

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 – Allogeneic Transplant

Patient Name: _____ MRN: _____

A successful blood and marrow 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 two caregivers** (one primary and one secondary), residing with you within 100 miles from Michigan Medicine and attending all of your medical appointments **for approximately 3 months 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 key aspect of care when seeking the best transplant outcomes. With or without a previous mental health diagnosis you can still be affected by depression, anxiety or have other coping concerns from your cancer diagnosis or treatment. Your transplant team may recommend consultation or ongoing follow-up with a mental health provider as part of your care.
- Lodging:** If you reside over 100 miles away from the hospital (mileage will be verified), you will be required to secure and pay for temporary lodging within 100 miles of the hospital (preferably in the Ann Arbor area) to ensure a safe recovery for both yourself and your caregiver **for approximately 3 months after hospital discharge.**
- 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 the driver and are required to attend all appointments with you.
- 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 pre-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 medical 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.

Patient Signature

Date

Caregiver Responsibilities Agreement: Allogeneic Transplant

Patient Name (Printed)

Patient Medical Record Number (MRN)

A successful allogeneic (donor) blood and marrow 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. Please consider the following list of responsibilities and requirements from the transplant center before agreeing to this commitment.

- I/we will be available 24 hours a day upon discharge, **for about 3 months 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 **about 3 months or for as long as required by the BMT doctor.** If the patient's primary residence is not within 100 miles, I/we will arrange temporary lodging post-transplant in a 100-mile radius preferably in the Ann Arbor area.
- I/we will attend discharge training (required by the transplant center) to learn intravenous (IV) care.
- 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 be with the patient at all appointments (**early morning** 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 the 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 necessary support throughout the transplant process, I will communicate with the patient and an alternate caregiver to arrange for 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: _____

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.**

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 important 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