

# **Autologous Transplant**

## **Patient and Family Resource Information**

**Bring this binder with you to all appointments  
and to your hospital stay**

## **Adult Blood and Marrow Transplant (BMT) Program**



**MICHIGAN MEDICINE**  
UNIVERSITY OF MICHIGAN

**BMT & CELLULAR THERAPY PROGRAM**

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## **Welcome to the Blood and Marrow Transplant (BMT) Program**

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Dear Patient and Family,

Welcome to the Michigan Medicine Cellular Therapy & Blood and Marrow Transplant (BMT) program. Over 25 years ago we began performing the first transplants, today we are proud to have cared for thousands of BMT patients from Michigan and beyond. To provide outstanding medical treatment, we believe in a multi-disciplinary team approach that features expertise in all facets of the BMT process. Michigan Medicine is a leader in bringing innovative treatments, state of the art facilities, research and educational resources to serve our patients. We are very excited to partner with you as you embark upon this important journey!

This BMT resource binder is to provide a resource for information on some of the 'key steps' that you may find helpful as you proceed through the transplant process. Understand that it is common to have questions and to feel overwhelmed when you receive materials, the binder is only one resource and we encourage you to use the "Notes" pages in the front to write down information and questions. The BMT staff are available to you to help navigate through this entire process.

### **How should this resource information be used?**

- You and your family/caregiver will find information that will be useful before, during, and after your transplant.
- Read sections that address certain questions you may have.
- Review information with your family/caregiver.
- Write down questions that you may have for your transplant staff and bring them to your appointments. (Transplant Outcomes & Treatment

Decisions) from BE THE MATCH in section 1: Pre-Transplant Information is a guide to help you talk with your doctor.

**Who do I call if I have questions after I see the transplant team?**

- The BMT Clinic is open Monday -Friday, from 8am to 5pm. During these hours, call (734) 936-9814.
- After 5pm, on weekends, and holidays, call (734) 936-6267 and ask for the BMT physician on-call.
- You can also refer to the following handouts for further contact information on the next **page** labeled “BMT Pre-Transplant Contact Information” and also in **Section 5** labeled “*BMT Discharge Contact Information.*” These handouts give you several phone numbers that you may find helpful. If you have any questions or concerns about anything, do not hesitate to call.

Thank you for entrusting your care to us. We are committed to providing the very best comprehensive care for you and your family.

Sincerely,

Your Blood and Marrow Transplant Team

## BMT Pre-Transplant Contact Information

The list below includes contact information you may need pre-transplant.

Questions/Concerns:	Clinician:	Phone number
Medical Emergency		Call 911
Medical Questions (non-emergent)	MD/NP/PA/RN	Use on-line portal
Medical Questions (requiring same day follow-up)	BMT Nurse Coordinators (M-F, 8a-5p)	(734) 936-9814
Urgent Concerns that cannot wait for clinic hours (nights/weekends/holidays)	BMT doctor on-call	(734) 936-6267
Physicians	Clinic Days	Phone number
Sarah Anand, MD	Wednesday, Friday	(734) 936-9814
Monalisa Ghosh, MD	Tuesday, Thursday	(734) 936-9814
John Maciejewski, MD	Wednesday, Friday	(734) 936-9814
John Magenau, MD	Tuesday	(734) 936-9814
Attaphol Pawarode, MD	Monday, Wednesday	(734) 936-9814
Mary Riwes, DO	Monday, Thursday	(734) 936-9814

BMT Nurse Coordinators	Clinic Days	Phone number
Julie Fornwald	Monday - Friday	(734) 936-9814
Kim Kyro	Monday - Friday	(734) 936-9814
Denise Mouro	Monday - Friday	(734) 936-9814
Maureen Rose	Monday - Friday	(734) 936-9814
Christy Young	Monday - Friday	(734) 936-9814
Donor Nurse Coordinator	Clinic Days	Phone number
Isabel Vial	Monday - Friday	(734) 232-7564

Other assistance:		
Pre-Transplant Insurance Coordinators	Clinic Days	Phone number

Debbie Pratt (A-L)	Monday - Friday	(734) 615-5438
Walter Cole (M-Z)	Monday - Friday	(734) 615-6798
New Patient Intake Coordinator	Clinic Days	Phone number
Teresa Logerquist	Monday - Friday	(734) 232-8838
HLA Sample Coordinator	Clinic Days	Phone number
Nancy Custer	Monday - Friday	(734) 232-7589
BMT Scheduler	Clinic Days	Phone number
Tracie Taylor	Monday - Friday	(734) 232-7591
Apheresis	Monday - Friday (8a - 4p)	(734) 936-6900
Pharmacy location	Hours	Phone number
Cancer Center	(M-F, 9a-5:30p)	(734) 647-8911
Ambulatory Care/Taubman	(M-F, 9a-6p; Sat 9a-4:30p)	(734) 936-8260
Social Work	Clinic Days	Phone number
Jack Harrington (A-K)	Monday - Friday	(734) 232-9073
Toni Spano-English (L-Z)	Monday - Friday	(734) 232-5776
Billing and Insurance		
Patient Financial Counselors (PFC's) - (877-326-9155)		
Tangible (transportation, lodging, prescription cost resources, coordination of Medicaid travel benefits, etc.)		
Guest Assistance Program (GAP) - (800) 888-9825		
Lodging (short-term)		
Patient & Visitor Accommodations (PVA) - (800) 544-8684		
Supportive Assistance (Families Facing Cancer, PsychOncology, Symptom Mgmt, etc.)		
Patient and Family Support Services (PFSS) - (877) 907-0859 or (734) 232-6366		



# **Important Paperwork and Forms to Return**



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## Advance Directive Tips

Attached is the document, *“Start the Conversation: Making your healthcare wishes known - Advance Directives and Durable Power of Attorney for Health Care.”*

If you already have a **legal** Advance Directive, there is no need to complete the attached document. Rather, we ask that you please provide a **copy** of your existing legal document to your social worker who will then send it for scanning into your medical record.

If you do **not** already have a legal Advance Directive, Living Will, or Durable Power of Attorney for Health Care (DPOA-HC), we encourage you to complete the attached document.

- A notary is not necessary however, the **signatures below are required** for the document to be legally binding:
  1. Page 13 – Patient signature
  2. Page 14 – Patient full name and date of birth
  3. Page 16 – Patient signature and two witness signatures  
***Important note:** Witnesses **cannot** be family members, your identified patient advocates or members of your healthcare team*
  4. Page 17 – Advocate signature(s)
- Once the document is complete with signatures, please **keep the original and provide a copy of pages 8-17 (only) to your social worker.**
- **Note:** To be sure you have completed the document in its entirety, please refer to the “Advance Directives Final Checklist” sheet found after page 17.

If you have any additional questions, feel free to contact your social worker.

Sincerely,

Jack Harrington, LMSW   Barbara Rose LMSW, ACSW   Toni Spano-English, LMSW  
Phone: (734) 232-9073   Phone: (734) 232-8757   Phone: (734) 232-5776

# Pre-Transplant Patient Checklist: Autologous Transplant

Patient Name: \_\_\_\_\_ MRN: \_\_\_\_\_

A successful stem cell transplant requires commitment not only from you and your medical team, but from your support system as well. To ensure the best transplant outcomes, it is vital that you, BMT staff, and your family and friends all partner together before, during and after stem cell transplant. To ensure this, all areas below must be addressed before moving forward with your transplant admission and will be confirmed by your BMT doctor, nurse coordinator and social worker.

**Please note that failure to comply with, or providing false information regarding any of the following may result in your transplant candidacy being placed on hold temporarily or indefinitely, as determined by the transplant team.**

- ☐ **Caregiver:** One of the most important requirements for every patient is to have a **minimum of one full-time primary caregiver and one secondary caregiver** to act as back-up and/or provide general relief should the primary caregiver need (a total of 2), residing with you within 100 miles from Michigan Medicine and attending all of your medical appointments, **for approximately 2 weeks after hospital discharge.**

**Note:** Private duty caregivers/home care agency staff as well as alternate care settings such as nursing homes, assisted living centers or group homes are **not** acceptable caregiver options.

- ☐ **Treatment compliance:** A crucial part of a successful transplant is for you to participate as a partner in achieving your required health care goals. You are therefore required to follow the treatment plan recommended by the transplant team before, during and after transplant. This includes but is not limited to attending all appointments and taking all medications as prescribed.
- ☐ **Alcohol, nicotine and illicit drug use:** All patients are required to stop the use of non-prescription substances before, during and after transplant. Alcohol abuse screening as well as drug and nicotine testing will be used as necessary to ensure your safety. If you smoke you will be referred to our Tobacco Consultation Service (TCS) team for evaluation.

- **Mental health:** Your mental health status is a crucial component for best transplant outcomes. Whether or not you have a prior mental health diagnosis, depression, anxiety and other coping concerns can occur from your cancer diagnosis and treatment. Your transplant team may recommend consultation or ongoing follow-up with a mental health provider as part of your care commitment.
- **Lodging:** If you reside over 100 miles from the hospital (mileage will be verified), you will be required to secure and pay for temporary lodging within 100 miles (preferably in the Ann Arbor area), **for up to 1 week after hospital discharge** to ensure a safe recovery
- **Transportation:** While you are in need of caregiver support (item #1 above), you are also in need of transportation assistance. You will be unable to drive until cleared by the BMT doctor. Caregivers are often also your driver and are required to accompany you at all appointments.
- **Dental care:** You are required to undergo a complete dental exam, including a full set of dental x-rays or Panorex, and to provide a copy of the completed evaluation or treatment plan to the transplant nurse coordinator.
- **Advance Directives / Durable Power of Attorney for Health Care (DPOA-HC):** As an able, competent adult, you have the right to accept or refuse medical treatment. Should you become too sick to make decisions regarding your medical care, even for only a period of time, “Advance Directives” allow you to identify who you would want to make the decisions on your behalf. To ensure your wishes are met, you are encouraged to provide a completed DPOA-HC document. See the handout: “Start the Conversation: Making your health care wishes known: Advance Directives and Durable Power of Attorney for Health Care BOOKLET and FORMS”: <http://www.med.umich.edu/1LIBR/AdvanceDirectives/ADBooklet.pdf>

By signing below, you indicate agreement with and commitment to the above transplant requirements.

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Patient Signature

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Date

# Caregiver Responsibilities Agreement: Autologous Transplant

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Patient Name (Printed)

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Patient Medical Record Number (MRN)

A successful autologous (self) stem cell transplant requires commitment not only from the patient and medical team, but from the patient's support system as well. Each patient requires a **minimum** of one full-time primary caregiver and one secondary caregiver to act as back-up and/or provide general relief should the primary caregiver need (a total of 2).

A **caregiver** is a responsible adult family member or friend who is able and willing to provide physical care, observation, reliable transportation and emotional support throughout the transplant process. Private duty caregivers/home care agency staff as well as alternate care settings such as nursing homes, assisted living centers or group homes are not acceptable caregiver options. The caregiver or alternate must be available as needed during the entire transplant process, including but not limited to:

- pre-transplant evaluation
- education sessions
- weekly visits during hospital admission
- full-time following discharge from the hospital

Being a caregiver for a transplant patient is a vital role in the transplant process. Please consider the following list of responsibilities and other requirements from the transplant center before agreeing to this commitment.

- I/we will be available 24 hours per day upon discharge, **for approximately 2 weeks or for as long as medically required by the BMT doctor.**
- I will carry a cell phone with me at all times.
- I/we will reside with the patient, within 100 miles of Michigan Medicine, **for up to 1 week or for as long as medically required by the BMT physician.**

If the patient's primary residence is not within 100 miles, I/we will arrange temporary lodging post-transplant, within a 100-mile radius, preferably in the Ann Arbor area.

- I/we will attend discharge training, as required by the transplant center
- I/we will review the transplant materials and treatment instructions provided by the transplant center
- I/we will ask the transplant center staff questions and be available for communication as needed
- I/we will provide the patient's transportation to all appointments
- I/we will accompany the patient at all appointments (**note: afternoon appointments are standard**)

- I/we will have an understanding of the patient's medications, assist with administration as needed and keep a log
- I/we will follow the transplant center instructions and precautions regarding infection prevention
- I/we will coordinate food preparation, maintain a clean home environment and assist with daily living functions
- I/we will follow the transplant center treatment plan and any additional requirements set by transplant center.

By signing below, I indicate that I have reviewed these potential responsibilities and feel comfortable being listed as a caregiver. **If I am unable to fulfill any support throughout the transplant process, I will communicate with the patient and an alternate caregiver to arrange coverage in my absence.**

### 1. Primary Caregiver

_____	_____
Patient Caregiver Name (Printed)	Relationship to Patient
_____	_____
Primary Caregiver Signature	Contact Number (Cell)

### 2. Secondary Caregiver

_____	_____
Secondary Caregiver Name (Printed)	Relationship to Patient
_____	_____
Secondary Caregiver Signature	Contact Number (Cell)

As additional caregiver(s) for \_\_\_\_\_, I/we agree to assist the primary and secondary caregivers with the previously listed responsibilities.

**3. Additional Caregiver Information:**

_____ Caregiver Name (Printed)	_____ Relationship to Patient
_____ Caregiver Signature	_____ Contact Number (Cell)

**4. Additional Caregiver Information:**

_____ Caregiver Name (Printed)	_____ Relationship to Patient
_____ Caregiver Signature	_____ Contact Number (Cell)

**5. Additional Caregiver Information:**

_____ Caregiver Name (Printed)	_____ Relationship to Patient
_____ Caregiver Signature	_____ Contact Number (Cell)

**6. Additional Caregiver Information:**

_____ Caregiver Name (Printed)	_____ Relationship to Patient
_____ Caregiver Signature	_____ Contact Number (Cell)



## BMT Patient Dental Clearance Instructions

In order to minimize the risk for systemic infection before, during and after transplant, you must have a complete oral dental exam with x-rays. Please arrange an appointment with your local dentist to obtain dental clearance for your BMT admission. You may also request that an appointment be arranged for you at Michigan Medicine Hospital Dentistry, as part of your initial BMT work-up.

- Please have your dentist complete the attached *Dental Evaluation Clearance Form* and have it faxed to our clinic. **Do not** have copies of your dental x-rays sent to our BMT clinic.
- Before **any dental procedure** being performed (including teeth cleaning), ask your dentist to contact the Blood & Marrow Transplant Team Nurse Coordinators at telephone number (734) 936-9814, as you may have low blood counts and require medical clearance to proceed with any dental procedures.
- You will not be able to have any dental work completed during the first six months following your stem cell transplant.

We are attaching recommendations from the faculty in Hospital Dentistry at the University of Michigan School of Dentistry to help you understand oral complications of bone marrow transplant and the frequent oral complications of graft versus host disease. Please contact your BMT Nurse Coordinator if you have any questions regarding your dental clearance.

## BMT Dental Evaluation Clearance Form

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Dental Office Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Date of Evaluation: \_\_\_\_\_

Initial Impression / Plan: \_\_\_\_\_

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### Conclusion:

- ☐ Patient is Cleared for Stem Cell Transplant
- ☐ Patient is **NOT cleared** for Stem Cell Transplant due to the following reasons: \_\_\_\_\_

Dentist signature: \_\_\_\_\_

Date: \_\_\_\_\_

Please do not send copies of the patient's x-rays to our clinic. If you need additional information regarding our request or the medical condition of this patient, please contact us at (734) 232-7589. **Please FAX your Clearance Form and treatment plan, if needed, to: (734) 232-9454.**

Version 1, effective date 4/2/19

## **Oral Care Instructions for People Undergoing Bone Marrow Transplant**

Your mouth will undergo some changes both during and after bone marrow transplant. The purpose of these instructions is to explain these changes and give some suggestions as to how you can protect your teeth and keep your mouth healthy.

### **How can a bone marrow transplant affect salivary glands?**

About 30-40 out of 100 patients (30-40%) who have bone marrow transplant experience changes in their salivary glands. This results in a decrease in saliva flow. This is sometimes called “xerostomia”, or dry mouth, and can be annoying.

### **How can I alleviate dry mouth?**

- drink plenty of water or take frequent sips of water
- humidify your home
- chew sugar free (xylitol based) gum or candy

There are some mouth rinses and gels that are also recommended to relieve dry mouth symptoms:

- Biotene oral balance gel
- Stoppers 4 Dry Mouth spray

Choose mouthwash without alcohol and toothpaste without whitening and tartar-fighting properties to decrease irritation:

- Crest Pro Health Mouth rinse
- Biotene Mouthwash
- Biotene Dry Mouth toothpaste
- Any children's tooth paste

## **How do I prevent tooth decay?**

Saliva plays a very important role in preventing tooth decay (cavities). You will not only be experiencing a reduction in amount in saliva, but also a change in its decay-preventing properties. Follow these recommendations:

- a) Before bedtime, brush for at least five (5) minutes. Floss. Use a regular soft or electric toothbrush and take care to clean well at the gum line, as this is where plaque develops.
- b) Use fluoride gel every night by using the “Brush-on” technique: Place a pea-sized portion of fluoride gel on your toothbrush. Brush on all surfaces of your teeth; try to use your brush to squeeze the fluoride in between your teeth. After one full minute, spit out the excess. Don’t eat, drink, or rinse for one-half hour.
- c) Reduce or stop eating high sugar foods and drinks such as Coca-Cola, candy, etc.
- d) If you must have high sugar foods (Pediasure, Ensure) rinse your mouth with water to loosen sugar and prevent it from sticking to teeth. Drink at least 1 cup/glass of water after having high sugar foods.
- e) Continue regular dental visits every 3 to 6 months. Early detection of cavities is very important so that they can be filled when small and your prevention techniques can be evaluated. Your family dentist should still be comfortable treating you even though you’ve had a bone marrow transplant. If your dentist has any questions or concerns, they should feel free to call us for advice.
- f) Consider chewing gum to increase salivary flow. Gums that contain xylitol (Spry, Trident) or calcium phosphate (Trident Extracare) may also prevent tooth decay.

Studies have shown that unfortunately your saliva amount may not return to normal levels even years after bone marrow transplant. For this reason, the fluoride should be used for the rest of your life.

## **Will I have mouth sores?**

The soft tissues in your mouth will normally replace cells on a regular basis. Transplant slows down this process during and for a period of 1-2 months after treatment. This is called **mucositis**. Combined with the dryness, your cheeks can become quite uncomfortable. We recommend that you rinse with a salt and baking soda rinse, as this creates a buffer against the acids which tend to burn mouth tissue.

- Mix 1/8 tsp. salt and 1/8 tsp baking soda in a cup of water and rinse. Do this as often as you wish. If you find the tissues are still uncomfortable after this, please let us know and we can discuss other solutions.

It is import to realize that **you** play the most important role in preventing dental problems. Sticking to a preventive regimen as described above, plus regular recall visits to your dentist will help. In addition, we are always available to answer any questions for you or your family dentist regarding the impact of radiation therapy on your oral health.

## **What are the oral health care instructions for infants and children?**

Consult with a pediatric or local dentist and establish a regular dentist by 12 months of age. Routine dental check-ups are recommended every 3-6 months, depending on the stage of treatment.

### **Guidance for primary caregivers:**

We understand that your child needs to eat, drink and take medications. However, it is very important to note the high sugar content in milk, juice, high-calorie supplements and medications in order to make them more flavorful. Paying careful attention to sugar content can help prevent unnecessary pain and infection from dental decay. Here are some suggestions to follow:

**Diet:**

- Decrease sugar exposure by restricting feeding (breastmilk, bottled-milk, pediasure) to meal times with at least 2 hours between feedings.
- Avoid feeding at will or allowing your child to fall asleep while feeding.
- Do not fill the bottle or sippy cup with milk, chocolate milk, pediasure or juice and allow your child to carry this around. Have your child drink this in one sitting.
- If frequent feedings are necessary, wash teeth with a wash cloth or rinse the mouth with water after each feeding.
- If your child carries a sippy cup or bottle around, fill it with water.
- Medications are high in sugar content to make them more flavorful. Do not let your child fall asleep immediately after taking medications. Wash teeth with a wash cloth or rinse the mouth with water after taking medications.
- Avoid sharing food or drink with your child, especially if active decay is present in the mouth.

**Oral hygiene for infants:**

- Clean your child's teeth with a wash cloth or soft toothbrush as soon as they start showing.
- By age 1, brush teeth with a regular tooth brush and water. Do not use toothpaste until your child learns to spit.
- Brush with a pea-size amount of fluoridated toothpaste as soon as your child has learned to spit excess.

**Who can I call if I have questions?**

- Samuel Zwetchkenbaum, DDS, MPH
- Carol Anne Murdoch-Kinch, DDS, PhD
- Benjamin Cornwall, DDS
- Call: (734) 936-5955
- Email: [szwetch@umich.edu](mailto:szwetch@umich.edu)



## BMT & CELLULAR THERAPY PROGRAM

### **Autologous**

#### **Section 1**

#### **Pre-Transplant Information**

Transplant Outcomes & Treatment Decisions  
Your Health Care Team  
Common Pre-Transplant Tests and Procedures  
Central Line Information  
Before You Get Your Peripherally Inserted Central Catheter (PICC)  
Donor Neupogen/G-CSF Instructions  
Mozobil  
Apheresis Instructions  
Preparing to Collect Stem Cells: When to Call the Doctor  
Preparing for your Hospital Stay  
Consents  
Patient Calendars  
Teaching Slides

## **Your Health Care Team – Autologous Transplant**

**Your Blood and Marrow Transplant Team includes the following professionals:**

### **Doctors**

While undergoing your transplant, medical care is provided by a transplant doctor. They see you on a daily basis to answer questions you may have and keep you informed of your progress. Responsibilities of the transplant doctors change every 2 weeks. This means that you will have the opportunity to receive care from a few doctors during your hospital stay and recovery period. Weekly meetings between the doctors and other team members keep everyone up-to-date on the status of every patient.

### **Nurse Practitioners and Physician Assistants:**

These providers have advanced training in transplant patient care and have day-to-day responsibility for your care while you are in the hospital or in the clinic. They work in close collaboration with the doctors in both the inpatient and outpatient setting.

### **Pre-Transplant Nurse Coordinators**

Your pre-transplant nurse coordinator tracks your treatment before your transplant admission and plans the necessary testing and treatment you will need to get ready for transplant. The BMT nurse coordinator is your primary contact as you work your way toward transplant.

### **Inpatient Nurses**

These nurses are experienced in the care and specific needs of transplant patients. Your inpatient staff nurses organize your care from the time you are admitted until you are discharged from the hospital. Once admitted, your nurse will discuss the transplant process and what will be expected of you during your hospital stay. They also will be available to help you and your family with



physical or emotional problems as they arise. Throughout your hospital stay, they will provide ongoing education about the transplant process in preparation for discharge.

### **Care Management**

Your case manager is a nurse that will partner with you, your family, and your healthcare team to coordinate a safe discharge. The team will begin working on your transition for a safe discharge as soon as you are admitted to the hospital. They help coordinate home care needs, which could include a visiting nurse coming to your residence as well as home care supplies.

### **BMT Clinic Nurses**

Once you are discharged, the outpatient clinic nurses will help develop your plan of care in the outpatient setting. These nurses are also experienced in the care and specific needs of transplant patients. Your clinic nurse will assist you and your caregiver through the recovery process.

### **Social Workers**

Part of your required pre-transplant preparation is an initial psychosocial assessment with a social worker that will give you the opportunity to discuss non-medical needs and other concerns you may have. Social work is available to provide as needed mental health support services, including counseling, therapy and support groups to help patients, families and caregivers adjust to the transplant process. Social workers are available to providing assistance for coping with the stress of hospitalization or post-transplant complications. They are available to address practical matters as well, including education regarding Social Security Disability, caregiver planning, community and Michigan Medicine resources, financial stress, and referrals to insurance specialists.

**Dietitians**

The transplant dietitian will meet with you while you are inpatient to explain any diet considerations during your hospital stay and when you go home. They also work with you to set nutritional goals to prevent weight loss, follow your nutrition intake and offer suggestions on how to achieve your nutrition requirements. The dietitian is available to you after you are discharged and during your recovery as your appetite returns to normal.

**Clinical Pharmacists**

A clinical pharmacist participates in the planning of your chemotherapy and other medications you receive while outpatient or inpatient. They are available to answer questions you may have about the medications you receive.

**Cell Therapy Technologists**

This team is involved in apheresis procedures and processes the stem cell products after harvesting. A cell therapy tech will bring your cells to the bedside on the day of transplant.

**Physical/Occupational Therapists**

A physical and occupational therapist may see and assist you while you are in the hospital, to help you maintain your strength and endurance during and after transplant. A physical therapy tech will also be available to encourage you to be active throughout your stay.

**Inpatient Spiritual Care**

A spiritual care counselor is a supportive care resource for coping with the stress of transplant. They are available to provide you with spiritual and religious resources.

**Medical Assistants and Patient Care Techs**

Medical Assistants in the clinic will check you in and obtain your vital signs before seeing the doctor. On the inpatient unit, they will assist you with daily activities including hygiene and mouth care, assess your vital signs, draw blood, and check blood sugars.

**Clerical Staff**

Clerical Staff will check you in at clinic appointments and when you are admitted to the inpatient unit. They coordinate communication between other departments or units in the hospital.

**Research Coordinators**

Research Coordinators ensure that protocol requirements such as diagnostic tests and lab samples are completed. They also ensure that study medications are dispensed and tracked for any clinical trials you may be enrolled in.

## **Common Pre-Transplant Tests and Procedures**

**Blood tests-** The most common test (called a “Complete Blood Count” or CBC) measures the number of red blood cells, white blood cells, and platelets in the blood. In addition to blood cell counts, tests to measure the values of many chemicals in the blood (such as a “metabolic panel”) can indicate how other parts of the body are functioning, including your liver, kidneys, heart and lungs. A metabolic panel is one test within a chemistry panel which are groups of tests that are ordered to determine a person’s general health status.

**Bone marrow tests-** Blood cells (white blood cells, red blood cells, and platelets) are made in the marrow. Bone marrow tests allow doctors to look at the fluid (inner liquid part of the marrow also known as the spongy part of the bone) and tissue in the marrow to determine whether cancer or another disease is affecting blood cell production or the structure of the marrow. Marrow tests can help determine the type and extent of the disease. Certain changes to blood cells can be detected in marrow samples before they can be detected in blood samples.

**Imaging tests-** Imaging or radiology tests create pictures of the chest, abdomen (belly), head, neck, and other parts of the body. Examples of imaging tests include X-rays, ultrasound, CT scans, MRI, and PET scans. Imaging tests are generally used to look for signs of disease or to check if the cancer (tumors or masses of cells) has spread to other areas.

**Some of the tests below may be ordered for you before your transplant admission:**

- **Echocardiogram-** An echocardiogram (echo) is a test that uses high frequency sound waves to make pictures of your heart. This tests helps your doctor to find out the size and shape of your heart, how your heart moves and the heart’s pumping strength.

- **EKG (Electrocardiogram)**-An EKG records the electrical signals in your heart. It's a common test used to detect heart problems and monitor the heart's status in many situations.
- **Pulmonary Function Tests (PFTs)**- PFTs are a group of tests that measure how well your lungs work. This includes how well you're able to breathe and how effective your lungs are at being able to bring oxygen to the rest of your body.
- **Chest X-Ray (CXR)**- A chest x ray produces images of the lungs, heart, airway, blood vessels and the bones of the spine and chest.
- **Positron Emission Tomography (PET) Scan** – A PET scan is an imaging test that measures blood flow, oxygen use, glucose metabolism and other body processes. It is commonly used to detect and monitor cancers because it shows tissue abnormalities at the cellular level.
- **Computed Tomography (CT or Cat) Scans**- A CT scan is an imaging test that combines a series of X-ray images taken from different angles around your body and uses computer processing to create cross-sectional images (slices) of the bones, blood vessels and soft tissues inside your body. CT scan images provide more-detailed information than plain X-rays do.
- **Magnetic Resonance Imaging (MRI)**- Is a medical imaging technique used in radiology to form pictures of the anatomy and the physiological processes of the body. MRI scanners use strong magnetic fields and radio waves to generate images of the organs of the body.
- **Skeletal Survey**- (also called a bone survey) is a series of x-rays of all the bones in the body.
- **Bone Marrow Biopsy and Aspiration**- Samples of fluid, tissue and cells are examined under a microscope to look for chromosomal changes and other changes in the cells. This test is used to evaluate the response to cancer treatment and to further identify the type of abnormality in the bone marrow.

- **Lumbar Puncture (LP)** - is a medical procedure in which a needle is inserted into the spinal canal, most commonly to collect cerebrospinal fluid (CSF) for diagnostic testing.
- **24 Hour Urine Collection**- A 24-hour urine test is used to check kidney function and measures certain proteins present in the urine.

# The Tunneled Catheter

## What is a tunneled catheter?

A tunneled catheter is a small tube made of a material called silicone. It is called “tunneled” because it is inserted into a large vein and tunneled under the skin to a place where it exits your body. In this handout, we will simply refer to it as a catheter.

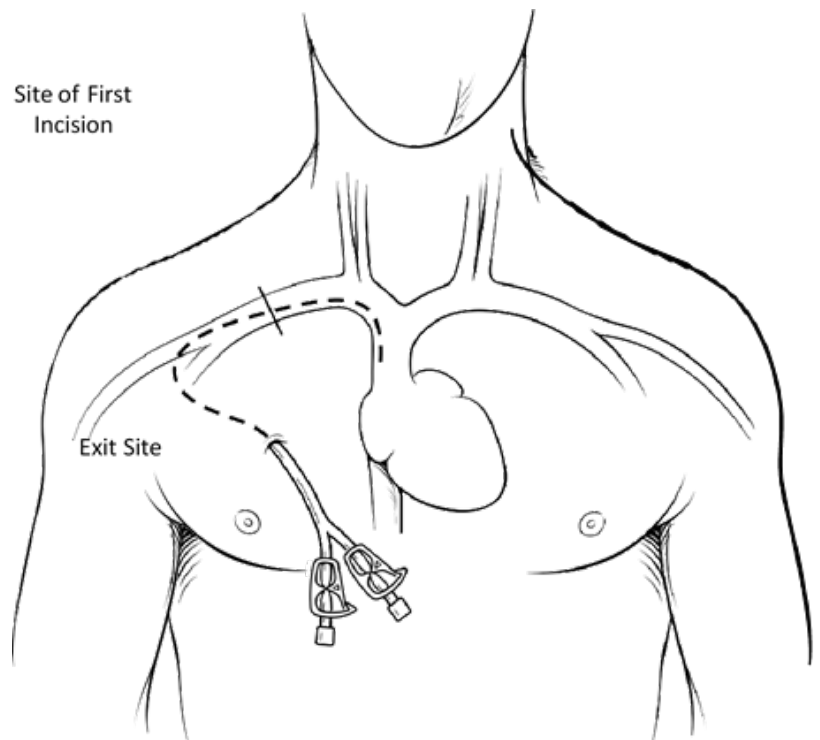


## Why are tunneled catheters used?

A catheter is used to give medications, fluids, blood products, chemotherapy, stem cells, or nutrition through a vein. It may also be used for drawing blood or for apheresis.

## How is the catheter inserted?

The catheter is inserted in an operating room or radiology department and should take about 30-60 minutes. The practitioner makes a small opening in the mid-chest area. Another opening is made where the catheter enters the vein. A tunnel is formed under the skin between the two openings. The catheter is passed through this tunnel and then gently threaded until the tip is near your heart in the large vein called the superior vena cava. After placement, the catheter will be checked to confirm it is in the right position.



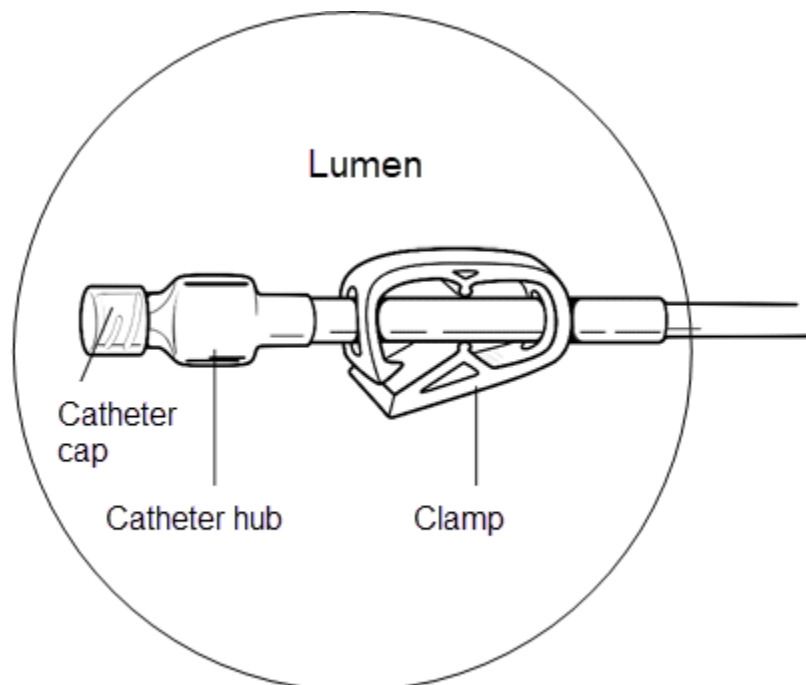
## What is a cuff?

Most catheters have a small cuff that lies beneath the skin about one to four inches from the exit site. The cuff serves two main purposes:

1. The cuff holds the catheter in place by forming scar tissue. Scar tissue will grow around the cuff after 1-2 weeks, making it difficult to pull the catheter out.
2. The cuff helps protect against infection by blocking bacteria from entering the exit site.

## What is a lumen?

The word lumen means the opening or path that is inside the catheter. It is through this opening that you give medications or blood can be drawn. We also use this word to describe the ends of the catheter that are outside your body. You will notice that your catheter has 1, 2, or 3 lumens (see image below).



Adapted from "Care of the Tunneled Catheter" Manual, 2016



# Before You Get Your Peripherally Inserted Central Catheter (PICC)

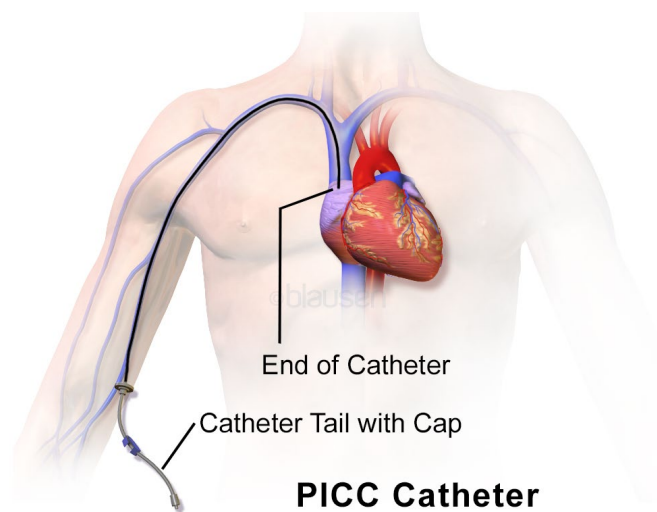
## What is a PICC?

A PICC is a type of intravenous (IV) device. It is a very long, thin, soft flexible catheter. In adults, we insert PICCs through a vein in your arm to provide intravenous medications or draw blood.

Depending on the duration of your treatment, a PICC can remain in place for weeks to months at the discretion of your doctor.

## Where in my body is a PICC located?

- We insert a PICC into a vein in your arm, usually just above the elbow.
- We thread the PICC through a vein in the arm so the end (called the tip) rests in one of the larger veins in your chest (near your heart). This position helps ensure that the PICC is safe to use.



By Blausen Medical Communications, Inc. CC BY 3.0, via Wikimedia Commons.

## Why do I need a PICC?

We often consider PICCs for patients who need one or more of the following:

- IV medications that can cause damage to the smaller veins in the arm
- IV treatment over a prolonged period of time such as weeks or months (example: antibiotics, chemotherapy, blood transfusions)
- Blood draws or infusions for people whose veins are difficult to access
- IV fluids for hydration or nutrition that can't be provided by mouth or absorbed by the stomach

## **How is a PICC inserted?**

A specially trained healthcare professional will insert the PICC. The procedure can be done in your hospital room or in a special procedure room, often the interventional radiology suite.

- Most patients feel little or no discomfort during the insertion. We may use a local numbing medication to minimize the pain associated with the needle stick.
- After the PICC is in place, it will be checked to make sure the end of the catheter is in the right location in your body. After this is verified, your PICC can be used to draw blood or receive treatments.

## **What are the risks of a PICC?**

The risks involved with inserting a PICC include:

- Accidental puncture of a blood vessel, nerve or tendon near the insertion site
- Bleeding
- Infection either at the site of PICC placement or in the bloodstream
- Blood clots in veins where the PICC is placed
- Incorrect positioning of the end (or tip) of the catheter requiring either an adjustment or removal of the PICC
- Breakage of the catheter
- Blockage of the PICC requiring medication to open the blockage or removal of the PICC

## **What precautions should I know about living with a PICC?**

You will be able to bend and use your arm as normal while the PICC is in place, but you will need to follow some precautions to ensure your PICC stays in place and functions well.

- Do not carry heavy weights (more than 5lbs).
- Do not exercise vigorously with your arm while the PICC is in place.
- Avoid contact with water when you have a PICC. You can shower with your PICC in place with a waterproof covering (plastic wrapping or commercially available products).
- Do not swim or take a tub bath (submerge) while the PICC is in place.

## How will I care for my PICC?

- Change the clear covering (bandage) on your PICC at least once a week or sooner if loose, wet, or soiled.
- You, a family member, nurse, home care agency, doctor's office, or infusion clinic will need to flush the PICC periodically to keep the line open

## What are the other options instead of a PICC?

There are other types of catheters that administer medications, nutrition or blood.

- **Regular Peripheral IV-** placed in your arm or hand for medications that you can receive through this route. Keep in mind you must change this every 3 to 5 days.
- **Midline-** placed in your arm by a physician or nurse. Remains in place for 2 to 3 weeks. Only certain medications can be given through this device.
- **Non-Tunneled-** inserted by a doctor into your neck, upper chest or groin. Often placed in an operating room. With this catheter in place you must typically remain in the hospital.
- **Tunneled Catheter-** placed in your neck or chest and anchored under your skin so that it does not come out as easily as a central line. These devices tend to be more difficult to insert and remove and are often used for chemotherapy.
- **Port-** implanted under your skin for long term use. This requires going to the operating room for insertion. A port may remain in place for many years and be used repeatedly. This is often used for chemotherapy.

## Donor Neupogen/G-CSF Instructions

Name: \_\_\_\_\_ MRN: \_\_\_\_\_

### What is my Neupogen® dose?

Inject \_\_\_\_\_ 300 mcg Pre-filled syringes at \_\_\_\_\_, and

Inject \_\_\_\_\_ 480 mcg pre-filled syringes at \_\_\_\_\_

beginning on: \_\_\_\_\_

**Total dose per day = \_\_\_\_\_mcg.**

### What is Neupogen® (Filgrastim)?

Neupogen® is a natural protein produced in the human body. It stimulates the bone marrow to make blood stem cells which then circulate through the blood stream. (Neupogen® is also called G-CSF).

### Are there any side effects?

Some people may experience bone pain (especially in the hips and lower back), fatigue, insomnia, headaches, nausea, vomiting, fever, allergic reactions, or skin rash. There may be pain, swelling or redness at the injection site.

### What should I do if I experience any of these side effects?

If you experience any of the above listed effects or other symptoms which are new while taking Neupogen® you must:

1. Contact your Nurse Coordinator during office hours: (M-F 8 am - 5 pm).
2. Your coordinator is: \_\_\_\_\_
  - Telephone number: \_\_\_\_\_
3. After hours, weekends, and holidays contact the BMT doctor on-call through the paging operator at (734) 936-6267. Ask to have the on-call BMT Attending Physician paged.

**Are there any medicines I should not take?**

There are medications that can interfere with the stem cell collection procedure. You must tell your doctor and nurse coordinator about any medications you may be taking including over the counter medications.

**Are there any medications I can take for bone pain?**

You may take Tylenol or Extra Strength Tylenol. If Tylenol is not effective, you may take a non-steroidal medication. These include Ibuprofen, Motrin, and Aleve. Follow the package directions. Again, please call if you are experiencing any side effects or if these medications are not helping your pain.

**Where should I keep my Neupogen®?**

You should store your medication in the refrigerator at a temperature of 36 - 46 degrees Fahrenheit. Do not freeze. You may let the medicine warm up to room temperature before you inject it. The medicine can stay out of the refrigerator safely for up to 24 hours, but only if necessary.

**What do I do with the syringes I've used?**

Place needles and syringes in a hard, closed container, such as a coffee can or empty laundry container that the needles cannot poke through. These containers should be marked and kept away from children and pets. Needles and syringes in a hard closed container may be placed in your trash.

**What if I forget to take my shot?**

Generally, you should try to take your shots at the same time each day. If you miss your regularly scheduled dose by a few hours, you should take your regular dose as soon as you can. If you are more than a few hours late, contact your doctor/nurse coordinator at the numbers listed on the front of this page.

## **Mozobil (Plerixafor) Information**

### **What is Mozobil?**

Mozobil (plerixafor) works in combination with granulocyte-colony stimulating factor (G-CSF) Neupogen to help move the stem cells out of the bone marrow and into the bloodstream. The stem cells can then be collected, stored, and given back to the patient during apheresis. This drug may or may not be added to your treatment plan.

### **What are the side effects?**

Diarrhea is a common side effect.

### **How do I prevent Diarrhea?**

Take 2 tablets of Imodium (Loperamide) approximately 30 minutes to one hour before the first dose of Mozobil. You will receive further instructions as needed.

This drug is administered as a subcutaneous (under the skin) injection in one of two places:

- Outpatient infusion area in Mott Hospital (7<sup>th</sup> floor, Reception B)
- or
- Cancer Center Infusion Area in University Hospital on Level B-1 Reception A.

## Apheresis Instructions

Apheresis is performed as an outpatient procedure and usually takes 5 hours per procedure. The patients or their donor will have 1 to 4 procedures done to collect the required number of stem cells. For several days prior to the procedure, a drug called Neupogen®, which is a growth-factor, is taken in injection form to produce a greater number of stem cells, which are released into the blood.

Apheresis is done by inserting a needle into one arm and connecting the IV tubing to a machine where the peripheral stem cells are separated and collected. The remaining blood components (white cells, red cells and platelets) are returned to you through another IV in your other arm. The only discomfort you may feel is when the IV needles are inserted. In some cases, an IV catheter is inserted in the chest, neck or groin if the veins in the arms are not large enough or strong enough for the procedure.



You will need to report to the Apheresis Unit early in the morning for your apheresis procedure. If you are traveling a great distance, arrangements can be made for lodging by calling the bone marrow transplant social worker or Patient & Visitor Accommodation Program. Someone should accompany you to this appointment in case you need to be driven home.

**Before your apheresis:**

- ☐ Eat a normal breakfast
- ☐ Drink a full 8-oz. glass of milk: you need the calcium for the procedure
- ☐ Take the prescription medication you usually take, unless you were told otherwise. (Notify the apheresis nurse of all medication taken)
- ☐ If you are on an **ace inhibitor** for your blood pressure, **do not take it the morning before your procedure.**
- ☐ Do not take over-the-counter medications unless approved by a transplant doctor. (You may take Tylenol, Motrin or Advil and Claritin)

You should not lift anything heavy for several hours after apheresis to allow the needle sites to heal.

**Location:** The apheresis procedure is done in the University Hospital-Apheresis Procedure Unit room. This is located on level 2 of the University of Michigan Hospital, near the hospital cafeteria.

**Questions?** If you have questions regarding your appointment, contact the Transfusion & Apheresis Procedure Unit at (734) 936-6900.



## Preparing to Collect Stem Cells: When to Call the Doctor

Everyone is different and may have slightly different complications after treatment. In order to help you, we need you to be aware of what is abnormal or unusual for you. Be alert for anything that is different and report it to us right away. This will help us respond more quickly as we work together as partners to meet your needs.

### When should I call my doctor or nurse?

- You have a temperature of 100.5° F (38.1° C) or higher by mouth
  - **Do not** take Tylenol® or aspirin until you speak with your doctor or nurse
- You have signs and symptoms of an infection. These include shaking and/or chills, a burning feeling when passing urine, a cough, sore throat, a general feeling of tiredness or “flu-like” symptoms, or fever.
- You are feeling confused, dizzy, overly tired or weak.
- You notice yellowing of your eyes or skin
- You have redness, pain or sores in your mouth
- Your heartbeat feels unusual or irregular
- You have been unable to eat or drink in the past 24 hours
- You have been nauseated or vomiting for more than 24 hours
- You do not have a bowel movement for 2-3 days
- You have diarrhea (loose, watery stool) for more than 24 hours
- You have blood in your urine or in your stools (either bright red or black bowel movements)
- You have any vaginal bleeding which is unusual for you
- You have a nose bleed that does not stop after 20 minutes

- You notice any other bleeding or bruising which is unusual for you
- You have pain that is not controlled by your current medication
- You notice any changes in your catheter, including a change in the appearance of the line, redness, drainage, swelling or pain. If you are unable to flush catheter ports, the catheter becomes dislodged or leaks

**Call if you have any other questions or concerns which are not listed above.**

### **Emergency Phone Numbers**

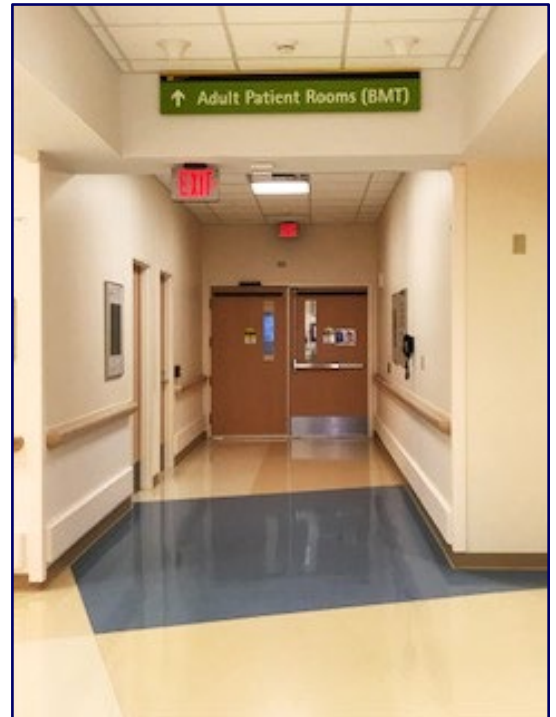
- M - F 8am to 5pm call: (734) 936-9814
- **After hours, weekends, holidays:** Call the paging operator and ask to have the on call BMT physician paged (734)-936-6267

## Preparing for Your Hospital Stay

Being in the hospital can be difficult. The transplant team encourages you to bring personal items to make the hospital room feel more at home. Items from home can also provide distraction and often help decrease stress and boredom. The items listed below are offered as suggestions. Remember, your room size is limited. Check with your nurse coordinator or social worker if you have questions about items not on this list.

### Items you ***must*** bring:

- ☐ One copy of your Medical Durable Power of Attorney and Living Will
- ☐ Your transplant education binder
- ☐ Your current list of medications you take



### Items to ***consider*** bringing:

- ☐ Pajamas, sweats, or loose fitting, comfortable street clothing to change daily
- ☐ Clean underwear to change daily
- ☐ Slippers with non-skid bottoms or slip on shoes
- ☐ Shoes to walk the halls/ride exercise bikes
- ☐ Hangers for the closet
- ☐ Turbans, scarves, or hats (in case you feel chilly after losing your hair)
- ☐ Pillows, blankets, and stuffed animals may be brought in, however they should be machine washed before bringing into the room. They must be sanitary. Avoid feather pillows. New items do not need to be washed before bringing them into the room
- ☐ Electric razors only
- ☐ Soft toothbrush, toothpaste
- ☐ Nail file or emery board
- ☐ Make-up in new, unopened containers only (keep to a minimum)

- ☐ Menstrual pads (we only stock very large bulky ones), do not use tampons
- ☐ Night light
- ☐ Silk plants/silk flowers
- ☐ Favorite family photos or decorations
- ☐ Personal address/phone book
- ☐ Cell phones and chargers
- ☐ Electronic devices (cell phones, laptops, tablets, etc) and chargers
- ☐ Leisure activities such as magazines, books, puzzles, games, cards, or crafts
- ☐ A journal, stationary, stamps and envelopes (consider pre-addressing them)
- ☐ Snacks for your room
- ☐ 1-2 days quantity of perishable food items may be brought in and stored in the refrigerator in room.

**Items *not* to bring:**

- |  |   |
|--|---|
| • Contacts   | • Disposable razors   |
| • Dental floss                                     | • Finger nail-clippers  |
| • Tampons  | • Artificial nails  |
| • Cologne/perfume/body spray/lotion with fragrance | • Multiple dose eye drops   |
| • Refrigerators or other small appliances          | • Sources of standing water (humidifiers, vases of water with flowers, etc) |
| • Fans   | • Home medications (Actual) - Do bring a list of current medications        |
| • Live plants and flowers                          | • Bar soap or loofah  |
| • Valuables  | • Diffuser  |
| • Tight restrictive clothing                       |   |

\* Refer to Section 4 for information on what to expect during your hospital stay.

.



## BMT & CELLULAR THERAPY PROGRAM

### **Autologous**

#### **Section 2**

### **Bone Marrow Transplant Basics and Individualized Information**

Chemotherapy Education Sheets

*Autologous Transplant Information (Be the Match)*

Disease Specific Information

Glossary of Terms



## BMT & CELLULAR THERAPY PROGRAM

### **Autologous**

#### **Section 3**

### **Psychosocial Support and Resources**

Psychosocial Support and Resources

Pre-Transplant Patient Checklist (Reference copy)

Caregiver Responsibilities Agreement (Reference copy)

Support Group Information

Letter to Family and Friends

## **Psychosocial Support and Resources**

### **Clinical social work role in transplant:**

A core member of your Blood and Marrow (BMT) team is the clinical social worker. You will work with two Masters-level social workers in the BMT program throughout your transplant; one in the outpatient clinic and one during your inpatient stay(s).

Included in the required transplant preparation process is for you and your caregiver(s) to meet with a social worker for an initial psychosocial assessment. All patients being considered for a transplant must be cleared by social work to proceed.

The assessment is a comprehensive review to help you and the social worker identify and discuss any concerns you and your caregiver(s) may have, as well as evaluating the following areas:

- Support system
- Caregiver plans
- Lodging plans (for patients traveling over 100 miles to Michigan Medicine)
- Work, financial, insurance and disability concerns
- Past and current use of alcohol, tobacco and drugs
- Understanding of the need for abstinence from alcohol, tobacco and drugs
- Coping and mental health support
- Supporters of your family and caregivers and how they are coping
- Understanding and adjustment to the transplant process by you, your family and caregivers
- Ability to follow your treatment plan
- Goals of care

In the folder titled “Important Paperwork and Forms to Return” within your transplant binder, you have been provided the following forms **to complete and submit to your social worker before transplant:**

- ☐ Advance Directive Tips, “Start The Conversation: Making your health care wishes known”
- ☐ Pre-Transplant Patient Checklist\*
- ☐ Caregiver Responsibilities Agreement\*

*\* Copies of these forms, minus the signatures, are included in this section for your reference.*

Our clinical social workers provide expert assistance with the psychological, social, emotional and practical needs of transplant patients and their families. Social work is available for supportive counseling, education, advocacy and resource identification before, during and after transplant as needed.

If the clinical social worker or your BMT medical team identifies a need for additional assessment, you may be referred for evaluation in the Rogel Cancer Center PsychOncology clinic.

<https://www.rogelcancercenter.org/locations/psychoncology-clinic>

### **Your BMT clinical social work team is comprised of:**

Jack Harrington, LMSW – outpatient/clinic (734-232-9073)

Barb Rose, LMSW – inpatient/hospital (734-232-8757)

Toni Spano-English, LMSW – outpatient/clinic (734-232-5776)

### **Social work locations at Michigan Medicine:**

At Michigan Medicine, we offer practical support and assistance at the following two locations:

1. Guest Assistance Program (GAP) office - in the main hospital (800-888-9825)



2. Patient Assistance Center (PAC) office - in the Rogel Cancer Center  
(877-907-0859)

Bachelors-level social workers are available in the GAP and PAC offices to assist you and your caregiver(s) before, during and after transplant as needed. GAP and PAC social workers are available to help address the numerous practical matters that you face throughout your treatment. This can include assistance with:

- prescription payment
- transportation
- wigs
- parking
- lodging payment
- meal vouchers
- gas cards
- information on community resources
- other unforeseen needs

GAP and PAC staff can also connect you to resources within and/or outside of Michigan Medicine, such as:

- **Clinical social workers** for assistance with psychological, social, emotional and practical needs
- **Medicaid** for coordination with your caseworker related to potential meal, lodging and/or transportation benefits while you receive care at Michigan Medicine
- **Patient Financial Counselors (PFC's)** for assistance with billing, insurance and payment concerns

Phone: (877-326-9155)

- **Patient and Visitor Accommodations (PVA)** for assistance with locating discounted lodging in the Ann Arbor area

Phone: (800-544-8684)

Website: <https://www.rogelcancercenter.org/support/financial-assistance/practical-assistance-center>

## **Additional support resources at Michigan Medicine:**

- **Hematology/Oncology Patient and Family Support Group**

For adult patients, or families and caregivers of someone undergoing hematology/oncology treatment or transplant. This support group is offered once a week and is an open forum lead by a social worker on the inpatient unit. Website: <https://www.rogelcancercenter.org/files/hem-onc-bmt-support-group.pdf>

- **Families Facing Cancer**

Parents or grandparents with cancer often have concerns about how to discuss the illness with their children. The *Families Facing Cancer* program specialist is a Certified Child Life Specialist who provides assistance to the patient and family in helping children understand and cope. Resource kits with information about talking with children, parenting during illness, and recommendations of appropriate books for children are available.

Website: <https://www.rogelcancercenter.org/support/managing-emotions/complementary-therapies/families-facing-cancer>

- **Symptom Management/Palliative Care**

Palliative Care offers pain and symptom management as well as emotional support. The goal of palliative care is to improve quality of life for the patient and family. It is appropriate at any age and at any state in a serious illness, and can be provided along with curative treatment. You can speak with your provider about a referral to the Symptom Management clinic at any point in your treatment.

Website: <https://www.rogelcancercenter.org/files/palliative-care-information-guide.pdf>

- **Fertility Assistance**

At the Center for Reproductive Medicine/Reproductive Endocrinology clinic, there are several resources available that offer information and support on fertility preservation and sexual and fertility changes. Some insurances may require a referral from your medical provider.

Website: <https://www.rogelcancercenter.org/files/fertility-cancer-information-guide.pdf>

- **Patient and Family Support Services (PFSS) Program**

Cancer affects not only the body, but the whole person and the whole family. To reduce the burden of cancer, which can take many forms throughout diagnosis and treatment, services of the Patient & Family Support Services (PFSS) Program are integrated into each patient's multidisciplinary treatment plan. Available services are listed below on the following pages.

Website: <https://www.rogelcancercenter.org/about/support-services>

## **Services Available through PFSS:**

- **Spiritual Care**

Clinically trained chaplains are available to listen and provide spiritual care and assistance to those working through the distress that can accompany disease and treatment. They represent a variety of religions and faith traditions. Chaplains are available Monday through Friday, 8am – 5pm for consultations (inpatient, outpatient, infusion settings). A chaplain is also on-call after hours and on weekends for urgent needs.

Website: <https://www.rogelcancercenter.org/support/managing-emotions/spiritual-care>

- **Complementary Therapies Program**

Providing activities which offer a creative and/or physical outlet to reduce stress and anxiety, such as the following:

- **Art Therapy**

A practice that complements standard cancer treatment by integrating artistic expression into your healing process. You will work with a Board Certified art therapist. Projects are based on individual needs and preferences.

Website: <https://www.rogelcancercenter.org/support/managing-emotions/complementary-therapies/art-therapy>

- **Guided Imagery/Meditation/Breathwork**

A licensed specialty clinician will customize resources to help you regain a sense of control and calm. You will learn tools and practices to manage anxiety, pain and other symptoms by using breath and visualization.

Website: <https://www.rogelcancercenter.org/support/managing-emotions/complementary-therapies/guided-imagery>

- **Music Therapy**

With the support of accomplished musicians and certified therapists, music interventions that are based on science and research will be utilized to meet your physical, emotional, cognitive and social needs.

Website: <https://www.rogelcancercenter.org/support/managing-emotions/complementary-therapies/music-therapy>

- **Legacy Therapy**

A legacy therapist guides individuals in legacy activities, providing a wide assortment of projects and supplies to help navigate the journey of life review and reminiscence through creative expression and discovery.

Examples include photography/film, art, music and visual/digital storytelling.

Website: <https://www.rogelcancercenter.org/support/managing-emotions/complementary-therapies/legacy-therapy>

**Other resources:**

- **Gifts of Art** – Utilizing arts to assist and enhance the healing process, reduce stress, support human dignity and renew the spirit.  
Website: <http://www.med.umich.edu/goa/>
- **Art Cart** – A volunteer can bring framed posters to the floor for patients to select different artwork to display in their rooms.
- **Bedside Music Program** – Certified music practitioners provide bedside music in your room.
- **Bedside Art Program** – Engage patients and families with art making projects at the bedside, free of charge (journals, beaded bracelets, paper folding, drawing, cards and more).
- **Story Studio** – Provides an opportunity for patients and families to record a personal story for someone special in their lives.

# Pre-Transplant Patient Checklist: Autologous Transplant

## Note:

A separate copy of this document is included in the “Important Paperwork and Forms to Return” folder in the “Patient and Family Resource Information” binder. Complete and return it to the BMT social worker before transplant.

A successful stem cell transplant requires commitment not only from you and your medical team, but from your support system as well. To ensure the best transplant outcomes, it is vital that you, BMT staff, and your family and friends all partner together before, during and after stem cell transplant. To ensure this, all areas below must be addressed before moving forward with your transplant admission and will be confirmed by your BMT doctor, nurse coordinator and social worker.

**Please note that failure to comply with, or providing false information regarding any of the following may result in your transplant candidacy being placed on hold temporarily or indefinitely, as determined by the transplant team.**

- ☐ **Caregiver:** One of the most important requirements for every patient is to have a **minimum of one full-time primary caregiver and one secondary caregiver** to act as back-up and/or provide general relief should the primary caregiver need (a total of 2), residing with you within 100 miles from Michigan Medicine and attending all of your medical appointments, **for approximately 2 weeks after hospital discharge.**

**Note:** Private duty caregivers/home care agency staff as well as alternate care settings such as nursing homes, assisted living centers or group homes are **not** acceptable caregiver options.

- ☐ **Treatment compliance:** A crucial part of a successful transplant is for you to participate as a partner in achieving your required health care goals. You are therefore required to follow the treatment plan recommended by the transplant team before, during and after transplant. This includes but is not limited to attending all appointments and taking all medications as prescribed.

- **Alcohol, nicotine and illicit drug use:** All patients are required to stop the use of non-prescription substances before, during and after transplant. Alcohol abuse screening as well as drug and nicotine testing will be used as necessary to ensure your safety. If you smoke you will be referred to our Tobacco Consultation Service (TCS) team for evaluation.
- **Mental health:** Your mental health status is a crucial component for best transplant outcomes. Whether or not you have a prior mental health diagnosis, depression, anxiety and other coping concerns can occur from your cancer diagnosis and treatment. Your transplant team may recommend consultation or ongoing follow-up with a mental health provider as part of your care commitment.
- **Lodging:** If you reside over 100 miles from the hospital (mileage will be verified), you will be required to secure and pay for temporary lodging within 100 miles (preferably in the Ann Arbor area), **for up to 1 week after hospital discharge** to ensure a safe recovery
- **Transportation:** While you are in need of caregiver support (item #1 above), you are also in need of transportation assistance. You will be unable to drive until cleared by the BMT doctor. Caregivers are often also your driver and are required to accompany you at all appointments.
- **Dental care:** You are required to undergo a complete dental exam, including a full set of dental x-rays or panorex, and to provide a copy of the completed evaluation or treatment plan to the transplant nurse coordinator.
- **Advance Directives / Durable Power of Attorney for Health Care (DPOA-HC):** As an able, competent adult, you have the right to accept or refuse medical treatment. Should you become too sick to make decisions regarding your medical care, even for only a period of time, “Advance Directives” allow you to identify who you would want to make the decisions on your behalf. To ensure your wishes are met, you are encouraged to provide a completed DPOA-HC document. See the handout: “Start the Conversation: Making your health care wishes known: Advance Directives and Durable Power of Attorney for Health Care BOOKLET and FORMS”: <http://www.med.umich.edu/1LIBR/AdvanceDirectives/ADBooklet.pdf>

# Caregiver Responsibilities Agreement: Autologous Transplant

**Note:**

A separate copy of this document is included in the “Important Paperwork and Forms to Return” folder in the “Patient and Family Resource Information” binder for completion and return to the BMT Social Worker prior to transplant.

A successful autologous (self) stem cell transplant requires commitment not only from the patient and medical team, but from the patient’s support system as well. Each patient requires a **minimum** of one full-time primary caregiver and one secondary caregiver to act as back-up and/or provide general relief should the primary caregiver need it (a total of 2).

A **caregiver** is a responsible adult family member or friend who is able and willing to provide physical care, observation, reliable transportation and emotional support throughout the transplant process. Private duty caregivers/home care agency staff as well as alternate care settings such as nursing homes, assisted living centers or group homes are not acceptable caregiver options. The caregiver or alternate must be available as needed during the entire transplant process, including but not limited to:

- pre-transplant evaluation
- education sessions
- weekly visits during hospital admission
- full-time following discharge from the hospital

Being a caregiver for a transplant patient is a vital role in the transplant process. Please consider the following list of responsibilities and other requirements from the transplant center before agreeing to this commitment.

- I/we will be available 24 hours per day upon discharge, **for approximately 2 weeks or for as long as medically required by the BMT doctor.**
- I will carry a cell phone with me at all times.
- I/we will reside with the patient, within 100 miles of Michigan Medicine, **for up to 1 week or for as long as medically required by the BMT physician.** If the patient’s primary residence is not within 100 miles, I/we will arrange temporary lodging post-transplant, within a 100-mile radius, preferably in the Ann Arbor area.
- I/we will attend discharge training, as required by the transplant center
- I/we will review the transplant materials and treatment instructions provided by the transplant center



- I/we will ask the transplant center staff questions and be available for communication as needed
- I/we will provide the patient's transportation to all appointments
- I/we will accompany the patient at all appointments **(note: afternoon appointments are standard)**
- I/we will have an understanding of the patient's medications, assist with administration as needed and keep a log
- I/we will follow the transplant center instructions and precautions regarding infection prevention
- I/we will coordinate food preparation, maintain a clean home environment and assist with daily living functions
- I/we will follow the transplant center treatment plan and any additional requirements set by transplant center.

# Hematology/Oncology Support Groups

For Adult Patients, Families & Caregivers



**The Hematology/  
Oncology & Bone  
Marrow Transplant  
journey can be very  
challenging**

Personal struggles, practical suggestions and everyday triumphs find their voice in this open forum moderated by a social worker.

These groups are for any patient receiving chemotherapy due to a blood cancer or having a blood or bone marrow transplant.

Walk-ins are encouraged to attend.

## **Where**

C. S. Mott/Women's Von Voigtlander Hospital  
Adult Inpatient Unit on 7 West  
Patient and Family Lounge

## **When & Who**

Every Wednesday 2:30 – 3:30 pm  
**Patient and Family Support Group**

## **Questions**

Barb Rose, LMSW 734-232-8757



**COMPREHENSIVE CANCER CENTER**  
PATIENT FAMILY SUPPORT SERVICES  
UNIVERSITY OF MICHIGAN  
HEALTH SYSTEM

Dear Family and Friends:

When a loved one is having a Blood or Marrow Transplant (BMT), it is common for people around them to want to help. People undergoing transplants face unique challenges. We have written this letter to share some ideas that have been helpful to other people. Please feel free to make copies and distribute this letter to others.

Having a BMT often results in added costs that are not covered by insurance, such as temporary lodging and travel expenses to and from Ann Arbor before, during and after transplant. Other costs can include lost wages, and medical and prescription expenses not covered by insurance. You can help your family member/friend financially by:

- **Buying gas cards or gift certificates:** For food or shopping to help offset medical expenses.
- **Holding a fundraiser (via an event or online):** Events can be a spaghetti dinner at a church or community center, a simple money collection, raffles, auctions, golf outings, car washes, or even a bowl-a-thon. **Online** fundraising is tax deductible and easy at:
  - <http://bonemarrow.org/one-2-one-funds/register/>
  - <http://www.helpHOPElive.org>
  - <https://transplants.org/take-action/>
- **Donating cash via Venmo or another digital wallet app:** Venmo is free to use. Credit card payments are subject to the 3% transaction fee that the card company charges, but debit card payments and transfers from a users' balance costs nothing.

Of course, financial help is not the only way to offer support. Other ways are:

- **Providing home and family care:** Organize neighbors, friends, extended family and/or church members to help with meals at home, grocery shopping, lawn or garden work, snow removal, chores, laundry, childcare or pet care. Offer babysitting to give the parent(s) a break, or to give their children extra attention.
- **Donating sick time:** If you work with the patient or their caregiver your company may allow you to donate your Paid-Time-Off (PTO). This allows them additional time-off without losing regular income.
- **Creating or maintaining social media updates:** If the patient is agreeable, create a support page in their honor ([www.caringbridge.org](http://www.caringbridge.org), [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com), [www.mylifeline.org](http://www.mylifeline.org)).
- **Visiting in the hospital or at home:** Ask the caregiver if and when it is okay to visit. The patient will have a compromised immune system for up to one year after transplant, so ***please do not visit if you are ill or have been exposed to others who are ill.***
- **Offering other gifts of caring:** Simple things mean a lot. These can include: prayers or meditations when appropriate, a book or DVD, hugs, a listening ear, silk flowers (**live flowers and plants are *not* allowed**), cards, letters and emails, or small gifts.

If you are interested in additional information, please contact the appropriate social worker below.

Sincerely,

Jack Harrington, LMSW

- Clinical Social Worker (Outpatient)
- Phone: 734-232-9073

Barbara Rose, LMSW

- Clinical Social Worker (Inpatient)
- Phone: 734-232-8757

Toni Spano-English, LMSW

- Clinical Social Worker (Outpatient)
- Phone: 734-232-5776



## BMT & CELLULAR THERAPY PROGRAM

### **Autologous**

#### **Section 4**

#### **Admission Information**

*What to Expect During your Hospital Stay*

*Frequently asked Questions about Bone Marrow Transplant*

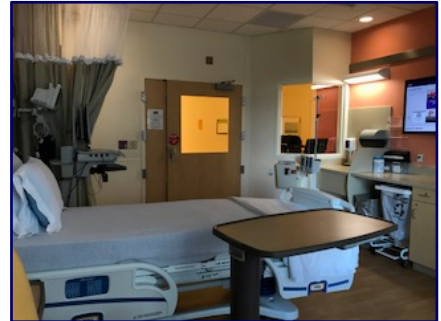
*What to Expect on “Day Zero” of an Autologous Transplant*

*Transplant Day Information and Puzzles*

University Hospital and Frankel Cardiovascular Center Guide: A Resource for  
Patients and Families

# Autologous Stem Cell Transplant: What to Expect During Your Hospital Stay

The following guidelines apply to being admitted to 7 West and what to expect during your hospital stay.



## Admission day:

- You will have an appointment the morning of your admission day with your transplant doctor to ensure that you are ready for your chemotherapy and transplant process to begin.
- You will then get a central line IV catheter (PICC line) placed. If you already have a Hickman central line IV catheter from apheresis, we can use that for chemotherapy/transplant instead of getting a PICC line placed.
- After your PICC line placement, you will go to the infusion area on floor 7 in clinic to receive chemotherapy and then be admitted to 7 West. If you are not due for chemotherapy until the next day, you will be admitted to 7 West at this point.
- Note: If 7 West does not have any open beds at this time, you will be sent to the admit lounge until we have a clean, open room for you. We are aware you are coming in, but sometimes we have to wait for patients to be discharged, housekeeping to clean the room, and then we can admit you.

## Admission and hospital stay:

- We will take a tour of the unit with you. We will show you where the nutrition room, family lounge, and laundry room are. We will also show you where you can walk in the halls.
- We will ask you several questions about your medications, screening questions, and other required documentation that has to be completed on admission day.



- We will review a list of current medications you are taking. If you brought medications that you are currently taking (actual bottles and pills), please send them home with your family. We will dispense all of your medications to you from our pharmacy. In the rare event that you take a medication that we don't stock, we will send your own home medication to pharmacy to verify it and then we can keep it locked up in the med cabinet in your room.

- We will show you how to order meal trays and guest trays from your room phone. You can order food from 6:30am to 8:00pm.
- There is a refrigerator in your room for food, it does not have a freezer component. There is a freezer in our nutrition room for any frozen foods that you plan to bring. Be sure to put your name on that food.
- There is a small couch or chair that converts to a bed for an overnight visitor. Minors need to be accompanied by an adult visitor at all times.

### **Routine nursing care:**

- We do vital signs every 4 hours at a minimum, even overnight.
- Nurses caring for you will do a full assessment of you and your symptoms. They will listen to your heart and lungs, look in your mouth, ask you questions about pain, nausea, diarrhea, etc.
- Labs and blood samples will be taken daily around 4:00am or 5:00am and sometimes in the evening.
- Weights are done every day.
- The doctor and other members of the transplant team will come each day to discuss and update your treatment plan.

## Day to day expectations of you:

- You need to shower every day with chlorhexidine soap that we will provide for you. This is to help prevent you from getting an infection.
  - We will show you how to use saran wrap to cover your central line to avoid it getting wet in the shower.
  - Do not use bar soap, use liquid soap only.
  - Do not use loofah, use a new washcloth each day.
- We will have you save all of your urine during your admission. We will show you how to do that and how to record it yourself.
- We will have you save your first bowel movement upon admission and at other times throughout your stay.
- You need to be walking in the halls at least 3 times a day. You do not need to wear a mask in the halls on 7 West but if you go off the floor for a test, we will have you wear a yellow mask.
- Once you are admitted, you cannot leave the unit. If you must leave, you will need to get nurse or doctor's approval.
- We will encourage you to drink 4-5 large cups of water per day to keep you hydrated.
- Use salt and soda mouth rinse 4 times a day to keep your mouth clean and prevent mouth sores.
- Brush your teeth 2 times a day.
- We will have you use an incentive spirometer several times a day. This is a breathing machine that will help keep your lungs expanded. The respiratory therapist will show you how to use it.
- We will show you how to use Sequential Compression Devices (SCD's) on your legs to help prevent blood clots.
- Be sure to put your call light on when your IV pump is beeping, it does not automatically alert us to when this occurs.





**Infection prevention:**

- Wash your hands often, at a minimum before eating, after using the bathroom, and every time you or your visitors come in and out of your room.
- No sick visitors allowed on 7 West or in your room.
- No real flowers or plants, no latex balloons. Fake flowers and non-latex balloons are allowed.
- Do not wear contact lenses. Eye glasses only.
- Your IV pole will be attached to your central line continuously while you are admitted on 7 West. We do not unhook you for showers. This is for infection control purposes and to keep your risk of infection as low as possible.
- Visitors should not use the bathroom in the room unless instructed otherwise. There are public restrooms and a shower located around the unit.
- Refer to your FDA Food Safety booklet or dietician for specific food related questions.
- Screening tests will be done upon admission and each week on Wednesdays to determine if you are a carrier of certain bacteria that can cause infection if it is spread. These screening tests are done using a swab on the inside of your nose, the other is a rectal or stool sample swab.
- If you are put into contact or droplet precautions (where staff wear gowns, gloves, and possibly a mask into your room) we will prohibit you from using certain areas on the unit. We will give you more information on this if you are put into precautions.

**Safety and fall precautions:**

- We will discuss fall precautions with you and give you a handout. Your safety is very important to us and there are multiple factors that could increase your risk of a fall.

- For your safety, please do not touch the buttons or manipulate your IV tubing on your IV pump. Put your call light on if pump is beeping.

### **Symptoms during your stay:**

- Keep us informed of all symptoms you are experiencing. Use your call light as needed to alert us to any symptoms you are having or if you need anything, this is how your nurses can help you be more comfortable.
- Symptoms to alert your nurse about:
  - Feeling hot or chilled
  - Difficulty breathing
  - Chest pain/tightness
  - Nausea/vomiting
  - Diarrhea
  - Mouth sores
  - Pain, headache
  - Nose bleed
  - Blood in urine or stool
  - **Or any other symptoms that are concerning to you!**

### **Blood counts:**

- We will write your labs/blood counts on the whiteboard in your room every day.
- Your chemo will make your white blood cell count and neutrophils decrease. This is when you are at most risk for infections.
- If your hemoglobin becomes too low, we will give you blood/red blood cells.
- If your platelets become too low, we will give you platelets. If you have a nose bleed or are bleeding from anywhere, we may give you platelets to help clot your blood at that point.
- Bleeding precautions - When your platelets are less than 50,000:
  - Do not floss

- Do not blow your nose harshly
- Do not rub your eyes
- Do not scratch your skin hard
- Do not strain with bowel movements
- Do not have sexual intercourse (vaginal or anal)
- Electric razors only
- Avoid popcorn and hard to chew items
- Avoid vomiting- call nurse for anti-nausea medications
- Nothing per rectum or vagina (no enemas, tampons, vaginal dilators)
- Notify staff of any signs of bleeding (nosebleeds, blood in urine/stool/vomit/sputum)

### **Engraftment:**

- Engraftment is when your stem cells that you got on transplant day are growing and now functioning as normal cells. Engraftment typically takes a few weeks after your transplant date. We will alert you as to when you are engrafting and when we anticipate you being discharged from the hospital.
- When can you go home?
  - Once engraftment has occurred
  - When your symptoms have resolved (no fevers, nausea/diarrhea controlled with oral meds, etc.)
  - Eating and drinking well
  - Able to take all medications by mouth

## Frequently asked Questions about Bone Marrow Transplant:

### Autologous

Bone marrow transplant is a very complex process that includes many steps. This handout provides answers to common questions patients and caregivers have. We hope it will help you better understand the process and learn the medical terms we often use. Please do not hesitate to ask us more questions as they come up.

### How are stem cells collected?

There are several ways to collect stem cells for future re-infusion.

**Cord Blood** is collected from the umbilical blood vessels in the placenta at time of the delivery and then frozen.

**Bone Marrow** is collected by multiple needle aspirations from the bone marrow space in the hips or chest.

**Peripheral Blood** – it is possible to collect stem cells directly from the patient's bloodstream. In order to have enough stem cells in the bloodstream, the patient receives growth-factor drugs (Granix)<sup>®</sup> and/or Mozobil<sup>®</sup> ) with or without chemotherapy. The drugs stimulate the movement of stem cells out of the bone marrow space into the bloodstream.

**Aspiration-** procedure that removes something from an area of the body

This process is called **mobilization of stem cells**. After the stem cells mobilized into the bloodstream the blood is collected through an IV connected to a special machine called an apheresis machine. The machine separates the stem cells and returns the remaining blood back to the donor.

## **How are stem cells stored?**

Autologous stem cells are frozen and mixed a preservative called DMSO, and frozen in liquid nitrogen at a temperature below 50° celcius. Cells can be stored indefinitely. Extra cells are sometimes stored in case the patient needs more cells.

## **How many cells are needed for transplant?**

The number of cells necessary for transplant has not been established and varies from center to center. At the Michigan Medicine we want 2-5 million cells.

## **What are conditioning regimens?**

Conditioning regimens are treatment plans that include a combination of chemotherapy and/or radiation before transplant. The purpose is to:

- Kill off any existing cancer cells
- Make room in the bone marrow for new cells
- Suppress your immune system to allow the transplanted stem cells to start growing and maturing.

## **How will the new stem cells grow in my body?**

You will receive the stem cells through your central line. Stem cells have a “homing” (from the word “home”) ability that allows them to migrate to the bone marrow where they will grow and mature. You will receive Granix® several days after transplant to help increase your blood counts.

## **How do I know transplant is successful?**

Transplant is successful when the new cells begin to grow and mature in the bone marrow. This is called **engraftment**. White blood cells are the first to engraft; platelets will engraft second and red blood cells third. When the new stem cells have engrafted you will see a gradual but steady increase in blood

counts. We define engraftment in one of two ways:

- ANC is over 0.5 or 500 for two days in a row, or
- Platelet count is over 20,000 **and** ANC is higher than 1,000 for 1 day

**ANC** = Absolute Neutrophil Count.  
Neutrophils are a type of white blood cell that fights infection.

## When will I engraft?

Time of engraftment varies per type of transplant and where stem cells are collected.

**Autologous:**                      Peripheral stem cells: average 10-14 days  
    Bone Marrow: average 15-20 days

## When can I go home?

We will discharge you when the following have occurred:

- Your cells have begun to engraft and your ANC is more than 1.0 or 1,000
- You have been without fever for 24 hours
- You are eating and drinking adequately
- Side effects such as pain, nausea, vomiting or diarrhea are all under control with oral medications
- You are not requiring daily blood transfusions

## How long do I have diet restrictions?

Transplant recipients receive specific food safety guidelines to help protect against bacteria and other harmful organisms found in some food and drinks. A FDA *Food Safety* booklet for bone marrow transplant recipients is included in this binder. You will be required to follow these guidelines for the first 100 days. The unit dietician will review guidelines in this booklet with you.

# **What to Expect on “Day Zero” of an Autologous Bone Marrow Transplant?**

## **What is Day Zero?**

Day Zero is the day you receive your new stem cells. This handout will describe in detail what you can expect to occur on this day.

## **Where will the procedure take place?**

- Your transplant will take place in your room with you lying in bed. You may have visitors if you like, as long as they are not sick.

## **How will I prepare for the procedure?**

- You may want to eat a light lunch or postpone lunch until after transplant.
- You will receive Tylenol® and Benadryl® prior to the procedure. You may also receive anti-nausea medications if needed.

## **What will happen during the infusion of stem cells?**

- The blood bank will bring your stem cells to the room still frozen and will thaw them in a body temperature water bath one bag at a time. We double check each bag to ensure you are receiving the correct stem cells.
- Your cells will be in a bag that looks similar to blood. They will be connected to your central line and infused through your line. You will see a syringe that we use to help facilitate delivery of your cells in a timely fashion. The cells cannot be run through a pump and need to be infused within 12-15 minutes of thawing. This will prevent the cells from breaking down at room temperature. Each bag will also be rinsed when empty to help capture all cells.

- We will monitor you closely during the infusion, and will take vital signs frequently.

### **What are the common side- effects?**

After stem cells are collected and before they are frozen they are mixed with preservative called DMSO. This preservative may cause some side-effects during the infusion, including:

- Taste of garlic or cream corn in your mouth. Others may smell the DMSO, a preservative on your breath for 48-72 hours following transplant.
- Tickle in your throat or a cough. Mints may help to clear the tickle or cough.
- Facial flushing.
- Shortness of breath.
- Tingling in chest, extremities (legs, arms and hands), and face.
- Heaviness in your chest or a feeling of pressure in your chest.
- Nausea and/or vomiting.
- Chills.
- Headache.
- Shivers or shakes, also called rigors.
- Itchiness and/or redness to skin.
- Change in vital signs: fever, increase in blood pressure and/or heart rate. There may also be a decrease in oxygenation and we may temporarily place you on oxygen.
- Red or pink tinged urine may occur due to break down of remaining red blood cells during infusion. You will be getting IV fluids to help flush out your kidneys so we expect this side effect to subside within 24-48 hours.

Side effects can be treated by slowing the infusion down and most of the side effects subside when your cells are not actively being pushed through your



line. We will monitor you closely during infusion of your stem cells with frequent vital signs and adjust the pace as needed.

The medications you received prior to the procedure, will help to prevent serious transfusion reactions such as:

- fever
- shortness of breath
- swelling of the throat
- itching/hives

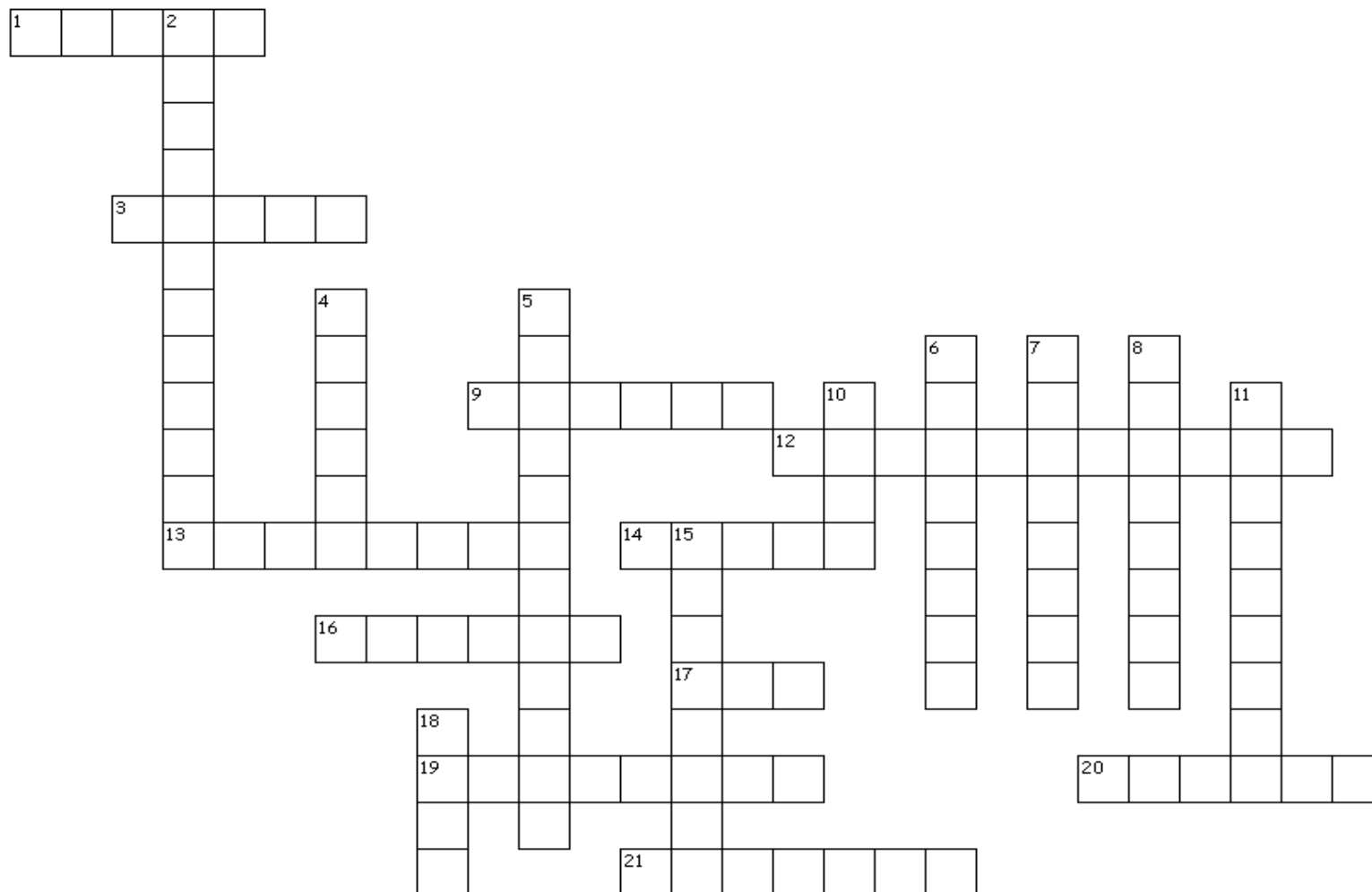
If this happens we would stop your infusion and manage your symptoms.

Once the procedure is completed, it is very unlikely you will have any further reactions.

### **What happens after the infusion?**

After transplant, patients are often tired from pre-medications and lack of sleep in anticipation of the procedure. We find a quick nap sometimes helps to feel better.

# Autologous Bone Marrow Transplant Crossword Puzzle on Discharge Education



## Across

1. You will not be able to \_\_\_\_\_ for at least three months following your transplant. This period may be shorter for patients receiving their own stem cells. It is essential to have someone available to drive you to your clinic appointments or to the hospital. You cannot resume driving without your doctor's approval.
3. Avoid sexual activity until your platelet count is at least \_\_\_\_\_-thousand. Use a condom for at least the first 100 days post-transplant for sexual activity. Avoid anal intercourse. Avoid kissing or oral sex if your partner has mouth sores.
9. Your \_\_\_\_\_ to work or school will depend on the type of transplant you received and how your recovery proceeds. Your doctor should approve your return. In general, autologous transplant recipients can return on a part-time basis in around 100 days. For Allogeneic transplant recipients, it may be anywhere from 6 months to a year.
12. Consult your doctor before taking any over-the-counter \_\_\_\_\_. In general, avoid aspirin containing products and products containing acetaminophen or ibuprofen unless discussed first with your doctor or nurse. Avoid herbal supplements.
13. Avoid prolonged exposure to \_\_\_\_\_. Wear hats, long sleeves, and SPF 30 or higher. Lifelong medications may increase your risk for sunburn.
14. Wash your \_\_\_\_\_ after using the restroom, before preparing or eating food, before caring for your central line care and after coughing or sneezing. Always sash your \_\_\_ when they look visibly soiled.
16. Notify your doctor before you plan to do this. It may not be wise to plan an extended vacation until you see how your recovery progresses.
17. Avoid \_\_\_\_\_ people and kids under 12 as much as possible. Avoid large crowds and people who have been recently vaccinated with a live vaccine (like chickenpox).
19. Loss of taste and \_\_\_\_\_ happens frequently following transplant. If you are having problems eating enough calories and protein, talk with our dietitian.
20. These can remain in the home. Avoid gardening, mowing the lawn, and other activities that stir up soil or the ground. Avoid handling fresh-cut flowers in vases.

21. Daily \_\_\_\_\_ is important. Shower every day and keep your private area clean after using the restroom. Use non-alcohol containing lotions for moisturizing.

## **Down**

2. After transplant, your body may no longer recognize previous childhood \_\_\_\_\_. Therefore, you will be re-immunized with several vaccines one to two years after transplant.

4. Continue your mouth care regimen that you practiced in the hospital. Continue your mouth care after meals and at bedtime. Notify your doctor of any mouth changes and plans for \_\_\_\_\_ work. You should have a \_\_\_\_\_ follow-up visit at six months after transplant.

5. Women- Use a dilator as directed by gynecology. Also use a water based lube to combat vaginal dryness which can be a result of \_\_\_\_\_ and radiation.

6. Avoid doing this in lakes, public pools, and sitting in hot tubs due to the possibility of exposure to excessive bacteria.

7. It is advisable to use only one \_\_\_\_\_ at home. They will have your complete records, can advise you on your prescriptions and will communicate with your doctor.

8. If you have \_\_\_\_\_, it is important to inform their school that you must be notified of communicable diseases like measles, chicken pox, etc. Notify your doctor if they have been exposed to one of these illnesses.

10. Household \_\_\_\_\_ can remain in the home, with the exception of birds and reptiles. Avoid contact with animal wastes. Do not let them sleep with you.

11. Observe your central line (venous access device) for signs and symptoms of this. Changes to the insertion area including areas of redness, tenderness, drainage, or a general change of appearance should be notified to your doctor.

15. Balance work and \_\_\_\_\_. Avoid contact sports. Fatigue is common but it's important to stay active to keep your body and lungs strong. Space out activities and schedule rest periods into your day.

18. You need to wear this when coming to the hospital or clinic appointments. It will not necessarily protect you from those who are sick, but is a reminder to those around you to be cautious. It is not necessary when you are at home or out for a walk in areas free of construction and free of large crowds.

## Autologous Transplant Medications Matching:

Match the medication use on the left to the medication on the right  
Some Medications may be matched to multiple numbers on the left

1	Injection to treat or prevent blood clots
2	To treat/prevent nausea
3	Antibiotic used to prevent/treat infections
4	Used to treat active viral infection
5	Antiviral medication to prevent virus
6	Antifungal
7	Used to prevent/treat gastric reflux
8	Anti-anxiety medication that also helps with nausea
9	Vitamin supplement
10	Antibiotic used to prevent/treat infections
11	Injection used to boost neutrophil count
12	Antifungal
13	To treat/prevent nausea
14	Short acting pain control

	<b>Ativan</b> / lorazepam
	<b>Compazine</b> /prochlorperazine
	<b>Diflucan</b> / fluconazole
	<b>Levaquin</b> / levofloxacin
	<b>Lovenox</b> / enoxaparin sodium
	<b>Neupogen</b> / filgrastim or <b>Granix</b> /tbo-filgrastim
	<b>Oxy IR</b> /oxycodone
	<b>Prilosec</b> / omeprazole
	<b>Valcyte</b> / valganciclovir
	<b>Vantin</b> / cefpodoxime
	<b>Vfend</b> / voriconazole
	<b>Vitamin D3</b> / cholecalciferol
	<b>Zofran</b> / ondansetron
	<b>Zovirax</b> / acyclovir

## Signs of Infection

G C M M C V P C W C U S S P S  
X N P O Q O G O O Y L V O J S  
P Z I J U U U N E E V K R J E  
Q Y Q L Z T F G W H B J E S N  
J Y P U E U H O H K R J T Y R  
P B M Z S E B S S L Y I H R E  
B N D I P E F R O C P D R X D  
Z D O L S K K G N R I V O V N  
N N Z O X M G E N B E L A B E  
I S O B R F G G E I G S T Y T  
B L B A N R R G N J N M D K N  
Y C N E U Q E R F D B R A B I  
G C H I L L S Q E N B Y U E K  
E N L U O C K R V N N U D B S  
U T I M U S C L E A C H E S G  
G N N L H E L N R V V U D Y S  
I R B R L K I H S F F D Z C Q  
T Q F L Z E W A U S M G I U O  
A J B J S K W Q L R O A Q L U  
F M K Z R E F S V P M G I V Y

Burningfeeling

Chills

Confusion

Cough

Fatigue

Fever (over 38\* celsius; or 100.5\*fahrenheit )

Frequency (with urination)

Loosebowels

Mouthsores

Muscleaches

Skintenderness

Sorethroat

Swelling

Urgency (with urination)

**If any of the above symptoms appear, notify your nurse or doctor immediately.**

## When to Contact your BMT Doctor

E T E T C P I N I G K G N B V  
 G H S A R Q X K H F R N Q L E  
 Z N E X E O V D O T S I O U C  
 G N I T I M O V V K H L Z R O  
 C Z Z D M A C Y I U Y L D R U  
 T V R W E C K N F A Q E Z E G  
 K P N H V E C H E Q P W S D H  
 O K V U V H L H P A O S C V N  
 V B B H A U R B I T Q A E I S  
 L V N N U R A N T A R M H S V  
 F F G I A U N B N F Q S S I F  
 W E E I M C I E Z W O B R O P  
 S C D V Q X R E D N E S S N K  
 H E Y Q E C Q H P J X P Q S Q  
 G O P C Q R E M M Q B K G C S

Bleeding

Blurred vision

Cough

Diarrhea

Fever

Pain

Rash

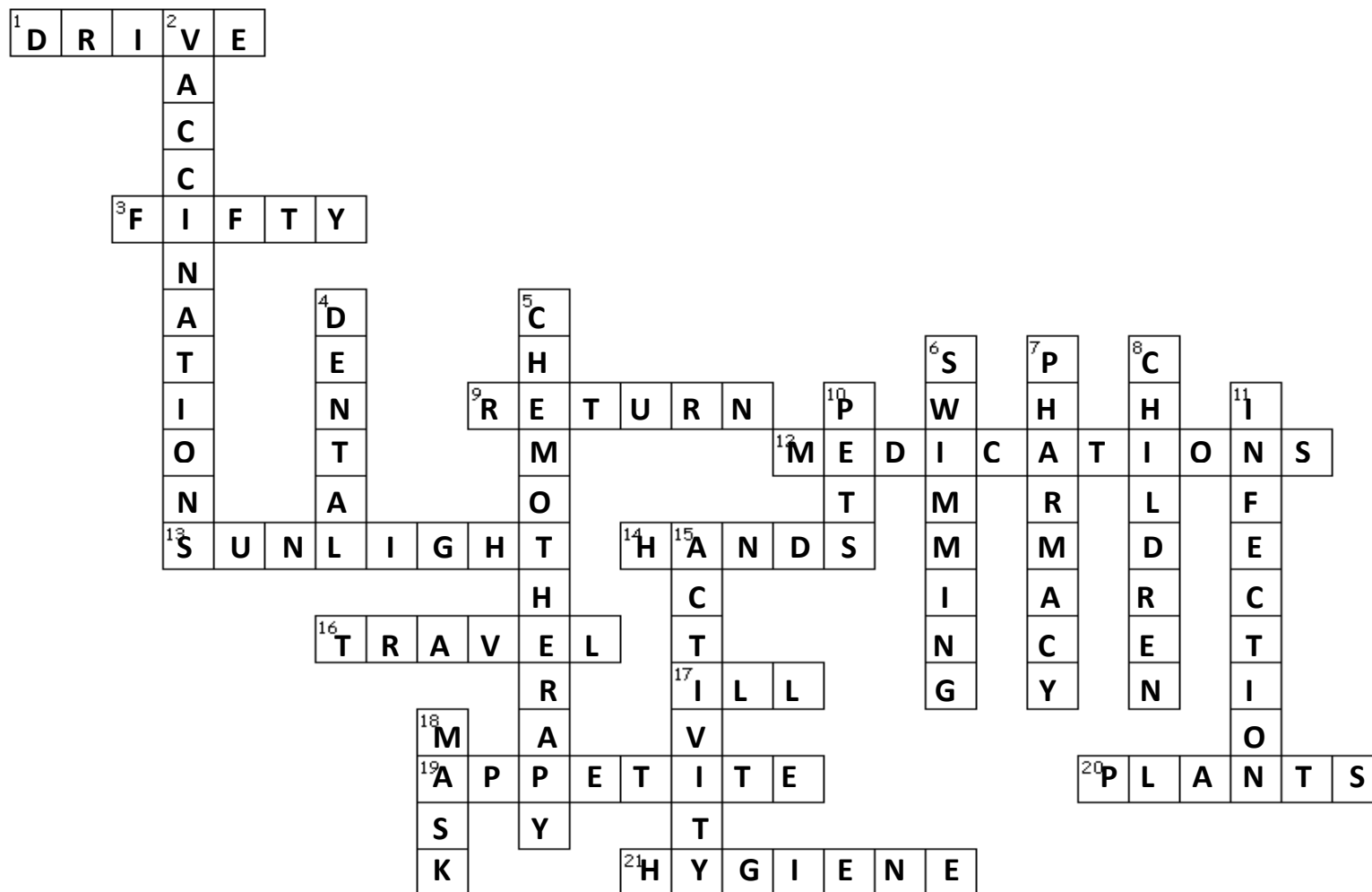
Redness

Skin changes

Swelling

Vomiting

# Autologous Bone Marrow Transplant Crossword Puzzle on Discharge Education





## Across

1. You will not be able to **drive** for at least three months following your transplant. This period may be shorter for patients receiving their own stem cells. It is essential to have someone available to drive you to your clinic appointments or to the hospital. You cannot resume driving without your doctor's approval.
3. Avoid sexual activity until your platelet count is at least **fifty**-thousand. Use a condom for at least the first 100 days post-transplant for sexual activity. Avoid anal intercourse. Avoid kissing or oral sex if your partner has mouth sores.
9. Your **return** to work or school will depend on the type of transplant you received and how your recovery proceeds. Your doctor should approve your return. In general, autologous transplant recipients can return on a part-time basis in around 100 days. For Allogeneic transplant recipients, it may be anywhere from 6 months to a year.
12. Consult your doctor before taking any over-the-counter **medications**. In general, avoid aspirin containing products and products containing acetaminophen or ibuprofen unless discussed first with your doctor or nurse. Avoid herbal supplements.
13. Avoid prolonged exposure to **sunlight**. Wear hats, long sleeves, and SPF 30 or higher. Lifelong medications may increase your risk for sunburn.
14. Wash your **hands** after using the restroom, before preparing or eating food, before caring for your central line care and after coughing or sneezing. Always wash your **hands** when they look visibly soiled.
16. Notify your doctor before you plan to do this. It may not be wise to plan an extended vacation until you see how your recovery progresses.**(travel)**
17. Avoid **ill** people and kids under 12 as much as possible. Avoid large crowds and people who have been recently vaccinated with a live vaccine (like chickenpox).
19. Loss of taste and **appetite** happens frequently following transplant. If you are having problems eating enough calories and protein, talk with our dietitian.
20. These can remain in the home. Avoid gardening, mowing the lawn, and other activities that stir up soil or the ground. Avoid handling fresh-cut flowers in vases. **(plants)**

21. Daily **hygiene** is important. Shower every day and keep your private area clean after using the restroom. Use non-alcohol containing lotions for moisturizing.

## **Down**

2. After transplant, your body may no longer recognize previous childhood **vaccinations**. Therefore, you will be re-immunized with several vaccines one to two years after transplant.

4. Continue your mouth care regimen that you practiced in the hospital. Continue your mouth care after meals and at bedtime. Notify your doctor of any mouth changes and plans for **dental** work. You should have a **dental** follow-up visit at six months after transplant.

5. Women- Use a dilator as directed by gynecology. Also use a water based lube to combat vaginal dryness which can be a result of **chemotherapy** and radiation.

6. Avoid doing this in lakes, public pools, and sitting in hot tubs due to the possibility of exposure to excessive bacteria. (**swimming**)

7. It is advisable to use only one **pharmacy** at home. They will have your complete records, can advise you on your prescriptions and will communicate with your doctor.

8. If you have **children**, it is important to inform their school that you must be notified of communicable diseases like measles, chicken pox, etc. Notify your doctor if they have been exposed to one of these illnesses.

10. Household **pets** can remain in the home, with the exception of birds and reptiles. Avoid contact with animal wastes. Do not let them sleep with you.

11. Observe your central line (venous access device) for signs and symptoms of this. Changes to the insertion area including areas of redness, tenderness, drainage, or a general change of appearance should be notified to your doctor. (**infection**)

15. Balance work and **activity**. Avoid contact sports. Fatigue is common but it's important to stay active to keep your body and lungs strong. Space out activities and schedule rest periods into your day.

18. You need to wear this when coming to the hospital or clinic appointments. It will not necessarily protect you from those who are sick, but is a reminder to

those around you to be cautious. It is not necessary when you are at home or out for a walk in areas free of construction and free of large crowds. (**mask**)

## Autologous Transplant Medications Matching:

Match the medication use on the left to the medication on the right

1	Injection to treat or prevent blood clots
2	To treat/prevent nausea
3	Antibiotic used to prevent/treat infections
4	Used to treat active viral infection
5	Antiviral medication to prevent virus
6	Antifungal
7	Used to prevent/treat gastric reflux
8	Anti-anxiety medication that also helps with nausea
9	Vitamin supplement
10	Antibiotic used to prevent/treat infections
11	Injection used to boost neutrophil count
12	Antifungal
13	To treat/prevent nausea
14	Short acting pain control

8	<b>Ativan</b> / lorazepam
2, 3	<b>Compazine</b> /prochlorperazine
6, 12	<b>Diflucan</b> / fluconazole
3, 10	<b>Levaquin</b> / levofloxacin
1	<b>Lovenox</b> / enoxaparin sodium
11	<b>Neupogen</b> / filgrastim or <b>Granix</b> /tbo-filgrastim
14	<b>Oxy IR</b> /oxycodone
7	<b>Prilosec</b> / omeprazole
4	<b>Valcyte</b> / valganciclovir
3, 10	<b>Vantin</b> / cefpodoxime
6, 12	<b>Vfend</b> / voriconazole
9	<b>Vitamin D3</b> / cholecalciferol
2, 13	<b>Zofran</b> / ondansetron
5	<b>Zovirax</b> / acyclovir

Some Medications may be matched to multiple numbers on the left



## Signs of Infection

G C M M C V P C W C U S \$ P \$  
 X N P O Q O G O O Y L V O J \$  
 P Z I J U U U N E E V K R J E  
 Q Y Q L Z T F G W H B J E S N  
 J Y P U E U H O N K R J T Y R  
 P B M Z S E B S S L Y I H R E  
 B N D I P E F R O C P D R X D  
 Z D O L S K K G N R I V O V N  
 N N Z O X M G E N B E L A B E  
 I S O B R F G G E I G S T Y T  
 B L B A N R R G N J N M D K N  
 Y C N E U Q E R F D B R A B I  
 G C H I L L S Q E N B Y U E K  
 E N L U O C K R V N N U D B \$  
 U T I M U S C L E A C H E S G  
 G N N L H E L N R V V U D Y S  
 I R B R L K I H S F F D Z C Q  
 T Q F L Z E W A U S M G I U O  
 A J B J S K W Q L R O A Q L U  
 F M K Z R E F S V P M G I V Y

Burningfeeling

Chills

Confusion

Cough

Fatigue

Fever (over 38\* celsius; or 100.5\*fahrenheit )

Frequency (with urination)

Loosebowels

Mouthsores

Muscleaches

Skintenderness

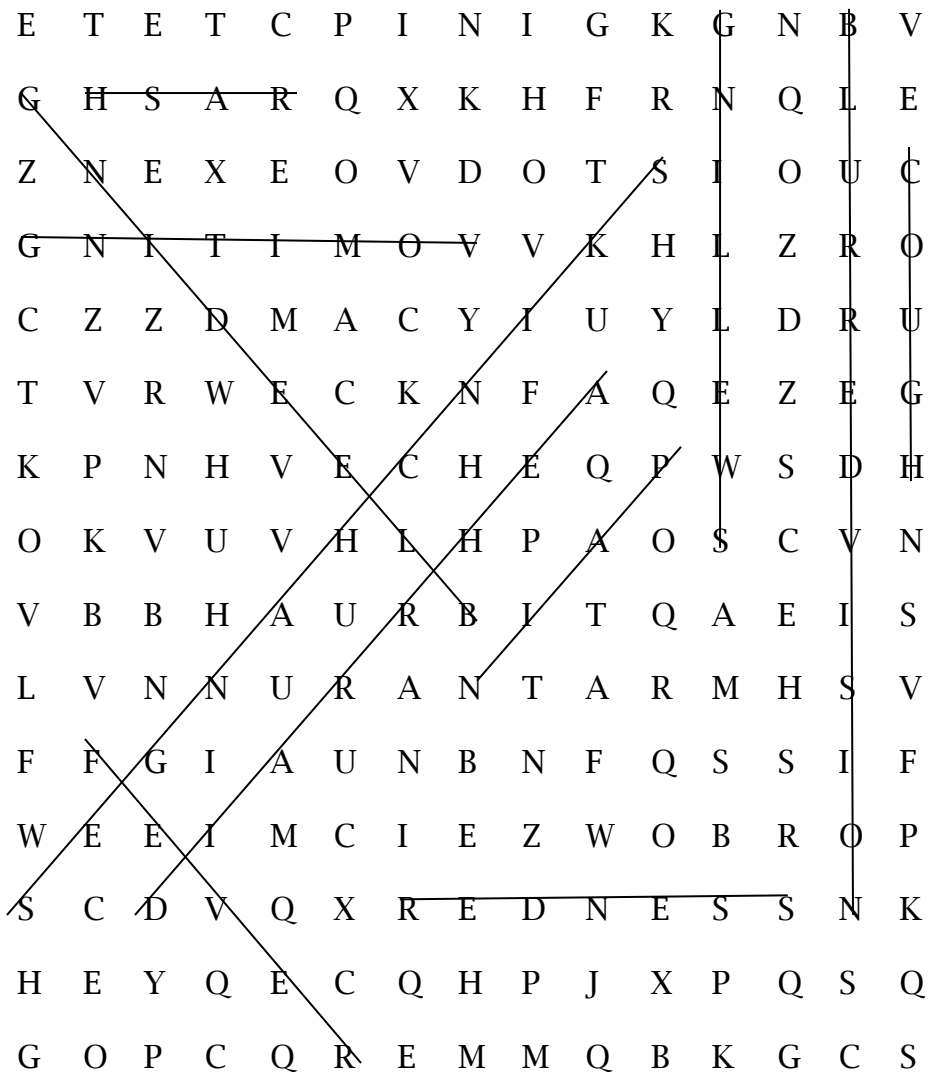
Sorethroat

Swelling

Urgency (with urination)

**If any of the above symptoms appear, notify your nurse or doctor immediately.**

## When to Contact your BMT Doctor



Bleeding

Blurred vision

Cough

Diarrhea

Fever

Pain

Rash

Redness

Skin changes

Swelling

Vomiting



## BMT & CELLULAR THERAPY PROGRAM

### **Autologous Section 5 Discharge Instructions**

Autologous Discharge Information

Contact Information

Water Safety

MyUofMHealth.org Patient Portal

How do I find BMT discharge videos and patient education handouts online?

Bone Marrow Transplant Discharge: Transitioning to Outpatient Care

*Care of the Tunneled Catheter (Booklet)*

*Be the Match: After Transplant Care Guides*

## **Autologous Stem Cell Transplant Discharge Instructions**

The following guidelines apply to your first 100 days after transplant. Ask your doctor for more specific instructions. Remember that the following may not apply to each individual patient. Please consult with the Bone Marrow Transplant team if you have additional questions.

**You also need to have a caregiver and stay within 100 miles of the hospital for the first 30 days.** If you do not have lodging set up, ask to speak with the BMT social worker before you are discharged.

### **When do I need to call the BMT doctor?**

- Temperature over 100.5 degrees Fahrenheit
- Shaking or chills
- New cough or difficulty breathing
- Persistent headaches
- Blurred or double vision
- Bleeding problems such as:
  - Nose bleeds
  - Blood in urine or stool
  - Vomiting blood
  - Increased bruising
- Pain with urination or bowel movements
- Decrease in frequency of urination
- New or persistent nausea/vomiting and/or if you have more than 3 vomiting episodes in an 8hr period
- New or persistent diarrhea and/or if you have more than 3 episodes in an 8hr period
- Problems with eating such as:
  - Unable to keep food, fluids, or medications down



- Having no interest in eating
- Difficulty swallowing
- Sore throat
- Development of mouth sores
- Pain that is not controlled with prescribed pain medications
- Changes or difficulty with your central line such as:
  - Difficulty flushing
  - Redness, drainage, pain, or site looks different
- Changes with skin color or new rash
- Reddened, swollen, or painful areas
- Change in wound (unusual pain, drainage, swelling, or redness)
- Changes in mental status or confusion
- Increased sleepiness
- Fevers, chills, or hives after getting a blood transfusion

## **How do I call?**

The BMT Clinic is open Monday through Friday, from 8am to 5 pm. During these hours, call 734-936-9814. After 5pm, on weekends, and holidays, call 734- 936-6267 and ask for the BMT physician on-call. You can also refer to the handout in this section “BMT Discharge Contact Information.” This gives you several phone numbers that you may find helpful. If you have any questions or concerns about anything, do not hesitate to call.

## **How will I care for myself at home?**

### **Handwashing and Hygiene**

- Wash your hands often! At a minimum, you should wash your hands before eating, after bathroom use, and after contact with people and/or pets.
- Shower every day. Use liquid soap and new washcloth each day, do not use bar soap or loofa.

## **People, Places, and Preventing Infections**

- Avoid anyone ill.
- Avoid crowds when possible.
- Limit exposure to children outside your immediate family who are less than 12 years old.
- Avoid wearing contact lenses. Wear eye glasses to prevent infection.
- Notify BMT clinic of exposure to communicable diseases (ie: chickenpox, shingles, flu, etc.).
- Deep cleaning of your house is not necessary before you go home, but have caregiver wipe down surfaces, dust, and vacuum.
- Avoid construction areas or anywhere dirt and soil are being moved.
- Avoid dirty, dusty, or moldy environments.
- Avoid lung irritants such as smoking, second hand smoke, aerosols, and spray paint.

## **Do I need to wear a mask?**

- You do not need a mask unless you have a low white blood cell count (neutropenic), you are around construction, or someone is mowing the lawn. It is a good idea to keep a mask with you at all times while out in public in case you run into a crowd, construction, or someone mowing grass.

## **Bleeding Precautions**

You are at highest risk of bleeding when your platelet count is 50,000 or less.

Take these precautions if this applies to you:

- Do not floss - use a soft tooth brush.
- Do not blow your nose harshly - use saline nasal spray to keep your nose moist and prevent nose bleeds.
- Do not rub your eyes - use artificial tears
- Do not scratch - use Eucerin lotion daily after showering.

- Do not strain with bowel movements.
- Do not have sexual intercourse (vaginal, anal).
- Do not shave with a blade razor – only use an electric razor for shaving and electric clippers for hair cutting.
- Do not play contact sports.
- Avoid popcorn and hard to chew items.
- Avoid vomiting – take your nausea meds as needed
- Do not put anything in your rectum or vagina (no enemas, tampons, vaginal dilators).
- Do not use Aspirin/Excedrin/Ibuprofen or medications that affect platelets.

### **Pets**

- Current pets are ok. No contact with new pets, birds, reptiles, or farm animals.
- No pets sleeping with you.
- Wash hands after direct contact with pets.
- No contact with cat litter or any animal excretions.
- Avoid pets on raw food diets.
- No reptiles or amphibians should be kept in the house or handled by you.
- It is a good idea to keep your pet clean and their shots up to date.

### **Plants/Flowers/Gardening**

- Plants may stay in the home but do not handle or care for them.
- Avoid direct contact with plants, trees, flowers and mulch.
- No yardwork, gardening or digging in soil.
- Go inside during lawn mowing.
- No live Christmas trees.
- Wood burning stoves & fireplaces may be used if vented properly. No wood should be stored in the house or handled by you.
- Avoid gardening, mowing grass, raking leaves.

## **Travel and Driving**

Ask your doctor when you can travel and drive.

## **Return to work or school**

In most cases, at or around 100 days after your transplant date you can return to work or school. Your return should be approved by your doctor, as individuals vary greatly in their time to recovery.

## **Skin and Sun**

You will need to take steps to make sure you are protected from the sun, beginning on your transplant date. Your skin will be much more sensitive to the sun and will burn easily because of the high doses of chemotherapy used in transplant.

- Avoid exposure to sunlight, especially within the first 100 days after transplant.
- If exposure to sunlight is unavoidable, use as much protection as possible such as long sleeve shirts, long pants, hat, and sunscreen SPF 30 or higher.

## **Physical activity**

- Gradually increase activity as tolerated. Activity outdoors, such as walking, is good for you.
- Trail Hiking is ok but no camping, hunting, fishing, or deep woods hiking.
- No contact sports such as soccer, hockey, basketball, football or strenuous weightlifting if platelet count is less than 50,000.
- No swimming in lakes, ponds, hot tubs, or public pools.

## **Sexual activity**

- You can resume intercourse when your platelet count is greater than 50,000.
- Use standard safe sex precautions.

- Use a condom to prevent risk of infection.
- No anal intercourse.
- No kissing or oral sex if your partner has any mouth sores.
- Use water-based lube for vaginal dryness.

### **Diet and Food Safety**

Use the FDA Food Safety booklet you received from the dietary team for the first 100 days after transplant, or as long as your doctor instructs you to use it.

### **Medications**

You will receive specific instructions before you leave the hospital about the medications you are taking.

- Bring all medications you are taking and your list of medications to your clinic appointments.
- Only take what is prescribed to you.
- Avoid Acetaminophen (Tylenol®), Ibuprofen (Motrin®, Advil®), Aspirin (Bayer®, Excedrin®), and Naproxen (Aleve®) unless instructed by your doctor.
- Avoid herbal supplements and over the counter medications unless prescribed by a doctor.

### **Immunizations**

You will need to be re-immunized beginning at 6 months after your transplant. You will be given an immunization schedule with recommendations.

### **What is my BMT follow-up care?**

- Before you get discharged from the hospital, you will be given a date and time of when your first BMT clinic appointment is. This appointment will typically be within a few days of being discharged from the hospital.

- Be sure to get labs drawn prior to this appointment at the blood drawing station on level 2 of Mott Children and Women's Hospital.
- You will then proceed to the 7th floor of Mott Children and Women's Hospital and check into the BMT clinic at reception B.
- Additional follow-up BMT clinic visits will be scheduled at this time.

## BMT/CAR T-cell Discharge Contact Information

You are being discharged to the care of the outpatient clinic providers, home care providers or outside resources. The list below will help you with who to contact for common needs that arise once you are out of the hospital.

### Medical follow-up

Questions/Concerns	Clinician	Phone number:
Medical Emergency		Call 911
Medical Questions (non-emergent)	MD/NP/PA/RN	use on-line portal
Medical Questions (requiring same day follow-up)	Clinic nurses (M-F, 8am-5pm)	(734) 936-9814
Urgent Concerns that cannot wait for clinic hours (nights/weekends/holidays)	BMT doctor on-call	(734) 936-6267
Dietician and/or Supportive Care/Symptom Management	Cancer Center	(734) 232-6366

Physician	Midlevel (NP/PA)	Registered Nurse	Clinic Days
Sarah Anand, MD	Adrienne Trentacosti, PA-C	Sally Straub	Wednesday, Friday
Monalisa Ghosh, MD	Mary Mathews, NP	Jaclyn Jirasek	Tuesday, Thursday
John Maciejewski, MD	Tim Higgins, PA-C		Wednesday, Friday
John Magenau, MD	Tim Higgins, PA-C	Sue Tschirret	Tuesday
Attaphol Pawarode, MD	Bethany Laurio, NP		Monday, Wednesday
Mary Riwes, DO	Kari Castillo, NP	Sue Tschirret	Monday, Thursday

Additional nurses you may encounter: Eileen Plezia-Mckenzie

Home assistance	Type	Phone number
HomeMed	Home Infusion Supplies	(866) 914-1453
Michigan Visting Nurses (MVN)	Visiting Nurse Care	
Other:		
Other:		

Other Assistance	Type	Contact information/Hours:
Billing and Insurance	Customer Service	PFC-counselors@med.umich.edu (877) 326-9155
Lodging	Short-Term	Patient & Visitor Accommodations (PVA) (800) 544-8684
Patient and Family Support Services (PFSS)	Supportive Care	(877) 907-0859 or (734) 232-6366
Pharmacy	Cancer Center	(M-F, 9am-5:30pm) (734) 647-8911
	Ambulatory Care/Taubman	(M-F, 9am-6pm; Sat 9am-4:30pm) (734) 936-8260
Social Work	Clinical (last names A-K)	Jack Harrington (734) 232-9073
	Clinical (last names L-Z)	Toni Spano-English (734) 232-5776
Tangible Assistance	Transportation, lodging, prescription cost resources, coordination of Medicaid travel benefits, etc.	Guest Assistance Program (GAP) (800) 888-9825



## **Safe Drinking Water and Other Beverages for Immunocompromised Patients**

### **Can I Drink Tap Water?**

Drinking tap water from municipal wells serving highly populated areas is regarded as safe from bacterial contamination. The water in these wells is tested at least twice a day for bacterial contamination.

Do not drink well water from private wells or from public wells in communities with limited populations. Tests for microbial contamination in these wells are not done often enough to detect bacterial contamination.

Boiling water is the best method of killing *Cryptosporidium* and other microbes in water. After boiling the water store it in the refrigerator in a clean bottle or pitcher with a lid. To prevent re-contamination, be careful not to touch the inside of the water bottle or lid.

Monitor news on TV and radio in your area to find out immediately if a boil-water advisory has been issued for people with compromised immunity. These advisories are issued by state or local governments. A boil-water advisory means that you need to boil all tap water for at least one minute before drinking it.

### **What is the best information about Water Filters?**

Water filters remove microbes such as *Cryptosporidium* Oocysts and *Giardia lamblia* from water. Use a filter labeled with an “absolute” (not “nominal”) pore size of one micron or smaller. This filter will remove all oocysts (viruses, however, can pass through a one-micron filter). Reverse Osmosis is a water purification system that prevents oocysts from passing through. These filters

may be either attached to a faucet or have a pour-through design. They treat water used for drinking or preparing foods.

To see if a certain filter can remove *Cryptosporidium* Oocysts, contact NSF-International directly at 1-800-673-8010 or 888-99-SAFER. You can also email: [info@nsf.org](mailto:info@nsf.org) or visit <http://www.nsf.org/certified/DWTU/>

### **Can I drink bottled water?**

You may drink bottled water if it has been processed by one of three processes: reverse osmosis, distillation, or 1 micron particulate absolute filtration. It is also acceptable to use bottled water that has been tested and certified by NSF Standard 53 or NSF Standard 58 cyst removal/cyst reduction. To confirm the bottled water has undergone one of these processes, contact the International Bottled Water Association (IBWA) at 1-800-928-3711 or visit their website at <http://www.bottledwater.org>. If IBWA does not have the information you are looking for, contact the bottling company directly.

Note: Bottled water labeled as: “artesian well water,” “well water,” “spring water,” or “mineral water” could still contain *Cryptosporidium* or other pathogens if the water has not been processed. That is why it is important to make sure your bottled water has gone through one of the three processes listed above.

### **What other precautions should I take?**

Ice made from an ice machine is ok. However, if ice is being scooped out of a large ice container, you should avoid it unless the server is wearing gloves.

Do not drink unpasteurized milk, fruit, or vegetable juices. Safe drink choices include:

- Nationally distributed brands of bottled or canned carbonated soft drinks and beer
- Commercially packaged non-carbonated drinks that contain fruit juice
- Fruit juices that do not require refrigeration until after opening
- Canned or bottled soda, seltzer or fruit drinks
- Steaming hot (more than 175 F) tea or coffee
- Juices labeled as pasteurized
- Nationally distributed brands of frozen fruit juice concentrate that are reconstituted with water from a safe source.

# **MyUofMHealth.org Patient Portal: Frequently Asked Questions**

## **What is MyUofMhealth.org?**

MyUofMHealth.org 's patient portal offers you personalized and secure online access to portions of your medical records. It enables you to use the Internet to help manage and receive information about your health securely. With MyUofMHealth.org, you can use the Internet to:

- Request medical appointments (and cancel appointments up to 24 hours before the scheduled time).
- View your health summary from the MyUofMHealth.org electronic health record.
- View test results.
- Request prescription renewals.
- Access trusted health information resources.
- Communicate electronically and securely with your medical care team.
- Request an electronic copy of your medical records.
- Pay bills associated with services received from the health system.
- Grant another adult proxy access to your health information.
- Request proxy access to your child's health information.

## **How do I sign up?**

First, you need a MyUofMHealth.org activation code. This code will enable you to create your own username, password and security questions for your personal portal account. There are two ways to get an activation code:

- You can get an activation code after your clinic visit
- You can request an activation code by completing the online request form on the website: [www.myuofmhealth.org](http://www.myuofmhealth.org) and clicking the "Request One Now" button.

## **Where do I enter my activation code?**

Go to [www.MyUofMHealth.org](http://www.MyUofMHealth.org). Click on “Sign Up Now” and follow the instructions.

## **How do I find my Medical Record Number?**

Your Medical Record number (MRN), is located on your After Visit Summary (AVS), yourblue U-M registration card, or any medical record documentation from UMHS.

## **What information is available to me on MyUofMHealth.org?**

In the patient portal, you may:

- View appointments, labs and medication lists
- Send secure messages to providers
- View past medical history
- Request prescription renewals
- Request appointments with providers
- Access immunization records and growth charts
- Request electronic copies of medical records
- Pay bills for medical services received at UMHS

Radiology results are available 14 days after verification. The portal only shows information from outpatient clinic visits from 8/15/12 forward. Information available to U-M staff is not always available in the portal.

## **What is proxy access?**

Proxy access allows others to view someone else’s health information available through the portal. Parents or Legal Guardians of children under the age of 11 are granted full proxy access. Between the ages of 11 and 17, access is granted for parents/legal guardians on a limited basis. Limited access includes access to allergies, immunizations, demographics, request medical records and care team

messaging. At age 18, parental access is terminated unless there are specific documented circumstances that warrant another access level. Adults may grant proxy access to another adult with the proper information. To learn more about proxy access visit: <https://www.myuofmhealth.org> and click on [FAQ's](#) on the right sidebar.

### **When can I see my test results in MyUofMHealth.org?**

Your test results are released to your MyUofMHealth.org account after your physician reviews them. Most Outpatient/clinic results are released in the range of 3-4 days, but some are delayed as long as 90 days. Test results are viewable by hovering over the “My Medical Record” tab in the portal and clicking on “Test Results” from the drop down menu.

If you are admitted to the hospital, you will be able to see most of your results while you are still admitted (results are generally available after 24 hours). Most results will be available to view in the portal upon discharge. Not all test results are available in the portal but may be requested by submitting a “Medical Record Request Form” located within the “My Medical Record” tab.

### **I forgot my password. What should I do?**

Click on the “Forgot Password” link on the sign-in page to reset your password. You will be asked to answer your security question that you set up when you signed up for your account. If you need further assistance, you may contact the Health Information Management department at HIM-PatientPortal@med.umich.edu, or you can call 734-615-0872 Monday-Friday 7:30 am -4:00 pm.

**Can I get a new activation code if I have lost it, let it expire or did not receive it?**

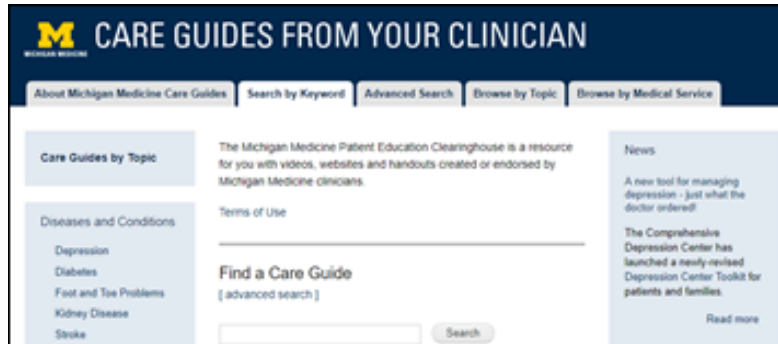
On the log-in page under “Need An Activation Code?” click “Request One Now.” Complete the online form and submit. You may also contact the Health Information Management department at HIM-PatientPortal@med.umich.edu or you can call 734-615-0872 Monday-Friday 7:30 am -4:00 pm. After we verify your information, we will e-mail you a new code.

**Can I view my patient portal on my Android or iPhone?**

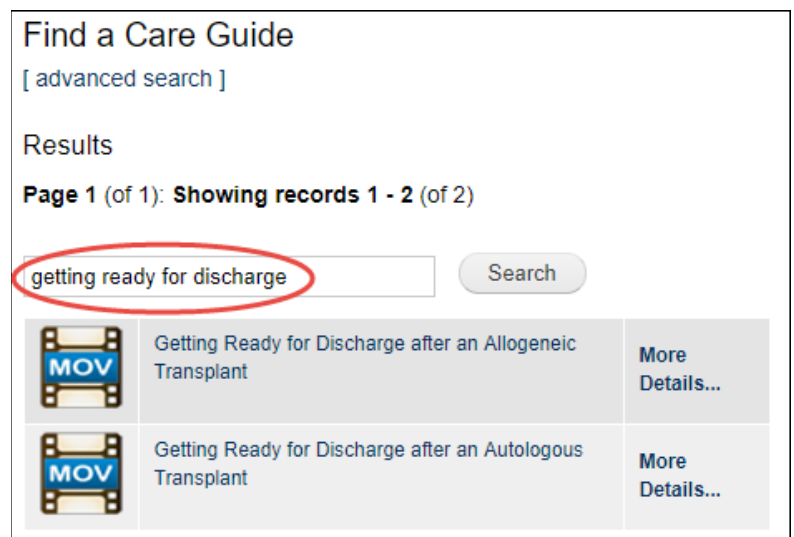
Yes, you can view your portal account by downloading the free MyChart app from Epic Systems Corporation for your Android or iPhone.

## How do I find bone marrow transplant (BMT) discharge videos and patient education handouts online?

1. Type “U of M Care Guides” into your search engine.
2. Click on “Care Guides - University of Michigan”. You can also type the website address into your search bar: <http://careguides.med.umich.edu/>.



3. In the search bar, type “Getting ready for discharge.”
4. On this page, you will find two BMT discharge videos. Select the video that applies to you:
  - a) Allos/MUDs/Haplos: “Getting Ready for Discharge after an Allogeneic Transplant.”
  - b) Autos: “Getting Ready for Discharge after an Autologous Transplant.”
5. To access other BMT patient education handouts from the BMT Discharge folder, follow the same steps above, but type “BMT” in the search bar. A list of BMT patient education handouts will be available for you to choose from.





# Bone Marrow Transplant Discharge: Transitioning to Outpatient Care

## How can I contact the Clinic?

- **The clinic call center is open Monday - Friday 8:00am – 5:00pm**

During these hours please call (734) 936-9814. Clerical staff will answer your call and take a message for clinic nurses to review. You should get a call back from the nurse on the same business day. Urgent calls are returned first.



- **After 5:00pm and on weekends and holidays:** contact the Michigan Medicine paging operator at (734) 936-6267 and ask for the BMT physician on-call.
- For **non-urgent concerns** you may send a message through the patient portal (<http://MyUofMHealth.org>).

## What can I expect at the outpatient clinic?

Once you are discharged, your care will be directed by your doctor and an advanced practice provider (nurse practitioner or physician assistant).

Registered nurses and medical assistants provide support to our providers in the outpatient clinic.

**Please arrive on time to your appointments.** If you will be late, call the clinic at (734) 936-9814 and indicate what time we should expect you. If you do not notify the clinic within 45 minutes of your appointment, you may be asked to reschedule.

## What can I expect at the outpatient clinic? (continued)

1. You will have labs drawn before each clinic visit at the blood draw station on Level 2 of Mott Children's and Women's Hospital. Labs should be drawn **1 hour before your clinic visit**. This allows time for the results to be ready at

your visit. Please remember to stop taking tacrolimus (and any other medications that you are instructed to) until after the lab draws your blood.

2. After you are done with labs, please check in with our clerical staff at the Mott Children's and Women's Hospital, on Level 7, Reception B.
3. A medical assistant will take your vitals and place you in a clinic room. The clinic nurse will review your medication list with you. Your nurse practitioner or physician assistant (and often your doctor) will examine you and review your treatment plan.
4. Remember to check out with our clerical staff once your visit is completed.

### **What happens if I need additional tests?**

Your provider may decide additional testing or treatments are necessary. At times these may be scheduled as an outpatient test or procedure. You may have to be admitted to the hospital based on your clinic evaluation. This will be decided at your clinic visit and cannot always be anticipated. Please be prepared for such unexpected circumstances.

### **Medications and medication list**

Bring your current medication list with you to every clinic appointment so that it can be reviewed.

### **How can I get medication refills?**

**Check your medication supply before your appointment.** This is the best time to ask for refills and will ensure that you always have what you need.

If needed, you may request medication refills by calling the clinic at (734) 936-9814. You can also request refills through the patient portal (<http://MyUofMHealth.org>). Please allow at least 72 hours for the processing of refills.

Some medications may not be available at community pharmacies. Some medications require insurance prior authorizations and may take longer to process. There may be times we ask you fill your prescriptions at a Michigan Medicine Pharmacy to prevent delays in your care. Michigan Medicine Pharmacies specialize in difficult to obtain medications.



Let your clinic nurse know if you have problems getting medications. We can speak with social work or the guest assistance program to address financial barriers to obtaining medications.

### **Disability paperwork and letters**

Bring disability paperwork that needs completion to your clinic visit. Please allow 7-10 days for the completion of the paperwork and letters. Completed paperwork can be submitted to your insurance company, employer, or other recipient as directed. A copy can be mailed to your home address if requested.



### **Lab draws**

Lab work may be ordered for non-clinic visit days. Please go first thing in the morning to help us get results quickly. If you would like to have labs drawn locally, be sure the clinic nurse has the name and contact information for the facility so that we can get the results. Certain labs that result quickly at Michigan Medicine may take several days at outside facilities. There may be times that an outside facility will not be preferred as it could delay your care. Please discuss this with your team.

You will not be called with your results unless there is a change in your treatment plan. Please contact the clinic if you would like your results.

## Binder feedback

The Adult Bone Marrow Transplant Program is interested in your feedback regarding this educational binder and resource information. The evaluation should take a few minutes to complete and is available on Qualtrics at the following link: \_\_\_\_\_. If you would like a paper copy please contact: \_\_\_\_\_

### Part A: About You

These questions will help us gather information to improve the educational resources provided to our transplant patients and their families. You may choose to answer only those you feel comfortable with.

Name: \_\_\_\_\_

1. Date of your bone marrow transplant: \_\_\_\_\_
2. What language do you prefer to speak?  
\_\_\_ English \_\_\_ Other (Which one?) \_\_\_\_\_
3. What type of transplant did you have? \_\_\_ Allogeneic \_\_\_ Autologous

### Part B: Binder use

1. Where did you receive your binder?  
\_\_\_ At my pre-admission appointment from the nursing coordinator  
\_\_\_ On the inpatient unit after admission  
\_\_\_ From the website  
\_\_\_ Other \_\_\_\_\_
2. Did someone from your healthcare team talk to you about the information in the binder? \_\_\_ Yes \_\_\_ No
3. Which do you prefer?  
\_\_\_ I prefer to receive hard copies of documents.

☐ I prefer this binder in an electronic format that can be downloaded from a website.

☐ I prefer this binder content to be given to me on a jump drive.

4. Did you read the information in your binder?

☐ Read the whole binder ☐ Read part of the binder ☐ Did not read at all

If not, what stopped you from using the binder? \_\_\_\_\_

5. Did you bring the binder to the hospital when you were admitted?

☐ Yes ☐ No

6. Did your healthcare team use the binder with you during your hospital stay (for example, to go over central line care, or to review your medications or diet, etc.)? ☐ Yes ☐ No

### **Part C: Did you use any extra education from outside sources?**

The following questions are about other information you may have been given.

1. Did you get any extra education from other sources?

☐ Yes ☐ No

If yes, which source? Check all that apply:

<input type="checkbox"/>	My healthcare team members
<input type="checkbox"/>	Internet
<input type="checkbox"/>	Books
<input type="checkbox"/>	Brochures and pamphlets
<input type="checkbox"/>	Videos
<input type="checkbox"/>	Support group
<input type="checkbox"/>	National organizations
<input type="checkbox"/>	Other

2. Was there any information that you would have liked that wasn't in your binder? ☐ Yes ☐ No

If yes, please tell us what you would have liked to see in your binder:

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Please tell us about section 1:					
<b>Section 1 – Pre-transplant information:</b>					
This included a pre-transplant phone list, maps, healthcare team information, common tests and procedures, central line information, consents, patient calendar, food safety, preparing for your hospital stay, teaching slides, medications you may be taking.					
	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
The language in the binder was simple to understand					
The information helped me understand what to expect and prepared me for hospital admission.					
The information helped me feel less anxious.					
<b>Other Comments</b>					

Please tell us about section 2:					
<b>Section 2</b> <b>Bone marrow transplant basics and individualized information:</b> This included disease specific information, chemotherapy education sheets, <i>Be the Match</i> information, Basics of Blood and Marrow Transplant, the process and complications.					
	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The language in the binder was simple to understand.					
The information helped me understand what to expect.					
The information helped me feel less anxious.					
<b>Other Comments</b>					

Please tell us about section 3:					
<b>Section 3</b> <b>Psychosocial Support and Resources</b> <b>This included information about</b> Social Work Services, Pre-Transplant Patient Checklist, Caregiver Responsibilities Agreement, Letter to Family and Friends, Psychosocial and Support Resources and Support Group Information.					
	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The language in the binder was simple to understand.					
The information helped me understand what to expect.					
The information helped me feel less anxious.					
<b>Other Comments</b>					



Please tell us about section 4:					
<b>Section 4</b> <b>Admission information</b> This included information about: What to Expect During your Hospital Stay, Frequently asked Questions about Bone Marrow Transplant, What to Expect on “Day Zero” of a BMT, Transplant Day Information i.e. Puzzles, Guide: A resource for patients and families.					
	Strongly disagree	Disagree	Not Sure	Agree	Strongly Agree
The language in the binder was simple to understand.					
The information helped me understand what to expect during my hospital stay.					
The information helped me feel less anxious.					
<b>Other Comments</b>					

Please tell us about section 5:					
<b>Section 5</b> <b>Discharge and post admission information</b> This included information about discharge, specific side effects and complications to watch for, contact Information, MyUofMHealth.org Patient Portal, Food and Water Safety, Care of the Tunneled Catheter, Transition to Outpatient Care Following BMT Discharge, Be the Match: <i>After Transplant Care Guides</i> , How to Locate the Discharge Video.					
	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
The language in the binder was simple to understand.					
The information helped me understand what to expect after discharge.					
This information helped me to care for myself at home.					
The information helped me feel less anxious.					
<b>Other Comments</b>					

Disclaimer: This document contains information and/or instructional materials developed by 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.

Edited by: Karelyn Munro BA; Denise Mouro RN, BSN; Sue Wintermeyer-Pingel RN, MS, ACNS-BC

Authors:

Shelly Akerley RN, BSN

Alex Blyler RN, BSN

Karen Harden DNP, MS, RN, AOCNS, BMTCN

Chelsea Harding RN, BSN, OCN

Jack Harrington LMSW

Sarah Price, RD

Barb Rose LMSW, ACSW

Toni Spano-English LMSW

Isabel Vial RN, BSN, CHTC

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## BMT & CELLULAR THERAPY PROGRAM