

## **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 carbonated soft drinks that are bottled, canned, or served as a fountain drink.
- 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?**

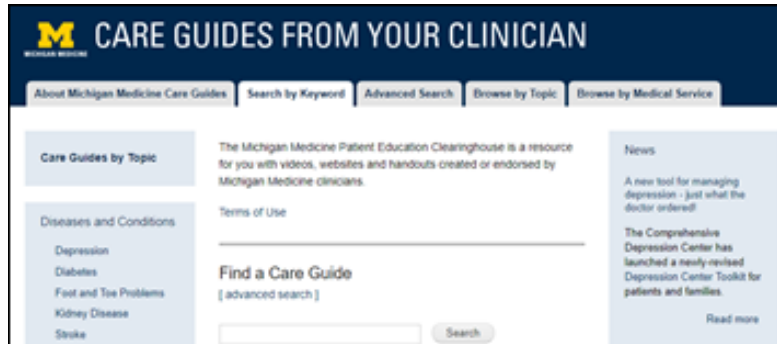
On the log-in page under “Need An Activation Code?” click “Request One Now.” Complete the online form and submit. You may also contact the Health Information Management department at HIM-PatientPortal@med.umich.edu or you can call 734-615-0872 Monday-Friday 7:30 am -4:00 pm. After we verify your information,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

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

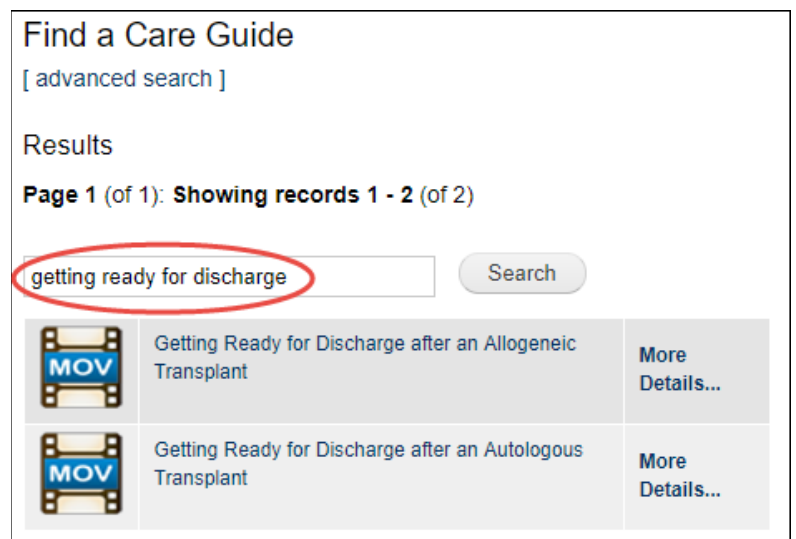
Yes, you can view your portal account by downloading the free MyChart app from Epic Systems Corporation for your Android or iPhone.

## 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.