduces the length of time that blood cells are their lowest, which lowers the risk of infection
- Started on standard days but may change for a research protocol:
 - Auto: Day +8
- Stopped: Once 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 cells. If this occurs, we will infuse additional cells which are saved.

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

- Side Effects of G-CSF
-

What are my goals for discharge?

Before discharge, we expect:

- Engraftment with stable counts
- No active infections
- No fever for more than 24 hours
- Tolerating oral medications
- Meeting goals for calories and liquid 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
- Caregiver demonstration of care (lines, meds)
- Successful transition day
- Home infusions ordered and delivered
- 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.

You may go home with a central line in place and may receive IV medications or fluids. If so, 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
 - Finalize Central Line Care
 - Discuss Upcoming Transition Day
-

What precautions should I take at home?

The following apply until you are 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 guests 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 and work:

- You may not return to school or work until cleared by your doctor
- You may continue your education at home via printed or computer material through a “homebound program.”

Other:

- You may not drive until cleared by your doctor
- You may not resume contact sports until cleared by your doctor
- 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.**

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

- Reinforce Appropriate Hygiene at Home
 - Reinforce Using a Mask
 - Discuss Fever Guidelines at Home
-

What do I need to know about sexual health post-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.

- Avoid kissing 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

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.

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

- Check Home Meds

What should I monitor for and when should I call 9-1-1 or go to the Emergency Room?

Call 9-1-1 if:

- If you/your child is having **trouble breathing, is not responsive**, or has any other **issues that may be life threatening**, please call 9-1-1 immediately.

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

- **Fever**- A thermometer has been provided for you. You do not need to routinely check temperatures unless concerned for fever. If you need to check 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 fever usually requires a hospital admission.

Call the clinic and go to the ER if your thermometer has these readings:

- Two temperature readings (1 hour apart) of 100.4° Fahrenheit (38° Celsius)
- A single temperature reading of 100.9° Fahrenheit (38.3° Celsius)
- Any temperature reading above 98.6° Fahrenheit with concerning symptoms such as cough, congestion, behavior changes etc.
- **Bleeding**- Such as nosebleeds that last longer than 10 minutes, red or black bowel movements, red or dark brown vomiting, red urine, or increase in bruising.
- **Cognitive**- Excessive drowsiness, changes in mental status/behavior, or complaints of vision changes, such as double or blurred vision. Increased pain or headaches that persist beyond several hours or are not controlled by prescribed pain medication.
- **GI Symptoms**- Constipation or vomiting not relieved with prescribed medications, diarrhea or pain with bowel movements, pain with urination, or inability to tolerate fluid or food intake, or inability to take oral medications.
- **Central Line**- Any pain, redness and/or swollen areas especially around central lines or port sites. A break, crack, or tear in the central line. Difficulty flushing or leaking from catheter.

What is the contact information for my BMT team?

With any concerns or the symptoms above please contact your BMT team:

- Monday-Friday 8am-5pm:
 - (734) 936-9814 -BMT clinic & nurse line
- After clinic hours and on weekends:
(734) 936-6267- On-call paging_____

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