

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: Allogeneic 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 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 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 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 your 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 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: Allogeneic 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. Please complete and return to the BMT social worker before transplant

A successful allogeneic (donor) blood 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.

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 Voigtländer 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



BMT & CELLULAR THERAPY PROGRAM

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 (www.bonemarrow.org, www.helpHOPElive.org, www.transplants.org).
- **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, www.lotsahelpinghands.com, 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