Pediatric Blood and Marrow Transplant: Patient Guide

Pediatric Blood and Marrow Transplant Program

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN
Dear Patients and Families,
Welcome to the Michigan Medicine C.S. Mott Children’s Hospital Blood and Marrow Transplant Program. This handbook has been designed by medical and nursing experts, along with former patients and their families to serve as a guide and resource especially for you and your child through your child’s transplant journey. Please refer to it often as it will help you and your child understand each part of the transplant process. You will find helpful hospital information, the medical aspects of transplant, life after transplant education materials, and inspirational stories of hope and courage. We understand what you and your family are going through and our team is dedicated to helping you make it through each challenge that lies ahead.

*Alone we can do so little; together we can do so much.* -Hellen Keller

In transplant, you will often hear of “the team”. At the center of our team is you and your child and your supporters. You are the most important players on the team and we are here for all of you. We will ask that you participate in setting goals and planning your care each step of the way. We bring together many different types of health care providers to bring you the best care possible. Other than the doctors and nurses these team members include social workers, psychologists, nutrition specialists, child life specialists, pain experts, palliative care specialists, physical and occupational therapists, music and art therapists and more. You and your child will meet some of those people directly and get to know them very well, and others will work behind the scenes to make your child’s treatment possible.

Together we will work with the hope that transplant represents: hope for a cure.

Thank you for allowing us the privilege of caring for you and your family.
Table of Contents:

Your Care Team: Who's Who?..................................................4

The Basics of Transplant: What is it?.................................11

How Are The Stem Cells Collected?.................................13

Who Gets Transplants?..........................................................15

How Long Is The Blood And Marrow Transplant Process?..........................................................16

What Should I Expect In The Pre-Transplant Phase?......17
   Step one.............................................................................17
   Step two..........................................................................17
   Step three......................................................................23

What Should I Expect During The Hospital Stay?........24
   Day in the life..................................................................24
   Amenities......................................................................27
   Packing list......................................................................31
   Things not to bring to the hospital.................................32
   Visiting guidelines.........................................................33
   Smoking.........................................................................34
   Parking and Transportation..........................................34
   Lodging .........................................................................35
Your Care Team: Who’s Who?

**Advanced Practice Providers (APPs)** are nurse practitioners and physician assistants with advanced education in pediatric oncology. These providers will coordinate your child’s care and teach you about your child’s disease and treatment plan. They also do many of the physical assessments and procedures. Children receiving a bone marrow transplant will be managed by an APP while hospitalized and outpatient.

**Attendings** (sometimes called staff physicians) are doctors who have completed both residency and fellowship and have a permanent position in our department. The attending will supervise all medical team members and is involved in all treatment decisions involving your child.

Your primary attending: _________________________

**Care Management/Practice Management/Discharge Planning** is a department that helps you arrange care that you need in the home. They will help coordinate care with visiting nurse agencies and medical supply companies before your child is discharged from the hospital. They also work with your insurance company to obtain coverage for both inpatient care and home care needs. Practice management is available at: (734) 764-0589.

**Certified School Teachers** are available during weekdays to help your child stay current with schoolwork while in the hospital. Your child may go to the designated school room or the teacher may work with your child at the bedside.

Your school teacher: _________________________
**Chaplains** are available to meet with children and families of all faith traditions. They are available to pray, listen, create or facilitate rituals, help you contact a leader from your faith community, explore sources of healing and hope, and provide extra support when you or your child feels alone, afraid, or discouraged during your hospital stay. Please ask your nurse for a referral to the chaplain/spiritual care department if you would like to learn more about available services.

**Child and Family Life Department** is available to help you cope with diagnosis and the hospital stay. This department is comprised of Child Life Specialists, Activity Therapists, Music and Art Therapists, and School/Teacher programs. Child Life Specialist offer developmentally appropriate education and medical play to help children and siblings understand and cope with illness. They also provide procedure support to reduce anxiety. Activity, Music, and Art Therapists use creative arts and developmental play to encourage feeling expression and coping during your child’s hospital experience. Child Life services are available in both inpatient and outpatient settings.

**Clerks** are available in both the hospital and the outpatient clinic. In the clinic, clerks will check you in and out of your clinic visit and help you schedule your child’s appointments. In the hospital, clerks will respond to your call lights, help coordinate your child’s inpatient testing and procedures, and can give you directions around the medical campus.

**Clinic Nurses (RNs)** are registered nurses in the outpatient clinic that help you coordinate your child’s care, provide patient and family education, and are available by phone to answer any questions or address any concerns you may have about your child’s diagnosis and treatment.
Clinical Nurse Specialist (CNS) is an inpatient-based advanced practice nurse with advanced education in pediatric hematology/oncology. They are available to you and your child to answer questions and solve problems. The CNS provides consistent communication between families, nurses, and doctors by attending rounds with the medical team, updating the nursing staff, and reinforcing patient education. In addition, the CNS works with your child’s medical team to coordinate education and prepare you and your child for discharge.

Your CNS:__________________________

Environmental Services (EVS) is responsible for maintaining a clean and healthy environment. A member of EVS team will clean your room daily and will also clean any common areas in both the inpatient and outpatient setting.

Fellows are doctors that have completed their training in pediatrics and are now specializing in pediatric oncology/hematology. The fellowship program lasts 3 years. All clinic visits during your child’s treatment will be scheduled on your fellow’s clinic day.

Guest Assistance Program (GAP) Patient Navigators are social workers that are available in the outpatient clinic to help you with non-medical needs during treatment, such as transportation, financial barriers, prescription assistance, lodging authorizations, and access to community resources.

Home Med Pharmacy & Staff will deliver the home care supplies you will need before your child’s discharge and may also provide education to you before you go home on central line care, home infusions, and other care you may need for your child at home.
Infusion Nurses (RNs) are registered nurses that provide care to your child when they are receiving infusions in the outpatient setting, such as chemotherapy treatments and blood product transfusions. You will also have a primary nurse in the outpatient infusion area.

Medical Students are training to become doctors. They will participate in your child’s care while in the hospital and in the outpatient clinic and are directly supervised by a physician. They may take your child’s health history and perform examinations.

Parent Hosts offer support and assistance to our 7E families. They provide unit and clinic tours, assist in discharge needs such as picking up prescriptions from the pharmacy, and host other special activities. Parent hosts have knowledge of resources available within Mott, as well as the surrounding communities.

Patient Care Techs/Medical Assistants assist the nurses with your child’s medical needs. In the hospital, they are here to help with many aspects of your child’s daily care, including vital signs, weights, and activities of daily living such as baths. In the clinic and outpatient infusion center they will perform vital signs, weights, and provide immunizations (if necessary) during your visit.

Pediatric Palliative Care Team is a multidisciplinary team made of physicians, nurses, social workers and spiritual care providers that are available to help improve your child’s quality of life during and after a serious illness. They can assist your child’s care team with pain control, symptom control, and overall comfort. This team is available to assist patients in both the hospital and outpatient clinic.
**Pharmacists** work directly with your child’s medical team to help the physicians and nurse practitioners to select and prescribe the appropriate medications for your child. They will also check for potential interactions of medications that have been prescribed. The pharmacists on 7E have additional knowledge on chemotherapy and medications used to manage the side effects of cancer treatment.

**Physical therapists** are specially trained health care providers that help improve mobility, gain strength and endurance, and reduce muscular pain. They can provide strength bands, stationary bikes, tricycles, and stretching routines that can all be used during transplant. Physical therapist will work with you regularly throughout your hospitalization to reduce complications.

**Psychologist/Psychiatrists** are healthcare providers who are specially trained in mental and behavioral health. Our psychologists meet every patient who is hospitalized for transplant. Transplant can greatly impact your mood and mind. Psychologists offer support and tools to help you manage the stress of transplant, as well as identify problems before they develop. Psychiatrists are medical doctors who specialize in diagnosing and treating mood and thought disorders. A child psychiatrist is a medical doctor that uses their specialized training to create a treatment plan to help a child with a behavioral or mood disorder.
Registered Dieticians are here to help your child maintain good nutritional status during your hospital stay and throughout your child’s treatment. They can explain special diets, help you choose the best foods, and make suggestions to deal with nutritional symptoms during medical treatment. If your child requires IV nutrition or other nutritional supplements during treatment they will manage the prescriptions. They will also assist in your transition to home and follow you in the outpatient clinic to address any on-going nutrition related questions or concerns.
Your registered dietician: _________________________________

School Liaison is a social worker who specializes in working with schools (elementary school through college) to make accommodations for your child while in treatment, provide education to your child’s teachers and peers about your child’s diagnosis and treatment, and support you while making decisions about your child’s education during this time. The school liaison is available while you are both inpatient and outpatient.
Your school liaison: _________________________________

Social Workers are available to help with financial concerns, housing and employment issues, provide community resource information, as well helping your family to cope during this difficult time. Your social worker is available both in the inpatient and outpatient setting.
Your social worker: _________________________________

Staff Nurses (RNs) are registered nurses who will care for you and your child while you are on the inpatient unit. One RN will assume a primary nurse role for your child. Occasionally a student nurse may be assigned to care for your child, but only under the direct supervision of the RN.
Your primary nurse: _________________________________
**Unit Hosts** are here to assist you with non-medical needs and to help make your hospital stay as comfortable as possible. They can assist with supplies, linens, beverages, DVDs, and video games. They are also available to provide you with directions around the hospital campus and are familiar with available services on the unit and within the hospital.

**Volunteers** from various departments may interact with you and your child. Child life volunteers may staff the playrooms, sit with your child if you need to be away from your child’s hospital room for a short period of time, or are available to play and do other activities, such as art projects, with your child at the bedside if your child is unable to visit the playroom. Other volunteers may work in the family resource center, gift shops, or the library cart.
The Basics of Transplant: What is it?

Bone Marrow Transplant (BMT) is a procedure in which stem cells are transfused through an IV into a person after they have received high doses of chemotherapy and/or radiation. You will hear the terms “Bone Marrow Transplant” and “Stem Cell Transplant” used. Both mean the same thing and are used interchangeably.

- **Bone Marrow**- the spongy tissue found inside bones. Its job is to make all blood cells: red blood cells, white blood cells, and platelets. It is also the body’s immune system.
- **Stem cells**- the parent cells that all cells in our body start as. These mature and develop into specific types of cells with specific jobs.

Preparative Regimen:
Almost all people receiving a bone marrow transplant must receive some chemotherapy, radiation, or immunosuppression before transplant, even if they do not have cancer. The reason for these treatments is to clear out the old bone marrow and make space for the new marrow to live and grow.

- For people who do have cancer, this chemotherapy can serve a dual purpose of making room for the new bone marrow and killing their cancer.

Engraftment:
The transplanted cells find their place in the patient’s body and begin to grow and make a new population of blood cells. This is a process we call “engraftment”. We can tell this has occurred by checking blood counts and neutrophil levels. This process usually takes 2-6 weeks. During that time, the person stays in the hospital where they can be monitored closely.
Types of Transplants
There are two types of BMT based on who the stem cells come from:

- **Allogeneic**-comes from another person (Donor)
- **Autologous**-Comes from the patient

Sources of stem cells:
Stem cells can come from different places in the body. The three places stem cells come from are: **bone marrow** from the hip bone, **peripheral blood** from a vein, and **umbilical cord blood** from umbilical cords and placentas.

Facts about the actual stem cell transplant process:

- It looks very similar to a red blood cell transfusion where a bag or syringe of blood is delivered to the room and is given to the person through your central line
- It takes place in the person’s regular room in the hospital
- Families and other caregivers are allowed to stay with the person during the transfusion
- There is no surgery or procedure required when the person is given the transplant

For more information, please refer to: “Transplant Basics: Understanding transplant and how it works” (pages 4-10).
How are the stem cells collected?

Before a person can receive stem cells, we must first collect them from the donor. You may hear this process being called a stem cell or bone marrow “Harvest”. There are different sources of cells:

**Bone marrow cells** (stem cells): This process can take 1-3 hours to collect. The donor is asleep (under anesthesia) in the operating room for the procedure so that they do not feel any discomfort.

- These (bone marrow cavities) are normally located deep inside your bones.
- Your hip bone (pelvis) in particular, contains large amounts of bone marrow. In a bone marrow harvest, doctors obtain bone marrow cells (stem cells) from the hip bone of the donor by placing a special needle into the hip bone and aspirating (withdrawing) the marrow into a syringe.
- Similar to donating red blood cells, the donor's body quickly regenerates the bone marrow that was removed. There is no permanent loss of bone marrow.
- After the marrow is harvested, it is filtered to remove fat, clots, and bone particles. It is then taken in bags to the laboratory for processing. The marrow can be infused the same day or frozen and stored until a later time.

**Peripheral blood stem cell** collection typically takes place in the Apheresis (blood collection) Unit in the main hospital. The procedure is similar to the collection of platelets from a donor.

- This is how patients donate their own marrow (for autologous transplants) and how some donors donate stem cells.
- The donor is connected to a machine that separates out the stem cells it needs and then returns the rest of the blood to them.
- The whole process usually takes about 3 to 5 hours for 1 to 3 days. The number and length of collection depends on how many stem cells are
needed and how easy they are to collect. This is different for everyone and can be difficult to predict beforehand.

- After they are collected, the stem cells are frozen and saved to be transfused at a later time. The donor is awake during the procedure and feels very little discomfort.
  
  - For **autologous transplants**: Patients who donate to themselves will have a large IV placed in the operating room before this procedure, and the IV line will be removed once the needed number of cells have been collected.

**Umbilical cord blood stem cells** are obtained from the umbilical cord and placenta of a newborn infant. Blood stem cells are collected from the cord after it is clamped and cut from the mother and baby.

- The cells are then frozen and stored. There is a registry of stored umbilical cord blood stem cells. Cord blood from unrelated donors or family members can be used for transplant.
Who gets transplants?

Transplants can be performed to:

- Correct certain **genetic and metabolic diseases**, such as: Severe Combined Immunodeficiency (SCID), Krabbe Disease or Severe Congenital Neutropenia
- Treat diseases that cause **bone marrow failure** or that cause the body to make **defective blood cells**, such as: aplastic anemia, sickle cell disease, Fanconi’s Anemia, Shwachman-Diamond Syndrome and thalassemia.
- Treat **various types of cancer** including leukemia, lymphoma, myelodysplastic syndrome (MDS), neuroblastoma, and some brain and other solid tumors.

Transplants are considered **only** when other less invasive treatments are unlikely to cure or effectively manage the person's disease. You and your child and your child’s doctor will discuss the diagnosis and disease individually. Your child’s doctor will decide which type of transplant (autologous or allogeneic) and which source of stem cells (peripheral blood, bone marrow, or umbilical cord) are the best for your child.

The goal of all types of blood and marrow transplant is to enhance the person’s disease free survival.
How long is the blood and marrow transplant process?

Preparing for transplant can be a difficult and stressful time for people and their families. Even when a transplant needs to happen right away, the length of time leading to transplant can be variable. The person will need to undergo an in-depth work up of their health status, including appointments with other specialists. During this time, we will also need to verify insurance coverage.

Whether these issues take days or months depends on several things, including the type of transplant your child will have, their disease status, and general state of health. We will try to give you an approximate time frame so that you can make the necessary preparations for your child’s admission and recovery period. We will go over this in more depth below based on the type of transplant you are planning to have.

**Please refer to:** “Transplant Basics: Best type of transplant for me” (page 8).
What should I expect in the Pre-Transplant phase?

Phase 1: Pre-transplant outpatient

Step 1. Initial consultation (1-12 months before transplant):
The first phase begins at the initial consultation with the transplant team. You and your child will spend time meeting with the BMT doctor reviewing all medical history, laboratory values, radiology results, and your child will have a physical examination.

- This is when the doctor determines to proceed with transplant or not, and if transplant needs to happen right away or can wait some time.
- Your child may have blood tests done at this visit.

For Allogeneic Transplants, we will begin a search to find a donor for your child at this time. Matching a donor and a recipient is done based on human leukocyte antigen (HLA). This antigen is a protein marker found on most of the cells in your body.

Your doctors will first check your family members. Only about 30 out of 100 (30%) of people have a family member match, where about 70 out of 100 (70%) of people will need to find an unrelated donor. Please see pages 12-14 in Transplant Basics for more information about finding a donor and HLA matching.

Step 2. Evaluation and workup (1-2 weeks before admission for transplant):
During this phase, your child will have some long appointments requiring multiple trips to the hospital or off-site clinics with various specialists and care providers. You may be asked to participate in various research studies during these appointments. Please plan at least 3 hours for consultation appointments. If you need assistance with transportation for these appointments.
appointments, please inform your social worker. The Guest Assistance Program (GAP) can provide and connect you with these types of resources- (800) 888-9825.

You should expect the following during step 2:

- **A clinic appointment** with you and your child's BMT doctor at which time they will recommend a treatment regimen and consents for transplant will be signed.
  - Your doctor will discuss central venous access and ensure your child will have adequate access for transplant.
  - You and your child will also see the BMT nurse coordinator during this visit for an educational overview of transplant.
  - You and your child can expect to discuss fertility and possibly sperm banking during this appointment:
    - It is very important to discuss the possibility of infertility with your doctor no matter the age of your child. The chemotherapy and/or radiation necessary for transplant will likely lead to infertility or sterility. Sperm banking for men and fertility preservation methods for women may be options.
    - You may be referred to a reproductive endocrinologist (specialist in helping patients receiving chemotherapy with fertility) for this.

- **Assessment of disease status**: depending on your child’s disease type this may involve:
  - Bone marrow biopsy: a procedure where marrow is removed for study
  - Lumbar puncture (spinal tap): a procedure in which a thin needle called a spinal needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give drugs.
  - Blood tests
  - Imaging (MRI, PET, or CT scans): a process that makes pictures of areas inside the body.
• **Assessment of your/your child's overall health** - pulmonary function tests (PFT’s), GFR (a blood test to check the function of the kidneys) echocardiogram (heart ultrasound) and EKG (checking heart rhythm) will be performed.
  o Additional screening tests like urine screening and hearing tests will also likely need to be done.

• **Dental exam** - The mouth and teeth can be a source for infection during transplant especially. Your child will need to see the dentist for all routine care including teeth cleaning, x-rays and routine exam **before** transplant. Be sure to notify your transplant team before your dental appointments.
  o If your dentist discovers any problems, **notify your transplant Nurse Coordinator right away**. Most often, your child will need to have dental problems fixed before transplant. You will need to provide a summary of your child’s dental health before transplant admission.

• **Specialty consult appointments** - your child may need to see doctors who specialize in cardiology, dentistry, radiation-oncology, ophthalmology, and/or gynecology. As mentioned above, this could also include reproductive endocrinology for fertility preservation.

• **A social work appointment** - this appointment could possibly be done over the phone or in person. Every patient and family will have a social worker throughout the transplant process.
  o You and your child and your child’s social worker will discuss your understanding of the transplant process and recovery period, and how you and your child may cope during this time. The social worker can help you identify your strengths in coping and resources which may be helpful to improve your coping. You will also discuss potential
problems you anticipate such as transportation/parking, lodging, or finances. **Please refer to:** “Transplant Basics: Before Your Transplant” (pages 13-19)

- **Securing a caregiver plan**- All people who have a bone marrow transplant of any kind at any age need help after transplant, children especially.
  
  o **Before transplant, you and your child will need to identify a caregiver with the transplant team who will need to be present 24 hours a day/7 days a week** (aside from necessary breaks and personal care). You should also identify a back-up caregiver in order to give the primary caregiver breaks and assistance.
  
  o Make arrangements for a caregiver to be present in the hospital at the bedside at all times for pediatric patients, with the exception of taking short breaks, meals, and personal care.
  
  o Younger children will need to be supervised by their parent or responsible caregiver **at all times**, just as they would at home.
    
      ▪ The hospital staff is not able to provide constant supervision to all patients.
  
  o Caregivers will also need to learn how to take care of your child at home, which will take place in formal education sessions, but most importantly just by being with your child and learning from hospital staff throughout the transplant hospital stay. You will also be expected to participate in a transition day near the end of hospital stay; this involves you providing the care for your child with nursing assistance.
  
  o If you have any concerns about being able to be present at the bedside in the hospital throughout transplant **or** with your child around-the-clock at home, please discuss this with the team as soon as possible.
• **Securing a post-transplant lodging plan**- After an allogeneic bone marrow transplant, your child and designated care givers must live (or stay) within 60 minutes of the hospital for the first 100 days. You must be able to get to the hospital within 60 minutes, which is not a specific distance from the hospital but typical commute time.
  o Some people live this close to begin with, but some will need to find an extended lodging arrangement which could be a hotel or an apartment. Social work can help you with this.

• **Insurance approval**- Understanding costs and insurance benefits can be difficult and confusing at times. Approval for transplant must come from your child’s insurance company before transplant.
  o Be aware, this can sometimes be a lengthy process. Sometimes the insurance company may require additional tests or work-up before approving the transplant.

**Questions to ask your insurance company**: Please know we are here to help you with insurance. Before discharge we double check your medication coverage and confirm your child’s co-pays. However, it is very helpful to have this information before that time as discharge after transplant can be a busy and stressful time. Here are some questions you may want to ask:
  o Are costs of lodging and transportation related to treatment covered or reimbursed? You will want to save receipts and documentation of these expenses if so.
  o Will I be assigned a case manager? Is there a case manager available I can contact?
  o Do I have prescription coverage?
  o Can I fill prescriptions at the Michigan Medicine pharmacies?
  o What are my prescription co-pays?
  o Do I have a yearly limit or cap for prescription coverage?
o Do I have coverage for home infusions (IV fluids, IV medications, IV nutrition)?
o Do I have coverage for visiting nurses (home care nurses)?

How insurance approval works:
1. A Michigan Medicine Patient Accounts Representative who is specially trained in BMT will contact your child’s insurance provider to find out their requirements for payment of transplant services.
2. Your doctor will provide your insurance company a letter explaining why your transplant is necessary, this is called a letter of medical necessity. Your insurance company will review this and confirm that the transplant is necessary.
3. Once this has been determined, the Patient Accounts Representative will provide you with two copies of your child’s transplant insurance confirmation. You may keep one copy for your records.
4. You will need to carefully review the other form you receive and sign the “Guarantee of Account” section of the form and return one copy to the Michigan Medicine Patient Accounts Department as soon as possible.

What if Michigan Medicine is not “in-network” for my insurance?
We will work with your insurance provider to determine if Michigan Medicine is an “in-network” provider and can appeal for your child to be covered “in-network”.
- Please be aware that some companies will initially deny these requests, require more information, or more work-up before approving. An appeal may be necessary to facilitate insurance coverage.
- Our patient account representatives and BMT doctors can help you with this process if necessary to ensure your child receives the most appropriate care in a timely manner.
Step 3: Final pre-transplant appointment and admission

The third step will be your child’s final pre-transplant appointment scheduled within the month before their admission for the transplant. Final testing will be done during this period (as detailed in the second step).

*For autologous transplants, there will most likely be two admissions; one for line placement and collection and one for the actual transplant. The period of time during this third step is when collection will take place.

- You and your child will have a final pre-transplant consult with your child’s doctor and transplant coordinator.
- You may discuss research protocols that your child may be eligible for at this time.
- Upon admission to the hospital, your child will have a special IV (catheter placement):
  - People undergoing an allogeneic transplant require a special IV catheter with 1-3 tubes (lumens) to be placed for the transplant:
    - These are used to administer IV fluids, antibiotics, chemotherapy drugs, transfusions, other medications, and the transplant itself.
    - This also allows for frequent blood draws. There may be times your child may still have to be poked, but most of the time the special IV can be used.
    - You and your child will receive further education about the line before going home. Please plan to go home from the hospital with the IV in place, and plan for the line to remain in place for at least the first 100 days.
      - You and your child will have to care for this line at home.
      - We will ensure you and your child are comfortable with the expected care before you go home.
What should I expect during the hospital stay?

Spending time in the hospital can be difficult, whether you’re experienced with hospital stays or if this will be new to you and your child.

- Most people are in the hospital between 3-6 weeks for their transplant, this varies depending on many factors. No one can predict exactly how long your child will need to stay, but this is the average of most of our patients.
- The transplant unit is on the 7th floor and is referred to as 7East or the “Coach Carr Cancer Unit”. Not everyone on 7East has cancer, just as not everyone receiving a transplant has cancer. This unit cares for hematology, oncology, transplant, and general pediatric patients.
- Transplant patients sometimes require intensive care. The Pediatric Intensive Care Unit or “PICU” is located on the 10th floor and is referred to as 10East.

In this section, we will try to prepare you and your child for what to expect during this time, from the routines of day-to-day life in the hospital to what to bring. Your team encourages you to bring personal items that will make your child’s hospital room feel more like home and less stressful. However, please note that the rooms are small. It is also of utmost importance to keep your room neat so that environmental services staff may clean appropriately to minimize your risk of infection.

Day in the life:

Your transplant hospital days will follow a typical routine involving the care and medication your child needs and their personal care. Keeping a regular schedule while your child is in the hospital will help set you up for a successful routine at home and promote the best possible outcomes for your transplant. If there is anything you are finding difficult or don’t understand about these routines or requests, please discuss them with your nurse and the transplant team so that we may come up with a plan that works for everyone.
There are standard things that will be required each day, some will be completed by your child's nurse and/or team and some will be your responsibility. You and your child and caregivers are the most important parts of the team and your daily involvement and participation are absolutely essential.

This is a sample of how your days will typically look:

<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>4-6:00am</td>
<td>Labs drawn, Vital signs</td>
</tr>
<tr>
<td>9:00am</td>
<td>• Oral medications, vital signs, breakfast, weight</td>
</tr>
<tr>
<td></td>
<td>• Personal care – Bath/shower/CHG wipes, brush teeth, mouth rinses, lip balm, change into clean clothes.</td>
</tr>
<tr>
<td></td>
<td>• Your child may bathe in the morning or evening as long as CHG wipes and baths are 24 hours apart.</td>
</tr>
<tr>
<td></td>
<td>• Activity – Take a short walk around the room, sit up in the chair or in bed</td>
</tr>
<tr>
<td>9:30-10:00am</td>
<td>Rounds begin. “Rounds” are when the whole transplant team comes to see you and your child and discusses how you are doing and makes a plan for the day ahead.</td>
</tr>
<tr>
<td></td>
<td>• It takes time for the team to see each patient so your child may be seen earlier some days and later others.</td>
</tr>
<tr>
<td></td>
<td>• We need you and your child to participate in rounds each day. This is a time to share concerns, ask questions and learn from your entire team.</td>
</tr>
<tr>
<td></td>
<td>• Any consulting doctors or teams will come throughout the day. Physical therapy may occur at any time of day and should not be deferred.</td>
</tr>
<tr>
<td>10-12:00pm (noon)</td>
<td>Between rounds and lunchtime – Rest, visit with friends or family, crafts, movies, leisure activities.</td>
</tr>
<tr>
<td>Time</td>
<td>Activity</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>11:30-12:30pm</td>
<td><strong>Lunch.</strong> Even if your child is not feeling up to eating, this is a good time to perform oral care, sit up in the chair, try small sips of liquids or bites of food.</td>
</tr>
<tr>
<td>1:00pm</td>
<td><strong>Vital signs and Activity</strong> – Take a longer walk, walk the unit, get a change of scenery</td>
</tr>
<tr>
<td>2-5:00pm</td>
<td><strong>Rest or Activity/School Work</strong></td>
</tr>
<tr>
<td>5:00pm</td>
<td><strong>Vital signs and Dinner Time</strong> – Even if your child is not feeling up to eating, this is a good time to perform oral care, sit up in the chair, try small sips of liquids or bites of food.</td>
</tr>
<tr>
<td>7:00pm</td>
<td><strong>Activity</strong> – One more walk or trip out of the room for the day</td>
</tr>
<tr>
<td>9:00pm</td>
<td><strong>Oral Medications, Vital Signs, Oral Care</strong></td>
</tr>
<tr>
<td></td>
<td>o Bathe or CHG wipes may be performed at this time if preferred, as long as CHG wipes and baths are 24 hours apart.</td>
</tr>
<tr>
<td></td>
<td><strong>Wind down for bedtime</strong></td>
</tr>
<tr>
<td>9-10:00pm</td>
<td><strong>Bedtime</strong> – Attempt to keep a normal bedtime and sleep routine as much as possible. Please discuss difficulty sleeping or discomforts that make it hard for your child to sleep with your child's nurse and team. Please remember how important it is that you and your child are awake and participating in your child's care during the day</td>
</tr>
<tr>
<td>12:00am (midnight)</td>
<td><strong>Vital signs</strong></td>
</tr>
</tbody>
</table>

- Vital signs are approximately every four hours. **We must obtain them throughout the night and day during transplant, this is not negotiable.**

This allows us to detect even small changes sooner and treat possible infections earlier.
• Medications may be administered at different times throughout the day, however when your child goes home they will typically have morning and bedtime medications.
  o Some medications are time dependent. Your child will be required to take these medications at specific times in the hospital and at home.
• Building your day with small amounts of activity with long periods of rest in between tends to work well when your child is feeling more fatigued.
• Throughout the day, expect the nurse and or respiratory therapist to remind your child to take deep breaths with the Incentive Spirometer (or blow bubbles) to help keep the lungs healthy.
• Activity can happen anytime throughout the day but should be done three times minimum. Even getting out of bed into the chair is helpful.
  o Physical therapy will also see your child throughout your stay to help them maintain their strength and keep up their activity.
• School work can be incorporated into your child’s day when they are feeling up to it. Please ask to see the hospital teachers for help with this if needed.

Amenities and other information for hospital stay:
• Mail: Your child can receive mail while they are admitted to the hospital. Please let friends and family know that live plants, latex balloons, flowers and fresh fruit baskets are not allowed due to infection risks. Mylar balloons are allowed. Expect mail to take a little longer than usual coming through the hospital. Also, write the word “patient” in the lower left-hand corner to facilitate quicker delivery of your letters or cards. Mail can be addressed as:
• **The room:** All rooms in Mott Children’s Hospital are private rooms. The entire hospital has a High-Efficiency Particulate Air filtration system (HEPA). Transplant rooms are specially cleaned before your child’s admission.

  Each room has:
  o A hospital bed or crib, a chair that reclines or pulls out into a single bed, and a sleeping space (chair bed or pull-out couch) for one caregiver.
  o A small closet with two shelves, a bedside dresser with three small drawers, and an over the bed table with a small drawer.
  o Some counter space and 2-3 wall shelves.
  o A window with light minimizing shades.
  o A small refrigerator, but not a freezer.
  o A wide flat screen TV programmed with the GetWell Network. This allows access to standard cable TV, a selection of recent movies, a music system, internet, and games at no charge. The TV is controlled with a portable wireless keyboard that can be used anywhere in the room. Wireless internet (WiFi) is also available to all patients, caregivers, and visitors at no charge.
  o Your child’s room will be cleaned by environmental services staff each day, but it is you and your child’s responsibility to keep the room neat and tidy. Throw all waste in the trash immediately and
place soiled linen in the linen bags so that they may be removed regularly from the room.

  - When you leave the room, your child will need to wear a mask to protect themselves from germs.

**Meals** - Room service style meals are available by order from 06:30am to 8:00pm. Caregivers may also order a “guest tray” for a small fee that will be billed at a later date. Many local restaurants also deliver to the hospital, lists and menus are available from your nurse or floor staff. **Your child will need to show the team they are able to eat and drink before going home. Nutrition is of utmost importance to healing.**

  - Boxed meals are available afterhours if your child is hungry after the kitchen is closed.

  - For food safety and diet, please refer to “Food Safety for Transplant Recipients” from the USDA handbook in this binder.

  - Transporting food:
    - Foods that are refrigerated or frozen should be in a cooler on ice.
    - Food transported freshly prepared from home or a restaurant can be brought directly in if transport time is **less than** 10 minutes. If transport time is **more than** 10 minutes, food should be thoroughly cooled in the refrigerator or frozen and transported in a cooler on ice.

**Other unit amenities include:**

- **Washers and dryers** with free detergent are available 24/7 free of charge off the family lounge. Please plan to change into clean clothing each day.

- **Full size shared refrigerator and freezers** in common nutrition rooms and family lounge areas (3 total on the unit). Food must be labeled and dated or will be thrown away.
• **Coffee and tea** 24/7. Milk, juice, and water are available in each nourishment room for your child.
  - Your child may have ice from machines but should have tap water rather than the machine water.
  - Nourishment rooms are also stocked with some basic items like saltine crackers, peanut butter, jelly, cereal, popsicles, ice cream, broth, and baby food purees and baby cereal.

• **Family fitness center** (located on 7West) has a treadmill, bike, and elliptical machine available for families only. This can be a great way for caregivers to manage stress and take personal time away from the bedside to recharge while maintaining their own health and fitness.
  - Patients may not use this room at this time.
  - You must sign in with guest services at the front desk and obtain a key from security to access this room.

• **Child life:** There is a general child life room full of fun toys and activities staffed by child-life specialists who are especially trained to work with hospitalized children, as well as volunteers to facilitate activities and play. Toys, crafts, and activities can also be provided to your child in their room if needed.
  - There is a teen room for patients over age 13 only
  - There is special playroom for BMT patients who are neutropenic. This separate playroom allows for time away from the bedside in a safe area with toys and activities that are specially cleaned just for them. Only one patient is allowed in this room at a time.

• **Quiet gathering or sitting spaces** are available throughout the unit. These can be used for visiting with friends and family or for quiet time away from the bedside for your or your child:
  - There is a small alcove overlooking the arboretum that is an open space with sitting room
There is a Meditation Room overlooking the river and surrounding parks and a Family Lounge with kitchenette and TV.

**Packing List:**

- This Handbook!
- One copy of any important medical documents such as Medical Durable Power of Attorney and Living Will
- Comfortable pajamas and clothing. Plan to bring layers as the temperature is not always predictable. Tops that open in front or one piece outfits that snap are easiest with IV lines and monitoring cables.
- Clean underwear, socks, and bras (if needed).
  - *Please plan to **change into clean clothes and bathe daily**, both patients and caregivers staying at bedside. This helps to minimize germs living on clothing and is pertinent to minimizing infection risks. Washers and dryers are available on the unit. Further details on bathing and skin care will be discussed in another section.
- Shoes or slippers for walking, riding stationary bikes, or ride-on toys in the halls.
- Your child's favorite hats/head covers in case they feel chilly after hair loss.
- Pillows, blankets, stuffed animals, and comfort items.
  - *These items **must all be freshly machine washed in hot water** just before coming to the hospital and must be sanitary. **No feather pillows or feather down blankets.** Please limit to 1-2 favorite stuffed animals/comfort items as these can hold germs.
- Yoga mat or play mat for play or exercise on the floor. The hospital also has these if you do not.
- Electric razors **only** (if needed) due to risk of bleeding.
- Make-up in clean, new, unopened packages. Opened make-up can contain germs.
- Nail file or emery board. No nail clippers please due to risk of bleeding.
☐ Soft bristle toothbrush and toothpaste. The hospital can provide these items however your child may prefer their own from home. Specific mouth rinses and lip balms are provided to help prevent infection. Further details are in the next section.
☐ Night light if desired
☐ Favorite posters or personal pictures. Removable wall decals are acceptable and can be a fun way to brighten the room.
☐ Cell phone with charger. The hospital does not have cell phone chargers available.
☐ Favorite movies, books, quiet activities like puzzles and small crafts
☐ Any prescription glasses with case, no contact lenses allowed
☐ A notebook or journal, stationary, envelopes, stamps
☐ School work
☐ Laptop or tablet with charging cords, although you will have internet access through the TV in your child’s room.
☐ Favorite food items, no more than 2-3 days’ supply, may be brought in and stored in your room refrigerator or the unit freezer. Please refer to the USDA Food Safety Guide.
☐ Sanitary pads

**Things not to bring to the hospital:**
- Highly valuable items. The hospital staff cannot be responsible for these items.
- Tight restrictive clothing
- Finger nail clippers
- Contact lenses
- Artificial nails
- Any items with fragrance such as cologne, perfume, lotion, body spray
- Oil diffusers
• Small appliances like toasters, toaster ovens, microwaves, blenders, or coffee makers (including Keurigs)
• Dental floss (due to bleeding risk)
• Tampons
• Fans
• Live plants or flowers

Visiting Guidelines
Visiting hours are flexible on the transplant unit and in pediatrics in general.
• We do encourage most visitations to happen between 9am and 9pm to promote adequate rest time for you and your child.
• We encourage limiting numbers of visitors to 2-3 at a time (in addition to the patient and caregiver). This helps minimize germs being brought into your child’s environment.
• Please be aware that your child’s nurses or medical providers may need to change visitation hours and allowances at any time based on your child’s condition.
• All visitors to Mott Children’s & Women’s Hospital are required to be screened and wear a visitor’s badge to maintain a safe and secure environment. There are no exceptions to this rule. There are 3 stations:
  o One in the lobby of Mott Hospital
  o One at the connector between the Taubman Center and Parking lot (P3) and Mott Hospital
  o One on level 3 at the end of the connector from the P4 parking structure
  o There is also screening on the 7th floor when they arrive if they have missed the other stations. The screeners provide badges and stickers indicating a health screening has been conducted.
Sick siblings, family members, or visitors

Visitors found to be ill are not allowed on the transplant unit. **If there is any uncertainty, it is best for those visitors not to enter the unit.** In general, children may visit if they are healthy and have not been exposed to contagious diseases (such as chicken pox, measles, colds, or flu) within the previous 48 hours.

- It is recommended to take their temperature before visiting as children aren’t always able to report symptoms of illness.
- All visitors must wash their hands when entering and leaving a patient room.
- During flu season (or other epidemics) the rules for visitors often change.
- Visit [www.med.umich.edu/flu](http://www.med.umich.edu/flu) for more information about influenza.

Smoking

Michigan Medicine has a no smoking policy for the entire complex **including all buildings, parking structures, and grounds.** It is imperative that you and no one around you smoke. Tobacco and marijuana contain fungus spores that can lead to a severe and often fatal pneumonia in transplant patients.

Parking and Transportation

You can park your car at the hospital for a small daily fee.

- Reduced parking is available through social work, however it is not free.
- Parking is available in three parking structures all connected to the hospital. **P4** is located near Mott and has a bridge connecting to the hospital. **P2 and P3** are located between University Hospital and Mott with entrances in the Taubman Center.
Other transportation resources:

- The city of Ann Arbor’s bus system, AATA, has several stops outside the health system. Bus maps and schedules are available in the lobby of the Cancer Center.
- Some local hotels offer shuttle service to and from the health system.
- UM Patient & Visitor Accommodations can direct you to these by calling (800) 544-8684.
- The Guest Assistance Program Office on Level 2 of University Hospital can help address your transportation needs. They can also be reached by phone at (800) 888-9825.
- The American Cancer Society offers a transportation program called Road to Recovery; they can be reached at 1(800) 227-2345

Lodging:

- Ronald McDonald House—information about this resource is available through the social worker. Availability changes constantly and is based on many different factors.
- Bedside— one adult may stay at the bedside, at times two adults could be accommodated.
  - No siblings may spend the night
  - No one under the age of 18 may spend the night

Disclaimer: This document contains information and/or instructional materials developed by the Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

Patient Education by Michigan Medicine is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 3.0 Unported License. Last Revised 07/2018