Note: We will refer to this booklet often.
Bring it with you to all appointments and hospital admissions.
We gratefully acknowledge the photography of Todd Hochberg and the patients and families who generously allowed us to illustrate their experience in this handbook.
# Table of Contents

A. Understanding Transplantation ........................................ 3
B. What Are Stem Cells ...................................................... 4
C. How Do We Collect Stem Cells .......................................... 4
D. Bone Marrow Harvesting .................................................. 4
E. Stem Cell Harvesting (Apheresis) ....................................... 5
F. Types of Transplantation ................................................... 5
G. Your Health Care Team ..................................................... 7

I. PREPARING for Transplant
A. Preparing for an AUTOLOGOUS transplant ........................... 11
B. Preparing for an ALLOGENEIC transplant ............................ 15
C. Pre-transplant Issues for all transplant patients .................... 19
   1. Fertility Counseling and Sperm Banking ......................... 19
   2. Dental Exam ......................................................... 19
   3. Nutrition, Exercise, Smoking ..................................... 20
   4. Transportation ..................................................... 20
   5. Prescription Payments, Parking, Meals etc ...................... 21
   6. Healthcare Durable Power of Attorney ........................... 21
   7. Insurance ................................................................ 21
   8. Lodging .................................................................. 23
   9. Fundraising ........................................................... 23
  10. Emotional Concerns .................................................... 24
  11. CarePages Online Communication ................................. 26
  12. Packing for the Transplant Admission ............................... 26

II. TRANSPLANT
A. The Transplant Hospitalization ........................................... 29
   1. Your Hospital Room .................................................. 29
   2. Amenities ............................................................... 30
   3. Visiting Guidelines ................................................... 31
   4. Family Facilities ..................................................... 32
   5. Telephone Service ................................................... 32
V. FAST FACTS
A. Bone Marrow Harvest ................................................................. 73
B. Peripheral Blood Stem Cell Apheresis ........................................ 74
C. Common Transplant Medications ................................................. 76
D. Developing a Caregiver Plan ...................................................... 77
E. Safe Water Handling ................................................................. 79
F. Food Safety for Autologous ......................................................... 81
G. Food Safety for Allogeneic ......................................................... 88

VI. FREQUENTLY ASKED QUESTIONS
A. Employment ............................................................................. 95
B. Disability .................................................................................. 96
C. Social Security .......................................................................... 96
D. Caregiver Needs ....................................................................... 97
E. Lodging ..................................................................................... 98
F. Insurance ................................................................................. 100
G. Prescriptions ........................................................................... 103

VII. GLOSSARY
A. Term Definitions ...................................................................... 105

VIII. RESOURCES
A. Community Assistance Organizations ........................................ 111
B. Lodging Information ............................................................... 115
C. Maps ....................................................................................... 119
D. Important Phone Numbers ...................................................... 122

Diagrams and Illustrations
Diagram #1: Overview of the Transplant Process ....................... 4
Diagram #2: Types of Transplant .................................................. 6
Diagram #3: Pre-transplant evaluation of patients ....................... 11
undergoing an AUTOLOGOUS transplant
Diagram #4: The stem cell collection process ......................... 14
Diagram #5: Pre-transplant evaluation of patients ..................... 15
undergoing an ALLOGENEIC transplant
Diagram #6: Phases of transplant complications ....................... 49
Introduction

The University of Michigan Blood and Marrow Transplant Program staff created this book to explain transplant and the treatment options available to you.

This is not a comprehensive guide to treatment options — they are changing every day. Rather, we hope this guide helps you move forward with a firm understanding of transplant, the transplant process, and what the experience may include.

With this information in hand, you will be better prepared to make thoughtful and educated decisions along with your transplant team.
Understanding Transplantation

Bone marrow and stem cell transplants offer treatment for many diseases in both children and adults. Among these are certain blood cancers like leukemia and lymphoma; tumors like neuroblastoma; blood diseases like aplastic anemia and sickle cell disease; and immune and genetic diseases.

Bone marrow is spongy tissue found inside your large bones. It is responsible for making blood cells including red blood cells, white blood cells and platelets. It is also home to your immune system. All of these cells are very important, so a change in bone marrow function can have life-threatening effects on your body. In a bone marrow transplant, old bone marrow cells are replaced by new ones. You may need a bone marrow transplant IF:

1. Your bone marrow is defective, containing either cancer cells or other abnormal types of blood cells (example — sickle cells), OR
2. Your bone marrow is not strong enough to survive the effects of high dose chemotherapy. For example, patients with tumors often require high doses of chemotherapy to kill their tumor cells. This chemotherapy may also be strong enough to destroy your blood and bone marrow cells. In this case, the bone marrow transplant is given as a rescue, to allow new bone marrow and blood cells to grow.

A basic overview of the transplant process is shown in Diagram 1. We will discuss each of these steps in detail in the following sections of this document.
What are stem cells?

Blood cells grow in the same way as other cells in our body grow. They develop in the bone marrow from a parent cell known as a “stem cell.” These stem cells begin to divide and mature until they are fully developed, forming all the different types of blood cells: white blood cells, platelets and red blood cells.

How do we collect stem cells?

In order to undergo a transplant, we must obtain stem cells from a donor. The process of collecting these cells is called harvesting. There are two basic ways to harvest or collect stem cells:

- **Bone marrow harvest**: The stem cells are collected directly from the hip bone of a donor.
- **Blood stem cell harvest**: The stem cells are collected directly from the blood (veins) of a donor.

Bone Marrow Harvest

Bone marrow cells (stem cells) are normally located deep inside your bones, primarily found in your backbone (vertebrae), hip bone (pelvis), thigh bone
Blood Stem Cell Harvest

Bone marrow (stem cells) can also be collected (harvested) from the bloodstream. At any given moment, there are stem cells present in your blood stream, traveling from one bone marrow site to another. A special machine, called an apheresis machine, filters these stem cells from the bloodstream. The apheresis process takes 3 hours per day. It will take 1-4 days to collect enough stem cells for transplant. The donor is awake during the apheresis procedure. Refer to the Peripheral Blood Stem Cell Apheresis Fast Fact Sheet in the RESOURCES Section for further details.

There are potential advantages and disadvantages with each type of collection. Your doctor will discuss the best way to collect stem cells for your transplant.

Types of Transplant

There are two basic types of transplants, autologous and allogeneic, depending on who donates the bone marrow or stem cells. In autologous transplants, the patient donates his or her own stem cells prior to treatment and receives them
back later. In allogeneic transplants, the donor is someone other than yourself, either a family member (related donor), an individual from a bone marrow registry (unrelated donor), or a cord blood from a cord blood registry.

Diagram 2 summarizes the two basic types of transplants.

![Diagram 2: Types of transplant](image)

**Autologous Transplant** — the patient donates his or her own stem cells prior to treatment and receives them back later.

**Related Donor Transplant** — stem cells are donated from a genetically matched family member (usually a brother or sister). Genetic matching, called HLA matching, is done from a blood sample.

**Unrelated Donor Transplant** — a type of allogeneic transplant in which the stem cells are donated by someone other than a family member. This donor is found in one of the worldwide donor registries. The University of Michigan is a participating center in the National Marrow Donor Program.

**Cord Blood Transplant** — Umbilical cord blood is collected from the umbilical cord and placenta after a baby is born. This blood is rich in stem cells. The donated cord blood is tested, frozen and stored at a cord blood bank for future use. The cord blood unit may be obtained from a family member (brother or sister) or selected from a registry of donated cord blood units.

**Syngeneic Transplant** — the person donating the stem cells is an identical twin.

Your doctor will discuss what type of transplant is available and best for you.
Your Health Care Team

The transplant team includes the following professionals:

Doctors

While undergoing your transplant, medical care is provided by a transplant doctor. He or she sees you on a daily basis to examine you, answer questions you may have and keep you informed of your progress. Responsibilities of the transplant doctors change every 2 weeks. This means you will have the opportunity to receive care from many doctors on our team during your hospitalization and recovery period. Weekly meetings of the doctors and other team members keep everyone up-to-date on the status of every patient.

After transplant, if you are an autologous patient you will see the transplant doctor at 30 and 100 days post-transplant and then will return to the care of your primary hematologist. If you are an allogeneic patient you will continue to be seen by the transplant doctor for regular follow-up visits for at least the first 100 days, and then less frequently for the remainder of the first year after transplant.

Pre-Transplant Nurse Coordinators

Your pre-transplant nurse coordinator tracks your treatment prior to your transplant admission and plans the necessary testing and treatment you will need at the Cancer Center to get ready for transplant. The BMT nurse coordinator also plans your donor’s schedule. The BMT nurse coordinator is your primary contact as you work your way toward transplant.
Inpatient Nurses

These nurses are educated in the care and special needs of transplant patients. Your inpatient staff nurses organize your care from the time you are admitted until you are discharged from the hospital. They will meet with you soon after admission to discuss the transplant process and what will be expected of you. They also will be available to help you and your family with physical or emotional problems as they arise.

BMT Clinic Nurses

Once you are discharged, the outpatient clinic nurses will help develop your plan of care in the outpatient setting and will assist you and your caregiver through the recovery process.

Nurse Practitioners and Physician Assistants

These caregivers 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.

Social Workers

Part of your required transplant preparation is an initial assessment with a social worker that will give you the opportunity to discuss non-medical needs and other concerns you may have. Transplant is a stressful event for you as a patient and on your support system. Social work is available for supportive counseling and therapy during the entire transplant process.
Dietitians

The transplant dietitians meet with you to explain the special diet you will follow during your hospital stay and at home post-transplant. They also work with you to set nutrition 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 medication you receive as an outpatient or inpatient. He or she is available to answer questions you may have about the medications you receive.

Blood Bank Technologists

This person coordinates all blood products for transplant patients and their donors. He or she processes all stem cell products after harvesting and coordinates the apheresis procedures.

Physical/Occupational Therapists

If you are receiving an allogeneic transplant, a physical and occupational therapist will see and assist you while you are in the hospital, to help you maintain your strength and endurance during and after transplant.

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.
Team Members for Pediatric Patients

Child Life Specialists: Child & Family Life professionals are integral members of your child’s healthcare team both in the inpatient and outpatient settings. Child Life Specialists, Activity Therapists and Creative Arts professionals create soothing environments and offer developmentally appropriate programs for children and teens that are educational, therapeutic and recreational. These include:

- medical play and education to help young people understand and prepare for treatment experiences;
- distraction, relaxation and imagery techniques to minimize anxiety and strengthen coping skills;
- play and activity programs focused on mastery, choice and self esteem and technology opportunities.

As your child or teen returns to school, Child Life Specialists can communicate with academic staff, and even classmates, to explain various aspects of the young person’s treatment, address questions and develop plans for a successful transition. The Child & Family Life team is committed to family centered care and especially, the well being of siblings. Siblings are celebrated, encouraged to share feelings and included in the healthcare experience as often as possible.

Teachers: Teachers are available to work with your child while they are admitted for their bone marrow transplant process. You should speak with your school to determine what work needs to be done while your child is admitted.
Preparing For Transplant

Preparing for transplant can be a difficult time for patients and their families. The length of time leading to transplant varies. The process of “tissue typing” family members for potential donors or the search process for an unrelated donor can be time consuming and emotionally straining. Some patients may need additional chemotherapy or radiation to reduce their disease further, prior to coming to transplant. Furthermore, additional testing is necessary to determine each person’s eligibility for transplant. Whether these issues take days or months depends on several things, including the type of transplant you are anticipating, your disease status, and your general state of health. We will try to give you an approximate time frame so that you can make the necessary preparations for your admission and recovery period.

Preparing for an Autologous Transplant

The **First Step** involves a consultation with the transplant team. Your medical history is reviewed, information about bone marrow transplants is shared, and a physical exam is performed to determine if a bone marrow transplant is the appropriate treatment option for you.
The **Second Step** will include several appointments. The testing associated with this visit will examine your organ function and disease status, which will help determine your eligibility to proceed to transplant. Your diagnosis and health history will guide what tests are ordered. The test results will be submitted to your insurance company for approval of the transplant procedure. You can expect the following appointments:

- **A Clinic Appointment:** The transplant doctor and nurse coordinator will meet with you to discuss your transplant options. You will receive documents called consents that review the recommended treatment regimens for you. The nurse coordinator will conduct an educational overview of transplant during this visit.

- **Assessment of Disease Status:** If you have a history of leukemia or cancer involving the bone marrow, a bone marrow aspirate and biopsy procedure will be done. In addition, a spinal tap (lumbar puncture) may be done, depending on your disease type.

- Other testing that may be scheduled includes: MRI, PFT, Echocardiogram, MUGA Scan, Blood Work, Urinalysis, Chest X-Ray, EKG, CT scan, and PET/CT Scan.

- **Consult Appointments** may include specialty areas of Cardiology, Dentistry, Radiation Oncology, Ophthalmology and Gynecology.

- **A Social Work Appointment:** Along with the social worker, you will discuss your understanding of the transplant process and anticipated recovery period, and how you may cope during this time. The social worker will talk to you about support and coping resources that you may have or need to identify, resources that your caregivers may require, financial information, referrals for lodging, and other needs. This appointment may be done over the phone or in person.
• **Securing a Caregiver Plan:** A successful transplant requires commitment not only from the patient and medical team, but from the patient’s support system as well. Each autologous transplant patient requires a minimum of 1 primary caregiver and 1 back-up caregiver. Pediatric transplant patients will need caregivers with them during hospitalizations and outpatient visits. Being a caregiver for a transplant patient is a vital role in the transplant process. Agreeing to fill this role is a serious commitment.

Along with this book you will receive a folder of forms that need to be returned to the transplant team. One of these forms is called the **Caregiver Responsibilities Agreement.** This form outlines the responsibilities your caregivers will face and each caregiver will need to review and sign this form. The transplant team will need to receive a completed form that reflects your caregiver plan before you are admitted for transplant.

Securing a reliable caregiver plan can be challenging for many patients and families. Family members and friends often work and have other responsibilities. Often, a “caregiver plan” consists of a number of people who are available to assist at various times and with specific duties/needs. Being a caregiver does not require medical experience. Examples of potential caregiver options that other patients/families have utilized can be found in the RESOURCES section of this handbook. Remember, a single option may not provide an adequate caregiver plan; combining a number of the options will often fulfill the need for a reliable caregiver plan.
The **Third step** in the transplant process is called “stem cell mobilization and apheresis (stem cell collection).” This stage involves the collection of stem cells from your body. Diagram 4 illustrates the collection process.

### Diagram 4: The stem cell collection process

<table>
<thead>
<tr>
<th>Mobilization of stem cells</th>
<th>Stem cell collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>Neupogen® administered</td>
</tr>
<tr>
<td>1-2 days</td>
<td>~ 10 days</td>
</tr>
</tbody>
</table>

- **Mobilization of Stem Cells** — The mobilization of stem cells refers to the administration of a chemotherapy agent plus daily injections of a bone marrow growth factor (typically Neupogen®). The combination of chemotherapy and Neupogen® pushes stem cells out of your bone marrow and into your bloodstream. In this manner, they can later be collected. The chemotherapy is usually given in the infusion area of the Cancer Center, and involves a 2 day process. The chemotherapy is administered on the first day and additional IV fluids are often given on the second day.

- **Apheresis** — Apheresis refers to the process used to collect stem cells. Blood is passed through an IV from your body and into the apheresis machine. The apheresis machine then filters the stem cells out the blood stream, and separates them from the rest of the blood cells. These stem cells can then be frozen for later use.
The apheresis procedure usually begins about 10 days after the chemotherapy is given. The procedure takes 3 hours per day, and can range from 1 — 4 days in duration. Your doctors calculate how many stem cells they want to collect from you. The collection continues until they reach this target goal. The apheresis procedure is done in the outpatient setting. You do not need to be asleep for the procedure. Refer to the Apheresis Fast Fact Sheet in the RESOURCES section of this handbook for further information.

Following a successful harvest procedure, you will then have a final evaluation for the bone marrow transplant. Some of the organ function testing and/or disease status testing may need to be repeated at this time, depending upon the length of time since it was last performed.

Preparing for an Allogeneic Transplant

Diagram 5: Pre-transplant process: ALLOGENEIC transplant

The First Step is a consultation with the transplant team. Your medical history is reviewed, information about the transplant process is shared, and a physical
exam is conducted to determine if a bone marrow transplant is the appropriate treatment option for you. Some blood work may be done. The preliminary blood testing that is required to identify a donor may be drawn.

The Second Step will include several appointments. The testing associated with this visit will examine your organ function and disease status, which will help determine your eligibility to proceed to transplant. Your diagnosis and health history will guide what tests are ordered. The test results will be submitted to your insurance company for approval of the transplant procedure.

You can expect the following appointments during the second step:

- **A Clinic Appointment:** The transplant doctor and nurse coordinator will meet with you to discuss your transplant options. You will receive documents called informed consents that review the recommended treatment regimens for you. The nurse coordinator will conduct an educational overview of transplant during this visit.

- **Assessment of Disease Status:** If you have a history of leukemia or cancer involving the bone marrow, a bone marrow aspirate and biopsy procedure will be done. In addition, a spinal tap (lumbar puncture) may be done, depending on your disease type.

- **Other testing that may be scheduled includes:** MRI, PFT, Echocardiogram, MUGA Scan, Blood Work, Urinalysis, Chest X-Ray, EKG, CT scan, and PET/CT Scan.

- **Consult Appointments:** in one or more specialty areas or clinics, as needed: Cardiology, Dentistry, Radiation Oncology, Ophthalmology and Gynecology.

- **A Social Work Appointment:** Along with the social worker, you will discuss your understanding of the transplant process and anticipated recovery period, and how you may cope during this time. The social worker will talk to you about support and coping
resources that you may have or need to identify, resources that
your caregivers may require, financial information, referrals for
lodging, and other needs. This appointment may be done over the
phone or in person.

- **Securing a Caregiver Plan:** A successful transplant requires
  commitment not only from the patient and medical team, but from
  the patient’s support system as well. Each allogeneic transplant
  patient requires a minimum of 1 primary caregiver and 1 secondary
caregiver (a total of two). Pediatric transplant patients will need
caregivers with them during hospitalizations and outpatient
visits. Being a caregiver for a transplant patient is a vital role
in the transplant process. Agreeing to fill this role is a serious
commitment.

Along with this book you will receive a folder of forms that need
to be returned to the transplant team. One of these forms is called
the Caregiver Responsibilities Agreement. This form outlines the
responsibilities your caregivers will face and each caregiver
will need to review and sign this form.

The transplant team will need a completed form that reflects your
caregiver plan before you are admitted for transplant.

Securing a reliable caregiver plan can be challenging for many
patients and families. Family members and friends often work and/
or have other responsibilities. Often, a “caregiver plan” consists
of a number of people who are available to assist at various times
and with specific duties/needs. Being a caregiver does not require medical experience. Examples of potential caregiver options that other patients/families have utilized can be found in the RESOURCES section of this handbook on page 81. Remember, a single option may not provide an adequate caregiver plan; combining a number of the options will often fulfill the need for a reliable caregiver plan.

- The **Donor Search Process** continues throughout this second step.

The **Third Step** will be scheduled within the month prior to your admission for the transplant. Final testing will be done during this period. You will have a final pre-transplant consult with your doctor and transplant coordinator. Research protocols that you may be eligible for are often discussed at this time. You can expect the following appointments:

- **Catheter Placement**: all patients undergoing an allogeneic transplant require a special IV catheter (example - Neostar, Hickman or Broviac catheters) to be present (or placed) for the transplant. These are used to administer IV fluids, antibiotics, chemotherapy drugs, transfusions, blood tests, and other medications during the transplant. If you have a catheter in place, you may require another one for transplant. Catheters are often placed at the time of admission for transplant or during the week prior to admission. You will have an appointment with the Skills Lab nurse educators who will teach you what you need to know to take care of your catheter.
Pre-Transplant Issues for ALL Transplant Patients

Time Commitment in Pre-Transplant Phase

We recognize that your time is valuable and you have other commitments. We ask that you are as flexible as possible in scheduling appointments during this time. We will make every effort to accommodate your needs.

Keep in mind:

1. Consult appointments in other clinics generally require a minimum of three hours. Each clinic has different hours and different scheduling requirements. We will make every attempt to schedule the appointment on the date and time you want, but it may not be possible.

2. Appointments vary in length of time.

3. Some laboratory or infusion appointments may be scheduled at an off-site or satellite clinic of the University of Michigan such as the East Ann Arbor, Domino Farms, Canton, or Briarwood Health Care Facilities.

Fertility Counseling / Sperm Banking: It is important to speak to your doctor about the possibility of infertility prior to your transplant, since the chemotherapy or radiation therapy you receive with transplant will likely lead to infertility or sterility. Sperm banking is a consideration for some men, although previous treatment may have already caused sterility. Fertility options for women and girls are limited. Discuss your options with your transplant doctor, nurse, or social worker.

Dental Exam

The mouth and teeth can be a source of infection. Before coming for your transplant you should have all necessary dental work done, including teeth cleaning, X-rays and routine exam. If major dental work needs to be done,
your dentist should call the transplant nurse coordinator at (734) 936-5719. A summary of your dental health will be needed prior to your transplant admission.

**Nutrition**

Prior to the transplant, it is important to maintain your nutritional intake by eating a well-balanced diet adequate in calories and protein. No food restrictions are needed unless you have a health problem that requires a special diet. Eating a variety of foods is recommended to get the nutrients you need. If you are experiencing eating problems, contact the transplant dietitian for help.

**Exercise**

You should remain active. Walking can be a good way to build your strength and increase your circulation. Remember not to overdo —this can be more harmful than no activity at all. You should not be in pain during or after your exercise. If you have questions related to your current nutrition or exercise level, call the transplant office and speak with the dietitian or your nurse coordinator.

**Smoking**

If you smoke any substance, you must quit immediately. This is necessary to prevent lung infections and lung damage, which may be increased by smoking. Make every effort to avoid second-hand smoke, as this is also harmful to your lungs. Talk to your doctor or nurse coordinator if you need assistance quitting or a referral to the smoking cessation program available at UMHS. Remember, you are not allowed to smoke in the hospital or on hospital property.

**Transportation**

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

**Prescription Payments, Parking Passes, Meal Tickets and Tangible Assistance**

Many pharmaceutical companies offer lower cost or free prescription medications to patients who meet financial requirements through Prescription Payment Assistance Programs. The UM Guest Assistance Program (GAP) can help determine your eligibility for prescription payment assistance programs and other assistance programs such as discounted parking passes, transportation assistance, and inpatient meal tickets. Note that patients must meet criteria for these services; they are available to those who meet these eligibility criteria. The GAP is located on level 2 of University Hospital and can be reached at 1-800--888-9825.

**Healthcare Durable Power of Attorney and Living Will**

A Durable Power of Attorney (DPOA) is a document that designates the person you trust to make medical decisions on your behalf if you are unable to do so yourself. It is usually part of an advanced directive or a Living Will. A blank DPOA is included in the forms folder of this packet. Review it, discuss your decisions with your family and support network and complete this form during the pre-transplant period. Bring a copy of the completed form with you to the transplant admission and give a copy to a family or support system designee.

**Insurance**

Understanding the costs and insurance benefits for transplant services can be difficult. The health system can provide you with the information you need to plan effectively for meeting the costs of the transplant services. Use this information as a reference guide to direct you to resources within the health system if problems regarding your insurance or medical bills arise.
Prior to transplant, a University of Michigan Patient Accounts representative will contact your insurance provider and confirm your insurance prior authorization requirements for payment of transplant services during the inpatient stay.

After the Patient Accounts representative has gathered this information, you will receive two copies of your transplant insurance confirmation. Carefully read the information provided. Sign the “Guarantee of Account” section of the form and return one copy to the UM Patient Accounts Department as soon as possible.

**Questions to ask your insurance company:**

- Are treatment-related lodging and/or transportation costs covered?
- Will I be assigned a case manager? Is one available?
- Do I have prescription coverage?

**Questions to ask your prescription insurer:**

- Can I fill prescriptions at the University of Michigan pharmacy?
- What are my prescription co-pays?
- Do I have a yearly limit (sometimes called a cap) on prescription coverage?
- Ask for a formulary list from your prescription provider. This will include the medications covered by your prescription provider. Ask if the medications used after transplant are covered and, if so, what is the co-pay fee? We have included a list of the medications commonly used during and after transplant in the RESOURCES section of this handbook. This list can be used to confirm coverage with your prescription provider.
Lodging

If you are receiving an allogeneic transplant and live more than 1 ½ hours from the University of Michigan, you will likely need to live in the Ann Arbor area for at least two months after discharge from the hospital. Patients receiving an autologous transplant may often have short-term (1-2 weeks) needs for lodging in the Ann Arbor area after transplant. These requirements change depending on your medical needs. Your transplant doctor will determine your lodging needs and the length of time you will need to stay in the Ann Arbor area.

Explore your options and financial ability to arrange lodging for you and your caregiver(s) in this pre-transplant period. Securing a plan for lodging after transplant is the responsibility of you and your support person and should be completed before the transplant admission; you will not be able to make formal reservations until you are hospitalized and ready for discharge or until your family or support person is ready to move in.

UM Patient & Visitor Accommodations (PVA) can locate lodging options that meet your needs. A variety of housing options are available to you and your family in the Ann Arbor area. We have compiled a list of housing options to get you started; however, this list is not exhaustive and may change. It can be found in the RESOURCES section of this handbook. You are welcome to explore other options and the Patient and Visitor Accommodations (PVA) can assist you at 800-544-8684.

Lodging expenses are rarely covered by medical insurance plans. Medicaid may pay a portion of lodging expenses, the GAP or your transplant social worker can provide you with more details.

Fundraising

Fundraising activities can help support lodging and other transplant expenses. Many people find it helpful to partner with friends or family members in fundraising efforts. We have included a letter in the RESOURCES Section of
this handbook to use for fundraising and financial assistance efforts. Several community organizations help transplant patients and families raise funds. They are included in the Community Assistance Organizations list located in the RESOURCES section of this handbook. If you have examined every option to find payment for lodging, and still are unable to find a way to pay, contact your social worker to discuss.

**Emotional Concerns**

Your social worker is available to help you identify and cope with the stress of the transplant experience. It is important to focus on the strengths that you and your support system have. Talk about your concerns and feelings with your social worker or those close to you. Our staff will encourage you to develop your physical, social, emotional and spiritual strengths.

Although each family’s emotional response to the transplant process is unique, many share similar reactions. You and your family are likely to experience some or all of the following feelings: stress, fear, anger, and guilt.

The first few weeks in the hospital can be difficult. You may be dealing with the stress of living in a new area, adjusting to the hospital routine, coping with a loss of control over your situation, and becoming comfortable with the inpatient health care team. You will be learning many new details about your treatment and the amount of information can be overwhelming. If you have questions or don’t understand what has been said, ask for clarification. This will relieve some of the stress you will be experiencing.
Fear can be an overwhelming emotion that patients and families experience before, during and even after the transplant procedure. These fears often include fear for the well being of your family, fear of discomfort, fear of what your future holds and fear of dying. Although a transplant unit is a place of hope, it is important to realize that patients can die during the course of transplantation. Sometimes family members and patients may not talk about their fears of death as way of trying to protect one another, but these fears are very real and sharing them with family and staff often helps.

Anger is another common reaction to illness. Some patients may be angry at a higher power; others direct their anger at their family or the health care team. Loved ones may feel angry at the patient for being sick and disrupting their lives. Although anger is a normal reaction to stress, it is important to find a healthy outlet (for example, talking to someone) to relieve the tension.

Many families also talk about feeling guilty. Parents may feel guilty because their child has cancer. Adult patients may feel guilty for being a burden to their loved ones. Caregivers may feel guilty for feeling angry or frustrated about their lives being disrupted or may feel helpless that they are unable to do more for the patient.

These feelings are perfectly normal human emotions and coping with them may be difficult. You and your loved ones should not hesitate to use the experience, understanding and support of the transplant team and unit staff to help you deal with these emotions.

Many patients find support groups helpful in coping with the emotions and stress of transplant. A group is held weekly on the adult transplant unit for patients and their families. There are also local support groups, telephone and online groups that you can find at the UM Patient Education Resource Center located on level B2 of the Cancer Center.
PREPARING

CarePages: Setting up a Communication Plan

The pre-transplant time is a good time to develop a communication plan for family, friends and your support network. One option for your plan is CarePages that offers free, private web sites and patient blogs. The University of Michigan Health System has partnered with CarePages to make it easier for you and your family to communicate. You will find a link to the CarePages private site as well as instructions for using the program at www.mcancer.org/patients. All you need is an e-mail address to register and get started.

Planning What to Pack

Being in the hospital can be difficult. There are ways to make this a little easier by bringing items from home. The items and ideas listed below are offered as suggestions. There are many items and amenities provided at no charge to you on the transplant units. Remember, your transplant room size is limited. 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. Many patients have found it difficult to read or concentrate during the hospitalization. It is often best to bring a variety of activities to occupy your time. Check with your nurse coordinator or social worker if you have questions about items not on this list.

Items everyone should bring:

- One copy of your Medical Durable Power of Attorney and Living Will
- Your completed Caregiver Responsibilities Agreement
- This handbook
Items to consider bringing:

- Pajamas, sweats, or loose fitting, comfortable street clothing to change daily (Tops that open in the front are preferable to pullovers; need loose collars for chest central lines. Short sleeve shirts for central lines in the arm (PICC lines)
- Bathrobe that opens down the front
- Clean underwear to change daily
- Slippers with non-skid bottoms
- Shoes to- walk the halls/ride exercise, bikes
- Hangers for the closet
- Turbans, scarves, or hats (in case your 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 into the room
- Electric razors only
- Toothbrush toothpaste/toothbrush holder
- 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, no tampons)
- Yoga pad for exercises
- Night light
- Silk plants/flowers
- Favorite posters, family photos
- Personal address/telephone book
- Prepaid telephone calling cards
- Cellular phones are allowed. However, regulations prohibit use within one foot of a medical device
- A journal, stationary, stamps and envelopes (consider pre-addressing them)
• Videotapes/DVD’s
• Leisure activities such as puzzles, books, magazines, crafts; audio books, and a container to keep them in when not in use
• Walkman/Small radio/CD player with CDs / IPOD (Bring a storage case to keep them secure in your room when not in use)
• Answering machine
• Laptops can be used on the unit.
• 1-2 days quantity of single serving food items may be brought in and stored in the unit refrigerator (snacks, frozen foods, popsicles, soda)

**Items not to bring:**

• Valuables
• Tight restrictive clothing
• Disposable razors
• Finger nail-clippers
• Artificial nails
• Contacts
• Multiple dose eye drops
• Dental Floss
• Tampons
• Cologne/ perfume /body spray / lotion with fragrance
• Refrigerators or other small appliances
• Fans
• Live plants and flowers

All sources of standing water are prohibited on the unit; this includes humidifiers, vases of water with flowers, etc.
Transplant

This section will review the transplant process and details of your anticipated hospitalization. It describes different types of transplants, so everything may not apply to you.

The Transplant Hospitalization

Once the pre-admission testing is completed and you are ready for transplant, you will be admitted to the transplant unit at Mott Children’s & Women’s Hospital either to 7 West (Adults) or 7 East (Children). These units specialize in the care of blood and marrow stem cell and cord blood transplant patients.

Your Hospital Room

All of the rooms on the transplant unit are private. Although the entire Mott Hospital is Hepa filtered, keeping the door to your room closed is clinically necessary. If you leave your room, you will be required to wear a mask. Each room has a small closet, a small bedside stand with 3 drawers, and an over-the-bed table. There is a small couch that converts to a bed and a lounge chair. You will also have your own refrigerator in your room — it does not have a freezer component. Each room is equipped with a wide screen TV programmed with the Get Well Network. This allows you access to television programming, a movie channel, a music system, the internet, and computer
games and comes with a keyboard at no charge. Wireless free internet access (WiFi) is also available through a guest network.

**Ideas and Amenities for Your Stay**

Most of our patients prefer to wear their own clothing during their stay. We encourage you to be comfortable in your choice of clothing. If you have a central IV catheter in your chest do not wear anything tight around your neck. If you have a PICC line it’s better to choose short sleeve shirts. If you are not sure, ask your Coordinator. You will need a fresh change of clothing for each day of your hospital stay. If needed, we have free laundry facilities in the family lounge room 7-241 with free detergent.

Exercise is very important in maintaining your stamina and preventing complications. In addition to physical therapy giving you exercises to complete daily and walking the halls, we have a family fitness center in room 7-231 with a treadmill, bike, and elliptical machines available. This room is just for families at this point in time. We are working to try to get patients a designated time of the day that they could use it too, but not yet. You need to obtain the key at the security desk to gain access to fitness center.

The Pediatric unit has activity areas that are designed for age appropriate activities for your child by our Child Life Department. There are a small activity room, 7-359, a large activity room, 7-411, and a teen activity room 7-418 filled with fun activities.

Sometimes peace and quiet are needed. We have two areas set aside as meditation areas. The first area is a closed room (Adults room 7-308 and Peds room 7-620). The second is an open alcove (Adults 7-375Z and Peds 7-475Z) where you can look out over the arboretum — it’s a nice sunny corner with a beautiful view.
Visiting Guidelines

Visiting hours are flexible. We encourage you and your family/caregivers to use your time to get your needed rest. Number of visitors should be limited at one time. There is a family room located behind the hospital elevator, room 7-201 for larger family groups. We also have a large family lounge on the unit 7-241. This is where the kitchen facilities are located as well as the laundry facilities. Our support groups are usually held in this room. The Pediatric unit also has a family lounge with kitchen facilities located on the unit in room 7-609. Lodging arrangements for visitors are available through the Patient and Visitor Accommodations Program. The nursing and medical staff may change visiting hours if patient care warrants it or the patient’s condition changes.

Sick siblings, family members, or visitors

All visitors to Mott Childrens & Women’s Hospital are required to be screened and wear a visitors badge to maintain a safe and secure environment. There are 3 stations, one in the lobby of Mott Hospital, one at the connector between the Taubman Center and Parking lot (P3) and Mott Hospital, and one on level 3 at the end of the connector from the P4 parking structure. There is also screening on the 7th floor when they arrive if they have missed the other stations. The screeners provide badges and validate visitor parking. Children found to be ill are not allowed on the transplant unit. In general, children may visit if they are healthy and have not been exposed to contagious diseases (such as chicken pox, measles, colds, or flu) within the previous 48 hours. It is recommended to take their temperature prior to visiting. All visitors must wash their hands when entering and leaving a patient room. Because this is a transplant unit where patients are at risk when exposed to any illness, we ask that visitors and family members wait to visit until they are well. During flu season (or other epidemics) the rules for visitors often change. Visit www.umich.edu/flu for more information about influenza.
Family Facilities

Each room has a nice couch that converts into a bed that one adult family member or caregiver is allowed to use to stay overnight in your room. Overnight guests may not use your bathroom. Separate family shower facilities are located in the hallway to 7 East room 7-357T. Family members will need to take all shower supplies with them as there are no supplies in the shower room. Family caregivers may have meal trays delivered to the room for a small fee that will be added to the hospital bill. Guest meal trays are ordered the same way patient meals are ordered, by calling the room service call center.

Telephone Service

There is no charge for local calls using the patient telephones. Long distance calls must be made collect or by a calling card. Standard telephone jacks are used in all rooms and personal phones, cell phones, answering machines or fax machines may be used.

Patient Mail

When you are in the hospital, you can receive mail at the following address. It is important to include your exact room number and hospital unit in the mailing address to ensure the mail gets to you. Also, write the word “patient” in the lower left-hand corner to facilitate quick delivery of your letter or card.

Patient Name
Mott Children & Womens Hospital
Bone Marrow Transplant Unit
Patient Unit 7Mott / Room #
1540 E. Hospital Drive
Ann Arbor, MI 48109
Care Pages

Access and update your Care Pages using the computer on your TV. This will help your family and friends keep track of your progress through your transplant and allow you to determine the amount and content of information being released through your journey.

Plants/Flowers

As a transplant patient, you will be susceptible to infections until your white blood cell count and immune system recover. During this time, fresh-cut flowers and plants are not permitted because they may carry a large number of germs in their water and soil. Fresh fruit baskets also are not permitted. Artificial flowers, balloons, and cards, are welcome.

Meals

Your meals are ordered by you through the room service call center 23663 between the hours of 6:30am and 8pm. Trays are delivered within 45 minutes of the order by the dietary staff. There will be some restrictions in your diet while you are hospitalized in order to reduce the chance for infection. A dietician will meet with you to review these dietary guidelines, restrictions, and options. Food is permitted from home if prepared following our guidelines and you will have your own refrigerator in your room. There is also a Nourishment room located on each unit, Adult, room 7-209, and Pediatrics, rooms 7-443 and 7-527, available for your use.

Bringing Food to Transplant Patients

Transplant patients are on a special diet throughout the transplant admission. Transplant patients may eat food brought in from the outside if the following guidelines are met:
Food Preparation Guidelines:

1. Always wash your hands and the surface the food will touch before handling food with soap and water. If you are handling raw meat you must wash your hands with soap and water after handling the meat and before touching another food substance.
2. If a plate, cutting board, or utensil was used for pre-cooked food, do not use again for cooked food.
3. Use separate cutting boards for meats and vegetables.
4. Do not thaw food at room temperature. Thaw frozen foods appropriately as follows:
   a. In the refrigerator OR
   b. In the microwave on the defrost setting OR
   c. By running cold water continuously over the meat until thawed
5. Cook foods thoroughly. Fresh vegetables must be cooked; do not eat them raw. Fruits with a thick peel (such as oranges, bananas) or those that can be eaten once peeled (such as apples) are allowed to be eaten fresh. Canned and cooked fruit sauces are allowed. Meats should be cooked until well done.
6. Seasoning (ex. Pepper, herbs, and spices) may be added PRIOR to cooking. Only salt may be added AFTER cooking.
7. Portion food into individual servings in tightly sealed containers and cool in the refrigerator or freezer prior to transporting to the hospital.
8. Do not leave food in a large cooking pot or let it cool on the counter. This leaves food in the “danger zone” temperature of 40-140 degrees which is prime temperature for bacteria to grow.
Food from a Restaurant or Grocery Store:

If purchasing food from a restaurant or the cafeteria, follow these guidelines:

1. Check “sell by” and “use by” dates and do not buy out of date items.
2. Do not buy damaged, bulging, or deeply dented cans.
3. Make sure that frozen foods feel solid and refrigerated foods are cold.
4. Store groceries promptly after shopping.
5. Do not buy bulk foods from self-service bins.
6. Avoid lunch meats from a delicatessen. Prepackaged ham and turkey slices are ok. Avoid bologna, salami, olive loaf.
7. Avoid cold deli salads, salad bars, or smorgasbords.
8. Avoid fountain pop/soda, milkshakes, frosties, frozen yogurt or soft serve ice cream from bulk serving machines.
9. Avoid unpasteurized and gently pasteurized honey, cider, or juices.
10. Avoid unpasteurized milk or dairy products. Pasteurized milk and dairy products including yogurt are acceptable.
11. Avoid aged cheeses or cheeses with molds (brie, Camembert, bleu, Roquefort, Stilton, gorgonzola, feta, farmer’s cheese).
12. Avoid raw nuts. Roasted nuts without shells are acceptable (i.e. roasted peanuts).
13. Avoid raw or undercooked meats, poultry, fish, and shellfish. Well-cooked meats, poultry, fish, and shellfish are acceptable.
14. Avoid selecting an item that has been held in a food warmer. Request that the item be freshly prepared.
15. Request the item be prepared without condiments (i.e. ketchup,
mustard, mayonnaise, and tartar sauce). Ask for individual packages instead.

16. Request that sandwiches be prepared without lettuce, tomatoes, and raw onions.

17. Bakery items with cream and custard fillings as well as baked custard, are only allowed if they have been refrigerated, or are fresh out of the oven. Shelf stable bakery items (Twinkies) are allowed.

Transporting Food to the Unit

1. Transport refrigerated or frozen food items in a cooler with ice.

2. If food is brought freshly made from home or from a restaurant and transportation time is LESS than 10 minutes, no cooler is necessary. If transportation will take LONGER than 10 minutes, the food should be thoroughly cooled in the refrigerator or frozen and then placed on ice in a cooler for transport to the Unit.

Food Storage and Preparation ON the Unit:

1. Food should be placed in your refrigerator

2. Food should be re-heated in the microwave until hot (steaming) and promptly eaten.

Smoking

The University of Michigan Health System has a no smoking policy for the entire complex including all buildings, parking structures, and grounds. It is imperative that you and no one around you smoke. Tobacco contains fungus spores that can lead to a severe pneumonia in transplant patients.
The Transplant Process

Conditioning

Conditioning refers to the treatment (chemotherapy, immunotherapy, and/or radiation therapy) given to eliminate cancer cells throughout the body including the bone marrow, eliminate non-cancerous diseases of the bone marrow, make room for the new stem cells, to suppress your immune system, and prevent rejection of the new donor stem cells. This conditioning phase may start before admission, may last one to ten days, and typically finishes one or two days before the infusion of the stem cell product (blood, marrow, or cord blood). The conditioning you receive has been very carefully planned as part of a treatment “protocol”, a precisely timed and organized approach to the treatment of your disease. The protocol outlines the treatment (chemotherapy, immunotherapy, and/or radiation therapy) you need as well as blood tests, x-rays, and other procedures. The protocol was written by a doctor who is an expert in the field of cancer and transplant. Before your admission, you will be asked to sign an informed consent that reviews your treatment protocol. This document assures that you have been given important information, including the risks and benefits about your treatment and the transplant process.

Reduced Intensity Conditioning:

In some cases for patients receiving allogeneic transplants, your doctor may elect to give you a less intensive or “reduced intensity” conditioning regimen.
Reduced intensity transplant are typically performed for older patients, or for those patients who are noted to have decreased organ function (such as heart, liver, lungs, or kidneys) prior to the transplant. In such cases, the transplant doctor may not feel that your body can tolerate the full dose of chemotherapy that may normally be given to patients for transplant. In a reduced intensity transplant, chemotherapy is given to suppress your immune system, thereby allowing the new stem cells to take hold and start growing. As the chemotherapy is less intensive, the complications you may experience in the first 2-4 weeks after transplant, such as mouth sores, infections, kidney or liver problems, are often much less. However, since a lower dose of chemotherapy is used, transplants do not immediately kill as many cancer cells as full dose treatments. Thus, patients undergoing reduced intensity transplants should be in remission or near complete remission. Your transplant doctor will be able to tell you if a reduced intensity transplant is possible for you.

Conditioning: Chemotherapy

Chemotherapy is an important part of the protocol and will consist of one or more different types of medications, depending on the type of disease you have and the type of transplant you are receiving. The chemotherapy is given on a specific schedule that is thought best for eliminating your cancer cells and/or bone marrow cells. You will be given a calendar indicating what drugs you will be given on each day of your protocol and how you should expect to feel. These medications will be given intravenously (IV) or in a tablet/capsule form to be taken by mouth. The doses of chemotherapy used in transplant are often much higher than those you may have received in prior treatments. To kill cancer cells in your body it is often necessary to use the highest doses possible. Therefore you may experience more severe and different side effects than the ones you may have had in the past. Unfortunately, chemotherapy also damage normal fast-growing cells such as those in your mouth, throat, bowels, skin, hair, and bone marrow. You may experience nausea and vomiting, mouth and
throat sores, diarrhea, a rash or change in the color of your skin, and hair loss. It will also cause your blood counts to become very low.

You will be given medications to minimize the nausea and vomiting. Good oral hygiene including frequent mouth care is required of all transplant patients to help limit the number of mouth or throat sores. A nurse will help you develop a mouth care plan. Pain medications are available if you develop sores in your mouth or throat. If you develop diarrhea, we will identify the cause and treat to correct accordingly. In most cases, the hair loss is temporary and should grow back within a few months.

Chemotherapy may also affect organs of the body such as the kidneys, liver, heart, and lungs. Although severe side effects are infrequent, they can progress and cause more serious problems. It is impossible to predict who will experience these side effects. We will monitor your kidney and liver function daily through blood tests and listen to your heart and lungs daily to check for changes. If you notice any changes, it is important for you to notify your nurse immediately.

**Conditioning: Immunotherapy**

Immunotherapy is most frequently used in patients who are receiving transplants for a non-cancer related diagnosis. When it is used as part of the conditioning regimen, it is usually given intravenously for several days prior to transplant and may also be given after transplant. The main goal of immunotherapy is to suppress the immune system and prevent the rejection of the new donor cells. The most common side effect of immunotherapy is an allergic reaction. For some of these drugs, test doses are given first to determine if you are allergic or can tolerate the drug.

**Conditioning: Radiation Therapy**

Radiation therapy (or irradiation) is a part of some transplant regimens. There are three types of radiation that can be given to patients: (1) Total Body
Irradiation (TBI) given to the entire body with some shielding of the lungs and liver, (2) Total Lymphoid Irradiation (TLI) given to the major groups of lymph nodes, and (3) a boost of radiation directed at certain body parts. Radiation is given by a machine that sends high speed x-rays (Photons) into your body.

The type of radiation you may receive will be discussed with you by your transplant doctor and the radiation oncology team. If radiation is planned, you will meet with the radiation oncology team before your transplant admission. The team consists of the radiation oncology doctor (who is in charge of your treatments), the radiation technologist (who administers the treatments), and the radiation nurse (who will monitor you for side effects). Depending on the type of radiation you receive, you may have a planning appointment call simulation. Simulation is composed of having you on lay on an x-ray table, making an immobilization device if needed, taking x-rays if necessary to prepare blocks (used to block tissue that will not be treated such as lungs, liver) and placing markings (permanent marker or tattoos) for lining up purposes on the treatment machine.

Radiation may be given as an outpatient (a boost of radiation directed at certain body parts) or following admission (TBI and TLI) while you are in the hospital. The radiation is given 1-2 times per day on the B2 level of University Hospital. The special machines in this department require the temperature to be cold, therefore, you may want to wear a robe and bring an extra blanket. You should take off all metal jewelry, safety pins, clips, etc) before your appointment.

The radiation therapy procedure often takes 30-60 minutes. During this time you will be asked to remain in a certain position (lying down, standing, or sitting). You will be alone in the treatment room but the technologist can hear you, talk to you, and see you on a video monitor. You will hear the machine making a humming noise but you will not feel anything.

Radiation may affect both cancer cells and normal cells. The side effects from radiation are due to its effects on normal cells. Initially you may experience
nausea, vomiting, and diarrhea. You will be given medications to prevent and treat these side effects.

After you complete the radiation treatments you may develop other side effects such as red, dry skin which may look like a suntan; dry mouth which occurs from the effect of the radiation on the salivary glands; parotitis (swelling of the parotid glands in front of your ears); infertility; lung changes and cataracts (see complications section for more information). Your doctors and nurses will be monitoring you very closely for these side effects. Some of these are easily treated while others may require long term follow-up. If you have questions regarding your treatments, ask a member or your transplant or radiation team.

**Stem Cell Infusion – “Transplant”**

After your conditioning treatment, you are ready to receive your stem cell infusion or transplant. If you are receiving stem cells from a donor (an allogeneic transplant), the infusion is given soon after the cells have been collected and processed. The transplant is given through your IV catheter just like other blood product transfusions.

If you receive your own stem cells (an autologous transplant) or cord blood stem cells, a blood bank technologist will bring the frozen product to your room. The product will be thawed at your bedside and immediately infused with a syringe through your IV catheter. DMSO, a preservative used to protect and nourish the cells during the freezing and thawing process, may cause some side effects. The most common side effect is its bad taste (fish, garlic, cold creamed corn, V8 juice). This taste can be very strong and cause nausea and
vomiting. Also, you will eliminate the DMSO from your body by breathing it out of your lungs. This contributes to the bad taste/breath as well as having this smell linger in your room for two to three days especially if you have a lot of bags of stem cells. Your urine may become red-colored for 24 hours. This is from any red blood cells that were in the product that did not survive the freezing/thawing process. You may also feel flushed or hot during the infusion. In rare cases, the DMSO can cause other problems such as shortness of breath, wheezing, and stomach pains. Your transplant team will monitor you closely during the transplant infusion.

**Recovery**

Within 7-10 days of receiving your conditioning therapy, your blood counts will decrease and remain low until the new bone marrow cells begin to grow. Every day during your hospitalization your nurse will post your counts on your board. This will allow you to keep track of your progress through the transplant phase.

Leukopenia (low white blood cells)/Neutopenia (low neutrophils: infection fighting white blood cells)

During this time, you are at great risk for developing an infection since you will not have white blood cells to fight bacteria, viruses, or fungi. If you develop an infection or a fever during the time when your white blood count is low, you will be worked up to identify the type of infection and placed on anti-infection medications (antibacterials, antivirals, antifungals) immediately. To help identify an infection early it is important to let your nurse or doctor know how
you are feeling as you will not have any infection fighting cells. Some of the symptoms of an infection are:

- Fever (over 38° degrees Celcius; or 100.5° degrees Fahrenheit
- Skin tenderness
- Chills/sweating
- A burning feeling when urinating
- Rectal pain/tenderness
- A cough, sore throat, or mouth pain or sores
- Loose bowels
- A general feeling of tiredness

If these symptoms appear, notify your nurse or doctor immediately. You may be given immunoglobulins (antibodies) through your IV. Immunoglobulin infusions are a boost of antibodies that can kill bacteria, viruses, and fungi. Infusions of immunoglobulin are a type of transfusion, as the immunoglobulins (antibodies) have been collected from healthy donors. The transfusion of antibodies lasts several hours and may also be given as an outpatient after you are discharged.

**Thrombocytopenia (low platelets)**

Platelets are also made in the bone marrow and help prevent bleeding, help you clot blood, and help keep blood cells inside the blood vessels. Your team will be monitoring you for signs of bleeding such as blood in the urine or stool, nose bleeds, bleeding gums. They will also look at your skin for small red dots called petechiae. This is caused by blood leaking out of the smallest blood vessels underneath the skin. You will be given platelet transfusions if your count is too low or if you show signs of bleeding.
Anemia (low red blood cells)

Red blood cells carry oxygen to tissues so when your level gets too low you will feel fatigued and short of breath. To ensure adequate organ function, you will be transfused with red blood cells until your new bone marrow can maintain an adequate red blood cell count (hemoglobin).

Blood Products/Transfusions:

During the recovery period, your body will require support through transfusions of red blood cells and platelets. This may take several weeks to months depending upon the type of transplant and the type of donor. Blood products are provided by the American Red Cross and are coordinated by the UMHS blood bank. It is not possible for your family and friends to supply all your blood product needs.

Patient Responsibilities

Throughout your recovery process, the most important member of the “team” is you. You play an important part in your care and will have many things to do every day. All of these are important for your recovery. You know yourself best, and your transplant team depends on your reporting and cooperation.

Nutrition:

Nutrition has a vital role in helping you achieve the best result for your medical treatment. Good nutrition helps prevent infections from developing and also helps maintain a sense of well-being. It is often difficult to stay well-nourished during cancer treatment. Side effects of the treatment that may impact your ability to eat may include nausea, vomiting, decreased appetite, altered taste, mouth sores, sore throat, and fatigue. The transplant dietician will help you meet your nutrient requirements by offering nutritional supplements or by suggesting nutritious foods that you can tolerate. This is very important for
your recovery after the transplant. If you are unable to eat, nutrition will be provided through an intravenous solution. This is called total parenteral nutrition.

Another aspect of your nutritional care is a low microbial diet. Its purpose is to decrease the risk of developing an infection by avoiding foods that may contain microbes (bacteria, viruses, or fungi). The diet allows only well-cooked foods and restricts foods that may be high in microbes such as fresh fruits and vegetables that are unable to be washed with soap and water and peeled. The dietician will meet with you and instruct you on the guidelines and principles of the diet.

Mouth Care:

Good oral hygiene will be important to you before, during, and after your transplant. Mouth sores and infections can be painful and life threatening. This is an area where you can make a difference.

The conditioning therapy you receive before your transplant affects the cells lining the inside of your mouth and throat. As a result, you may develop mouth sores. If your mouth is not kept clean, an infection can occur that can quickly spread. You will be given medications to help prevent infections if the sores develop and pain medication if needed. However, the most important part will be keeping your mouth clean. You should brush your teeth and tongue at least four times a day, after each time you eat and before retiring for the night.

Hygiene:

It is necessary for you to take a shower every day. Your nurse will provide you with a special antimicrobial soap to use that will kill bacteria on your skin. For children, there is a bath tub available in room 7-543. You will need to have a fresh change of clothing to put on after your shower each day. Always remember to wash your hands before and after using the bathroom, touching sores on your body, and performing mouth care.
Activity:

There are many reasons why we stress exercise and physical activity. You will feel better mentally and physically, keep your skin, muscles, heart, and lungs in shape, sleep better at night and prevent complications (pneumonia, blood clots) if you follow a regular exercise program.

You will work with a physical therapist to develop a personalized exercise program based on your experience, habits, interests, and physical condition. Walking in the hallways as much as possible is recommended.

It is important for you to stay out of bed during the day as much as possible. Activities that distract you are a good way to keep busy and decrease boredom. These include games, puzzles, listening to music and other hobbies you may have. If you have questions about an activity, ask your nurse, doctor, or physical therapist. For adults, the family lounge 7-241 has a small selection of games and puzzles. For children, the activity rooms, 7-359 and 7-411 and teens, room 7-418, provide a wide selection of age appropriate activities to keep them busy.

Engraftment

Approximately 10-21 days after your transplant, your bone marrow should show signs of engraftment, that it is starting to grow. We monitor your blood counts daily. The first sign of engraftment is the production of white blood cells (WBC) called neutrophils (ANC) — the infection fighting WBC. Platelets often take a little longer to begin producing. Red blood cells take the longest to begin reproducing. Often they do not start reproducing until after you have been discharged.
Discharge

Although each person varies in how long he or she takes to recover, the following are general criteria used for discharge from the hospital:

1. Stable vital signs and no fevers for 24 hours
2. Infections and graft versus host disease (GVHD) should be absent, stable, or under control
3. Not requiring daily transfusions (especially platelet transfusions)
4. Able to tolerate oral medications, food, and fluids
5. Active enough to function outside the hospital
6. Nausea, vomiting, diarrhea under control
7. Discharge teaching has been completed for you and your caregiver

Discharge is described in greater detail in the section of this handbook titled “After Transplant”.

Detailed information about discharge is included in the “After Transplant” section of this handbook.
Complications

There are many potential complications of transplant. The high doses of chemotherapy, prolonged periods of low blood counts, and effects from the donor cells themselves can all lead to serious complications. These can occur at a time during or after your transplant. Many of these complications can be treated with medications and careful monitoring. Some of them, however, can lead to life-threatening situations. There may be a time when you will need to be monitored very closely in an intensive care setting. If this occurs, the transplant team will continue to care for you with the intensive care staff.

Remember that all patients are unique and not every patient will develop these complications. We will watch you closely for the following possible complications. In general, we divide potential complications into four phases; each phase is separated by an approximate time point post-transplant. Day 0 is the actual day of transplant. Diagram #6 illustrates these phases.

Diagram #6: Phases of transplant complications

Diagram 6 serves only as a general reference for you. It provides a general overview of common transplant complications, and when they are likely to
occur following transplant. It is not meant to be all inclusive. Likewise, the
diagram does not mean that you will develop each of these complications, or
that the complications (if developed) will always be severe. Some complications,
such as GVHD (graft versus host disease) typically do not occur in autologous
transplants. On the other hand, patients who receive a transplant from a
partially matched donor are more likely to develop graft versus host disease.
Your doctor will review the common complications that you may experience
with transplant, based upon your particular transplant type, the intensity of
the chemotherapy you receive with the transplant and the degree of match you
have with your donor. This diagram can simply serve as a guide or reference to
help discuss your particular risks.

Infections

During and after your transplant, you will be at risk for developing many
different types of infections. Immediately after your transplant you are at risk
for bacterial and fungal infections, as well as for reactivation of certain viruses
that reside in your body (for example, the chicken pox or herpes simplex virus).
Even the slightest infection can become life threatening. You will receive a
number of preventative antibiotics during the transplant. These antibiotics
are intended to lower the risks for developing certain viral, bacterial or fungal
infections during the process.

During the first several months after your transplant you will continue to be
susceptible to infections, especially viral infections. Cytomegalovirus (CMV) is
a virus that may cause severe infections of the lungs, gastrointestinal tract or
liver, Special medications are required to treat CMV. Pregnant women should
avoid contact with patients who have an active CMV infection.

Your immune system may remain weakened for approximately one year (or
more) following your transplant. Although you can return to an active life, it is
important for you to be slightly more cautious and report lingering illness to
your transplant team. A common event for patients is to experience shingles
(herpes zoster), a reactivation of the chicken pox virus, in the year following transplant. Approximately 1 year after transplant you will need to have all of your childhood vaccinations repeated.

**Veno-Occlusive Disease (VOD)**

This is a complication that typically affects the liver. It is caused by the high doses of chemotherapy that may be used during the transplant. When VOD occurs, it becomes very difficult for the liver and subsequently lungs and kidneys to function normally. The signs and symptoms of VOD may include jaundice (yellow skin and eyes), a swollen and tender belly (especially where your liver is located), and weight gain. Treatment for VOD may include various medications, blood transfusions, careful monitoring of your liver and kidney function, and blood tests. If veno-occlusive disease occurs, you may be transferred to an intensive-care unit for monitoring. In some cases, your lungs may require extra support to breathe, requiring the use of a machine called a ventilator or breathing machine. In other cases, your kidneys may require the support from a dialysis machine to remove extra fluid from your body.

**Lung and Heart Complications**

Pneumonias are common following transplant. Approximately 30-40% of patients undergoing an allogeneic transplant and approximately 25% of patients undergoing an autologous transplant will develop pneumonia at some point during their transplant course. The pneumonia may be severe, even life threatening in some cases. Not all pneumonias are caused by infections. Approximately 50% of all pneumonias following transplant are non-infectious in origin, related either to (1) the effects of graft versus host disease (GVHD) in the lungs or (2) direct damage to the lungs from the chemotherapy given just prior to transplant. A condition called Idiopathic Pneumonia Syndrome (IPS) is a particularly dangerous condition that may occur in the lungs following a transplant. It is most likely to occur in patients who receive a transplant from a mismatched donor. However, it can occur in any type of transplant. Typical
signs and symptoms of IPS include shortness of breath, cough, and the need for oxygen support. There are special medications that may be required to treat IPS. In addition, many patients require a breathing machine to help them breathe when they have IPS. A test called a bronchoscopy is often performed to tell if you have an infection in your lungs. A bronchoscopy is a special tube (a type of periscope) that is passed into your lungs to see how they look. Lung fluid can be collected during the bronchoscopy procedure, and then tested to determine if an infection is present or not. Other tests, including Chest X rays and CT scans are often done to monitor the appearance of the lungs.

Since lung problems are common with transplant, you will typically have tests done before, during and after your transplant to monitor the condition of your lungs.

Heart and blood pressure problems are also common during transplant, especially in individuals who already have a history of high blood pressure, high cholesterol or triglyceride levels, blood clots, heart attacks, strokes or blocked arteries. In addition, patients with a history of diabetes are at higher risk for developing blood clots or heart problems during transplant. Such heart problems may include high blood pressure, irregular heart beat / arrhythmias, heart failure, or even heart attacks. Tests (blood tests, echocardiogram or MUGA test) will be done prior to transplant to help determine your risk for developing such problems during transplant.

**Bleeding**

Bleeding after transplant is common, especially when your platelet levels are very low. Platelet transfusions are given to try to prevent severe bleeding. Your platelet count and signs of bleeding will be monitored often by your medical team during your transplant. Blood in the urine (called hematuria) is also common after certain types of transplant, and is often due to a specific virus that infects your bladder. Your doctors will monitor you for such complications and treat you with specific antibiotics, if required.
Graft Versus Host Disease: (GVHD)

Graft versus host disease (GVHD) is a complication that occurs when the new stem cells (the graft) react against your body (the host). It can range from a very mild complication, or may progress to a life-threatening one. It is common in allogeneic transplants and rarely occurs in autologous transplants.

There are two general forms of GVHD: acute GVHD and chronic GVHD.

When does GVHD typically occur?

Acute GVHD typically occurs within the first 100 days after transplant. Chronic GVHD typically occurs following day 100 post-transplant. This is not a hard and fast rule. There are cases in which acute GVHD starts after day 100, and cases in which chronic GVHD starts before day 100 post-transplant.

What does Acute GVHD look like?

As above, the “acute” type of GVHD typically begins within the first 100 days after transplant. It may present as a skin rash on all or part of your body. The rash associated with GVHD is red, but generally not painful or cause severe itching. The rash often starts on the cheeks, ears, upper neck, shoulders, palms and soles of the feet. The rash can spread to the entire body surface. GVHD can also involve the intestines (causing diarrhea) and the liver (causing jaundice). GVHD of the intestines is typically associated with a crampy belly pain plus watery diarrhea. The diarrhea is often described as watery green, but it may be yellow or brown in color also. The belly pain may be severe and require pain medications to help control the painful cramps.

What does Chronic GVHD look like?

Chronic GVHD can develop three to 12 months after transplant. Sometimes it occurs after a patient has already had the acute type of GVHD. In other cases, chronic GVHD may occur on its own, without a preceding history of acute
COMPLICATIONS

GVHD. This type of GVHD commonly affects the skin, liver and intestinal tract, and can cause dryness of the eyes and mouth.

The skin rash associated with chronic GVHD is different than the rash seen with acute GVHD. With chronic GVHD, the skin may develop an eczema type appearance, may become dark (or very light) in appearance, or may develop a tightness (called scleroderma).

The lungs can also be affected by chronic GVHD, with scar tissue forming in the lungs. If this were to happen, your lung capacity would decrease and you would become short of breath more easily with exertion. You would be at greater risk for developing pneumonia if the chronic GVHD involved your lungs. Special tests call Pulmonary Function Tests (PFT’s) will be done at specified intervals after an allogeneic transplant to monitor for GVHD of the lung. It is VERY important that you do not skip these PFT tests.

Chronic GVHD may cause significant dryness of the eyes and mouth. It is very important that patients undergoing allogeneic transplants take eye drops prescribed during transplant and see an ophthalmologist (eye doctor) on a regular schedule. Your transplant team will help you schedule these appointments with an ophthalmologist. Your transplant coordinator will schedule an appointment for you to see an ophthalmologist at the University of Michigan prior to your transplant admission. Routine follow-up appointments with an ophthalmologist after transplant will be necessary.

Finally, it is not uncommon for chronic GVHD to cause significant dryness to the vaginal area in females. Thus, for females 16 years in age or older, your transplant coordinator will schedule an appointment for you in the Ob-Gyn (Obstetrics and Gynecology) clinic at the University of Michigan, prior to transplant. Follow up appointments with the Ob-Gyn service after transplant will be required.
How are acute or chronic GVHD diagnosed?

The diagnosis of acute GVHD is based upon symptoms such as skin rash, crampy diarrhea, and yellow jaundice. If the diagnosis is in question, then biopsies of affected areas are often performed. For example, skin biopsies are commonly done on rashes to determine if GVHD is present. Likewise, biopsies of the stomach or intestinal tissue are often done by a procedure called an endoscopy or colonoscopy to make the GVHD diagnosis.

The diagnosis of chronic GVHD is likewise done by exam of the skin, eyes, mouth, and lungs. Likewise, tests such as PFT’s (see above) are routinely performed to monitor for chronic GVHD of the lungs. Like acute GVHD, biopsies of tissue (skin, mouth, intestines) are often required to confirm the diagnosis of chronic GVHD.

How often do patients get acute or chronic GVHD?

Patients who undergo transplant from a fully matched sibling donor typically have a 33% chance of developing some form of acute GVHD after transplant. Patients who receive transplant from an unrelated donor may have a 50-60% chance of developing acute GVHD after transplant. If there is a mismatch between the patient and donor, then the chances for developing GVHD are even higher.

The chances of developing chronic GVHD depend upon several factors, including your donor source (sibling) or unrelated donor, and the type of process used to collect the stem cells (stem cell harvest or a bone marrow harvest). Patients who undergo transplant from a matched sibling donor have a lower chance of getting chronic GVHD than patients receiving transplant from an unrelated donor. In addition, patients receiving bone marrow from donors have a lower chance of getting chronic GVHD than patients receiving stem cells. For many transplants, the chances of developing chronic GVHD may range from 40-50% after transplant. Your transplant doctor will discuss with you your risks
How do we treat GVHD?

If you are undergoing an allogeneic transplant you will receive several medications to prevent severe GVHD from occurring. It is essential that you take all of these medications when they are scheduled. Prevention is the best way to fight GVHD. Typically, some of the GVHD medications (tacrolimus or cyclosporine) may be started even prior to the stem cell infusion, so that your body can start fighting GVHD as soon as the new stem cells are infused. In addition, the University of Michigan has historically participated in a number of clinical research studies designed to lessen the severity of GVHD. Your transplant doctor will tell you if you may be eligible for these clinical research studies.

What is ECP and how does it treat GVH?

ECP refers to “Extra-Corporeal Photopheresis. The letters (E-C-P) stand for the following:

- **Extra** refers to doing a procedure outside the body,
- **Corporeal** refers to the body or in this case, to blood cells, and
- **Photopheresis** refers to light therapy.

If you put all those definitions together, ECP means light therapy that is given to blood cells that are removed from the body. Doctors use ECP to treat or prevent acute or chronic graft versus host disease.

Each ECP treatment session typically lasts 2-3 hours, and is given at specified weekly or monthly intervals. You are awake during ECP therapy, and the therapy is usually not painful. During the ECP therapy, about 6 to 8 ounces of blood are removed from your body through and IV. The IV takes the blood into a special machine where it is exposed to ultraviolet light. This exposure to
ultraviolet light kills certain types of blood cells.

The goal of ECP is to kill the GVH causing cells and return the good blood cells back to you. ECP therapy is done at the bedside if you are an inpatient, or done in the ECP clinic if you are an outpatient. Your doctors may talk to you about ECP if you develop GVHD.

**How long does GVHD last?**

Unfortunately, we cannot answer this question. Every patient is different. Some cases may last several weeks, others several months, whereas others may last for several years.

**Does GVHD serve a useful purpose?**

GVHD may not only attack certain sites in your body (skin, liver, intestines) but may also attack cancer cells that remain in your body after transplant. Thus, patients who develop GVHD often have lower rates of relapse of their cancer, than patients who do not develop GVHD after transplant. We call this a “graft versus leukemia” (GVL) effect.

**Lack of Engraftment**

There is a possibility that the new stem cells will fail to develop or mature after the transplant. If this occurs, it is called rejection or non-engraftment. For the majority of transplants, the risk of rejecting the new bone marrow or stem cells is < 10%. There are various reasons why your body may reject the bone marrow or stem cells from a donor, including development of some of the complications listed above. There are medications (such as Neupogen®) that can be given to help stimulate the new bone marrow or stem cells to grow in your body. These medications are usually given by injection each day for several days until your blood counts begin to recover. If your blood counts fail to recover following a transplant, your doctors will talk with you about the potential need to perform a 2nd transplant.
Relapse and Secondary Malignancies

Unfortunately, transplant does not guarantee that you will be cured of your cancer or underlying disease. Even with transplant, your disease could still return or relapse.

In a small number of patients, a different type of cancer can occur after transplant. Such secondary cancers may be caused from (a) the chemotherapy or radiation given prior to transplant, or (b) associated with graft versus host disease occurring after transplant. Such secondary cancers may include skin or mouth cancer, or other types of leukemia. In general, the risks of developing secondary cancers are approximately 10% following many transplants. If this occurs, you and your doctor will discuss available treatment options.

Intensive Care Unit (ICU)

There may be a time during the transplant procedure when your condition becomes more serious. At this time you may require closer monitoring and will be transferred to the ICU. This is an intensive care unit with nurses and doctors who are trained and experienced in caring for patients requiring intensive and special-ized treatment. The bone marrow transplant team works very closely with the staff of the ICU and will continue to follow your care after your transfer.

There are different visiting hours and family guidelines than those on the transplant unit. The staff of the ICU will meet with your family to review these soon after your transfer.
After Transplant

Discharge Planning

The transplant procedure is very intensive and will continue to affect you and your activities for some time. The following instructions are very important to follow. There is no special time when all restrictions and precautions can be stopped. This will vary for each patient. You should follow these guidelines for a minimum of 100 days following transplant, possibly longer in some cases.

In general, allogeneic transplant patients will be followed in the transplant clinic one to two times a week immediately after discharge. The frequency of future appointments will depend upon how you are doing. Autologous transplant patients will be seen approximately twice after discharge before returning to the care of their referring doctor.

It is important to return to the clinic for appointments after transplant. In the beginning, your appointments will be quite frequent; they will become less frequent as you recover, regain your strength and are less likely to experience severe complications. Do not hesitate to contact the clinic or your doctor if you think you should be seen between scheduled appointments. Even after you return to your doctor in your community, we are available to you by phone or appointment.

The transplant team is always available to assist you with your discharge plan and care after transplant. This section of the handbook will answer many of the questions you have about this phase of transplant. If you have further questions, call the transplant clinic.

Precautions and Restrictions

Many of these precautions and restrictions are necessary to prevent infections and bleeding. Your bone marrow needs time to mature before it is considered fully recovered. Until that time, there are things you should watch for and help
prevent. These restrictions will lessen over time, as your bone marrow and immune system become fully functioning.

Your immune system may remain weak for an extended time period following your transplant. In autologous transplants, it often takes 3-6 months before the immune system fully recovers. In allogeneic transplants, it can take one or more years to fully recover. Although you can return to an active life, it is important for you to be slightly more cautious and report a lingering illness to your transplant team.

**Masks**

You should continue to wear a mask when you come to the hospital for your visit due to the construction around the hospital. A mask will not protect you from someone who is sick, but rather acts as a reminder for you and those around you to be cautious. This is the reason you are asked to avoid crowds and public places when you are first discharged. A mask is not necessary when you are at home or out for a walk.

**People**

Avoid close contact with anyone who is ill. Avoid crowded areas, especially during cold and flu season. Stay away from anyone exposed to communicable and/or childhood disease; even if you have already had them yourself, you are still at risk.

**Pets and Animals**

Household pets can remain in the home, with the exception of birds and reptiles. Avoid all contact with birds or reptiles and their droppings; they carry many infections. Avoid contacting animal waste. Do not kiss or hug your animals and do not let them sleep with you. Do not come in close contact with outdoor or farm animals.
Plants and Flowers

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; the water can carry large amounts of bacteria.

Travel

Notify your doctor before you travel. In general you should avoid swimming in lakes, public pools and sitting in hot tubs due to the possibility of exposure to excessive bacteria. Your skin will be very sensitive to the sun; therefore you should not plan a vacation that will require prolonged exposure to sunlight. You may be surprised at the time it takes to regain your pre-transplant stamina, and it may be wise not to plan an extended vacation until you see how your recovery progresses.

Miscellaneous

In general, it is important for you to avoid infection or items that might carry infections. Stay away from dusty, dirty, moldy things (construction, areas, remodeling areas, vacuum cleaner bags, etc.) stagnant water (flower vases; vaporizers, de-humidifiers, etc.) and things that might irritate your lungs (aerosol spray cans, smoke filled areas). If you question the appropriateness of an activity, it is probably safer to avoid it until you can clarify it with your doctor.

Sexual Activity

The stress of illness, transplant and hospitalization may cause changes in sex drive. Sexual activity can be resumed, although some precautions may be needed when you are first discharged. Women should use a water-based lubricant to combat vaginal dryness (which results because of chemotherapy and radiation). Discuss concerns you have about intimacy at the time of discharge or during your recovery from transplant.
Physical Activity

It is essential to maintain the activity program outlined in the hospital by your physical therapist. There is a potential for developing infections in your lungs after the transplant, and remaining active helps keep your lungs stronger. Activity outdoors, such as walking, is good for you. Remember to avoid construction areas or anywhere dirt or soil is being moved, as this increases your risk of developing a fungal infection in your lungs or sinuses. You may tire easily at first. This is normal after returning home. Try to build your endurance slowly; space out activities, do lighter tasks at first, schedule rest periods into your day’s activities. Avoid exhaustion and fatigue. Listen to your body. It could be up to a year before your full stamina returns.

Activating the Caregiver Plan

Now is the time you will activate your caregiver plan. Your caregiver will begin to take responsibility for:

- daily monitoring of your medical status,
- medication scheduling,
- driving and accompanying you to clinic appointments,
- your meal preparations,
- maintaining a clean living environment,
- shopping and other activities of daily living.

Other family members and friends are often willing and ready to help. Now is the time to let them!

Children

It is important to notify your child’s school that you must be notified of communicable diseases like measles, chicken pox, etc. Notify your doctor immediately if your child is exposed to one of these illnesses. It is advisable that toddlers and preschool-age children not attend day care or preschool in
order to decrease your chances of exposure to infection and disease.

Notify your child’s doctor that you will be having (or had) a blood or marrow stem cell transplant. It is important that you avoid contact with children who have received a live immunization (such as the chicken pox vaccine). If children are living in the home and vaccinations are necessary, inactivated vaccines are acceptable and may be administered.

**Driving**

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. Physical stamina is generally reduced and could lead to a decrease in the reflex time necessary for safe driving. Also, you may be taking medications that would make it unsafe to operate an automobile. It is important that you consider this as you make plans for your follow-up care. It is essential to have someone available to drive you to your clinic appointments or to the hospital if you should need urgent medical care.

**Returning to Work or School**

Your return to work or school will depend on the type of transplant you receive and how your recovery proceeds. For the first 100 days after your transplant you will not return to work or school (these are examples of public places referred to earlier). Patients receiving autologous transplants can expect to return to work on a part-time basis sometime after 100 days. Patients receiving an allogeneic transplant should not expect to return to work or school for up to a year. Although this is a general rule, remember that every patient is different and decisions are made by your doctor based on your physical condition and the work or school environment.
Reimmunizations

Since your immune system is so intensely affected by the transplant, it may no longer “remember” its previous exposures to childhood vaccinations. Therefore, you will be reimmunized with several of your “baby shots” one to two years after transplant. This will be discussed with you at your one-year post-transplant return visit. Arrangements can be made to have the vaccines given by your personal, or family doctor.

After your transplant you will not be able to receive a flu vaccine for a minimum of 6 months after transplant. But, it is very important that your family members and people that you are in close contact with receive the vaccine.

Diet

Loss of taste and appetite happens frequently following transplant. If you are having problems eating a diet adequate in calories and protein, talk with our dietitian.

After a transplant, eating a well balanced diet is important to help regain your strength and rebuild the normal tissues affected by chemotherapy. All patients are encouraged to practice good food safety guidelines. Autologous transplant patients do not have to follow a special diet after transplant.

Following an allogeneic transplant, you may initially need to follow a “strict low bacteria” diet often called a modified microbial diet or a neutropenic diet. Until your immune system is strong enough (approximately 100 days after transplant), it will be necessary to follow the general guidelines listed below.
General Food Guidelines after Transplant:

1. Use common sense in dealing with food.
   - Check expiration dates on perishable food.
   - Check for mold or insect contamination.
   - Do not keep leftovers longer than two days.
   - Discard questionable items.

2. Foods should be held at proper temperature.
   - Cold foods such as milk and dairy products, should be kept in the refrigerator.
   - Hot foods should be kept hot, not served at room temperature.
   - Portion food into individual servings in a tightly sealed container and cool in the refrigerator or freezer.
   - Thaw frozen foods appropriately either in the refrigerator, microwave on defrost, or by running cold water continuously over meal until thawed.
   - Do not thaw food at room temperature.

3. Avoid deli lunch meat or cheeses that are not pre-packaged.
4. Avoid smorgasbords and salad bars.
5. Discard leftovers after two days.
6. Well water should be processed through a filter or tested by the health department. (see appendix for safe water handling guidelines)
7. Fruits and vegetables must be washed thoroughly. Cut off bruised areas. Do not eat fresh strawberries, fresh raspberries, raw broccoli, raw cauliflower or sprouts. In general, it is best to avoid uncooked fruits or vegetables that cannot be peeled before eating. Frozen or canned berries are okay.
8. Avoid rare and medium-rare meats.
9. Avoid deli salads not prepared in the home.

10. Do not share eating or drinking utensils.

11. Avoid juices, honey and dairy products that are unpasteurized or gently pasteurized.

12. Until your appetite returns to normal, a daily multi-vitamin/mineral supplement is recommended. It is not necessary to take large doses of vitamins and minerals, as this may be dangerous as well as expensive. Select a simple, inexpensive, daily multi vitamin without iron, unless advised by your doctor.

Notify your doctor if you develop difficulties eating, swallowing or tolerating food.

**Hygiene**

Routine daily hygiene will continue to be important at home. Remember, frequent hand washing is your best protection against infection. The following are specific guidelines for daily care that will help prevent infections and assist your body in its recovery. Monitor these areas closely and notify your doctor if you notice changes or have concerns:

**Mouth care:** Continue the mouth care regimen that you practiced in the hospital. Continue your mouth care after meals and at bedtime. If you notice bleeding or if your platelet count is low, use a soft-bristle toothbrush (run hot water over your toothbrush). Notify your doctor if you notice sores, tenderness or other changes in your mouth or throat. Notify your doctor of plans for dental work. You should have a dental follow-up visit at six months after transplant.

**Skin care:** Continue good daily hygiene using a mild soap. You may notice your skin is drier than normal. If you use moisturizing lotions or creams they should not contain alcohol or perfumes. Your skin will be extremely sensitive to the sun. Always wear a hat and sunscreen with a minimal Sun Protective Factor
(SPF) of 30. Remember to wear a sunscreen on exposed areas, whenever you are outdoors (even if it’s not sunny).

Rectal care: This area will continue to be very sensitive and will require special attention. Keep this area very clean, cleanse after every bowel movement. Notify your doctor if you notice pain or tenderness when you have a bowel movement or other changes in this area. Do not use suppositories or enemas unless advised by your doctor.

Venous access devices: Continue to care for your venous access device and the dressing around or over it as you were instructed in the hospital. Observe the area around the catheter during dressing changes for redness, tenderness, drainage or changes in appearance. Notify your doctor if changes occur.

Cuts/bruises: Cleanse all cuts and scratches carefully with a mild soap and water. Keep them covered with a bandage until healed and notify your doctor if the area becomes reddened, tender, sore, develops drainage, or if you develop a fever. Increased bruising may indicate a decrease in your platelet count. If you notice bruises beginning to develop for no apparent reason, notify your doctor.

## Outpatient Transfusions

Until your bone marrow is fully recovered, you may need to receive red blood cell and/or platelet transfusions on an outpatient basis. After receiving a transplant you should receive only irradiated blood products.

Fever/chills or hives/itching are relatively common reactions to blood transfusions and may occur with the transfusion of blood products. These symptoms usually occur during or shortly after transfusion. On rare occasions, these symptoms may be noted several hours after the transfusion.

You will be given post-transfusion instructions regarding the signs and symptoms of a transfusion reaction. Notify your doctor immediately if these signs or symptoms occur following your transfusion.
When to Notify your Doctor

The following are general rules for notifying your doctor. If you are unsure of symptoms or have concerns about something, call your doctor. The transplant team remains available to you after your discharge for medical assistance or to answer questions. Call them at (734)936-9814.

Notify your doctor for the following:

- Fever (over 38°C; or 100.4° degrees Fahrenheit)
- New cough, shortness of breath
- Persistent headaches
- Blurred or double vision
- Bleeding (nosebleeds, blood in the stool or urine, vomiting blood, increased bruising or other bleeding)
- Pain during urination or bowel movements
- Reddened, swollen or painful areas
- New developments of diarrhea, constipation or vomiting
- Difficulty swallowing or development of mouth sores
- Changes in your venous access device or the area around it
- Fever/chill or hives/itching following a blood transfusion

Medications

Prescribed Medications

You probably will be discharged on several prescription medications. It is common to be discharged with supplements, such as potassium or magnesium that you will need for several days to a few weeks. Medications for nausea and vomiting may be needed until your appetite returns and you resume regular eating habits. You may also need to take oral antibiotics to prevent or treat infection. If you receive an allogeneic transplant, you will take an
immunosuppressive (such as steroids, Tacrolimus, Cyclosporin, Mycophenolate) for six months or longer if you develop graft versus host disease.

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. You may ask your pharmacy to deliver your medications or have a member of your family pick them up. Pharmacies (like hospitals) often are places where you may be exposed to infections.

“Over The Counter” Medications

Colds/Flu: You are susceptible to colds and flu for several months after discharge. At the first sign of the illness you should call your doctor.

If he or she suggests that you take an over-the-counter medication you should select a product with no aspirin. Aspirin can alter platelet function, which may cause bleeding. Products that contain acetaminophen or ibuprofen can mask a fever and should also be avoided unless discussed first with your doctor or clinic nurse.

Be sure to read the labels of all your medications or ask your pharmacist or doctor to suggest a product that does not contain aspirin. Products containing antihistamines and/or nasal decongestants are best to use for colds or flu. Do not use non-sedating antihistamines (Seldane, Hismanal) without talking to your doctor. Several medications taken after transplant may interact with these.

Avoid decongestant nasal sprays. These can be very irritating to the nasal tissues. Nasal sprays of this type are very short-acting and can do more harm than good.

A persistent cold or flu could be a sign that you may have a sinus or lung infection that requires an antibiotic. If your symptoms persist for more than four days, contact your doctor promptly. If you are feeling ill, remember to take your temperature frequently (several times a day and whenever you feel warm). Notify your doctor immediately if your temperature is above normal.
Pain: Minor aches and pains are normal after discharge. If your pain becomes worse or persists you should discuss it with your doctor. Pain may be a sign of infection.

If you need pain medication, choose one that does not contain aspirin or ibuprofen. Aspirin and ibuprofen products can alter your platelet function, you may be at a higher risk for bleeding.

You may take acetaminophen (Tylenol) for minor aches and pains if approved by your doctor. Acetaminophen can mask a fever and should be avoided unless discussed with your doctor or clinic nurse first. Many cold and flu products contain acetaminophen. Read your labels carefully.

Stomach Distress: Chemotherapy can cause damage to the mucosa of the mouth, esophagus, stomach and intestines that may take a few days to several weeks to completely heal. It is common for the nausea and vomiting to persist for some time after the transplant. You may need medication at home for nausea. Over-the-counter antacids can be quite effective in relieving the discomfort, but they should be used cautiously, especially if you are taking other oral medications. Because antacids “coat the stomach” they can prevent some medications from being absorbed. Therefore, they should be taken at least two hours before or after other medications. If you have specific questions about drug interactions with antacids and medications you are taking, discuss them with your pharmacist, doctor or nurse.

Antacids that contain aluminum may cause constipation. If you are having problems with diarrhea, this would be a good product to choose because it may help counteract the diarrhea.

Antacids that contain calcium or a combination of aluminum and magnesium may be less likely to cause either diarrhea or constipation. Examples of these are Maalox, Mylanta or Tums.
Milk of magnesia is an antacid that contains magnesium. It may cause diarrhea and should be avoided.

Liquid antacids usually are more effective and should be used if possible.

**Diarrhea:** Diarrhea is often a problem during hospitalization and may not resolve totally until you return home and resume your normal activities. There are products available over the counter that you may use at home that are effective for mild diarrhea.

Diarrhea (if new onset), or persistent diarrhea can be a sign of an infection, graft versus host disease or other problems. If you have severe diarrhea or diarrhea that does not subside, you should contact your doctor.

**Constipation:** Constipation is unusual after transplant but may occur in some patients. If it does occur it may be managed by increasing your physical activity or altering your food and fluid intake. If medication is recommended by your doctor, use a stool softener such as docusate (Colace or Surfak). Stool softeners do not act immediately and may take as long as three days to work. Drinking lots of fluids will help the stool softener work. Do not use rectal suppositories or enemas because they can cause rectal irritation and bleeding. Laxatives (Ex-Lax, Correctal, Dulcolax, Feen-a-mint) work by stimulating the intestine. Products like these should be avoided because they are very short acting and may be dangerous.
FAST FACTS

Fast Facts About: Bone Marrow Harvest

A bone marrow “harvest” procedure is performed in an operating room. The donor can be given general anesthesia so he or she is not awake and won’t feel anything during the procedure. Once in the operating room, the donor is positioned on their stomach. The doctors place needles into the hip bone (pelvis) and pull out the marrow with syringes. The needles are placed through the skin three to five times over each hip bone. For each time the needle goes through the skin there are many punctures into the bone. Once collected, the marrow is filtered and placed into blood bags. If an autologous transplant is to be done, the marrow is processed and stored frozen until later. If the marrow is donated for an allogeneic transplant, it is brought to the patient for transfusion soon after the harvesting is completed. When the marrow is donated from an unrelated donor, it is collected where the donor lives and brought by courier to the patient within hours of collection.

The entire harvesting procedure takes one to three hours. The patient/donor may receive a blood transfusion during the collection process to replace the blood removed with the bone marrow. Once completed, the patient/donor is taken to the recovery room with a large bandage across the hips that will remain in place for 24 hours. Discharge from the hospital is generally the same day. There is soreness from the harvesting, but pain medication is given as needed. Soreness can vary from person to person, but normal activity is usually resumed within three to four days and complete recovery occurs within approximately two weeks.
Fast Facts About: Peripheral Blood Stem Cell Apheresis

Apheresis is performed as an outpatient procedure and usually takes 3-4 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 blood bank 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 blood bank technologist of all medication taken)
• Do not take aspirin or other over-the-counter medications unless approved by a transplant doctor. (You may take Tylenol or Tylenol-Extra Strength)
• Empty your bladder

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

Location:

The apheresis procedure is performed in the UMHS Transfusion & Apheresis Services room. This is located on level 8 of the Children’s and Women’s Hospital

Questions?

If you have questions regarding your appointment, contact the Transfusion & Apheresis Services Program at (734) 936-6900.
Fast Facts About: Common Transplant Discharge Medications

Autologous Transplant

- ATIVAN / LORAZEPAM
- COMPAZINE / PROCHLORPERAZINE
- DIFLUCAN / FLUCONAZOLE
- NEUPOGEN / FILGRASTIM (most frequently utilized pre-transplant)
- PROTONIX / PANTOPRAZOLE

If your insurance does not cover this, one of the following may be substituted: PRILOSEC / OMEPRAZOLE or PREVACID / LANSOPRAZOLE

- ZOFRAN / ONDANSETRON
- ZOVIRAX / ACYCLOVIR

Allogeneic Transplant

- ACTIGALL / URSODIOL
- ATIVAN / LORAZEPAM
- CELLCEPT / MYCOPHENOLATE MOFETIL
- COMPAZINE / PROCHLORPERAZINE
- COUMADIN / WARFARIN
- DIFLUCAN / FLUCONAZOLE
- ENBREL / ETANERCEPT
- ENTORCORT EC / BUDESONIDE
- LEVAQUIN / LEVOFLOXACIN or VANTIN / CEPFODOXIME
- LOVENOX / ENOXAPARIN SODIUM
- MEDROL / METHYLprednisolone
- NEORAL / CYCLOSPORINE
- NEUPOGEN / FILGRASTIM (most frequently utilized pre-transplant)
- NORVASC / AMLODIPINE
- OXYCOTIN or OXY IR / OXYCODONE

Names in bold are the brand drug names
• **PROTONIX / PANTOPRAZOLE**
  If your insurance does not cover this, one of the following may be substituted: **PRILOSEC / OMEPRAZOLE** or **PREVACID / LANSOPRAZOLE**

• **PROGRAF / TACROLIMUS**

• **RAPAMUNE / SIROLIMUS**

• **RESTASIS Eye Drops / CYCLOSPORINE**

• **VALCYTE / VALGANCICLOVIR**

• **VFEND / VORICONAZOLE**

• **VITAMIN D3 / CHOLECALCIFEROL OR ERGOCALCIFEROL**

• **ZOFTRAN / ONDANSETRON**

• **ZOVIRAX / ACYCLOVIR**

**Fast Facts About: Developing a Caregiver Plan**

Securing a reliable caregiver plan is challenging for most patients and families, as family members and friends work and have other responsibilities. Often, a caregiver plan consists of a number of people who are available to assist at various times and with specific duties/needs. Below are examples of potential caregiver options that other patients/families have utilized.

A single option listed below may not be an adequate plan in itself, however combining a number of the options will often fulfill the need for a reliable caregiver plan.

**Caregiver Options Include:**

- A family member who utilizes FMLA time off from work
- A retired friend or family member who is available during the week when a spouse or significant other is at work
- A friend or family member who works part-time and is available to assist on their days off

*Caregivers do NOT need to have medical experience or training*
FAST FACTS

- A friend or family member who is available to reside with patient at home or in Ann Arbor for a specific period of time (i.e. 2 weeks when they are in town on vacation, a month in the summer when off work, during a leave from work)
- A friend or family member who is available weekdays, evenings, or weekends only — in conjunction with other friends/family who are available to cover the other times
- Private duty aides or caregivers available for an hourly fee (average $18-20/hour through various agencies). Patients either privately pay or have family/friends fundraise to pay for such services. The services are arranged by patients/families directly, and are rarely paid for by insurance companies.
- A friend or family member who is able to drive patient to clinic appointments partnering with another friend/family member who does not drive and is available to assist with home needs.
- A friend of a friend, co-worker, or family member of a friend
- Member(s) of a religious or community organization that the patient, family and/or friends are involved

Develop a Caregiving Calendar: Many patients/families find it helpful to utilize a blank calendar and to pencil in dates/times when caregivers are available, knowing dates and times can change according to patient recovery needs.

Have A Back-Up Plan for Emergencies: For patient safety, it is imperative to always have a back-up caregiver available should a primary caregiver become ill for a short period of time (i.e. with a cold or the flu).

Pediatric Patients: We recommend a plan that identifies a caregiver who will stay with pediatric patients during all hospitalizations and be present during all outpatient visits.
**Fast Facts About: Safe Drinking Water and Other Beverages for Immunocompromised Patients**

**Tap Water**

Do not drink well water from private wells or from public wells in communities with limited populations because tests for microbial contamination are performed too infrequently to detect sporadic bacterial contamination. However, drinking tap water from municipal wells serving highly populated areas is regarded as safe from bacterial contamination because the water is tested $\geq 2$ times/day for bacterial contamination.

Boiling water is the best method of killing Cryptosporidium and other waterborne pathogens. After the water has been boiled, it should be stored in the refrigerator in a clean bottle or pitcher with a lid. To prevent recontamination, be careful not to touch the inside of the water bottle or lid.

You should routinely monitor the mass media in your area to immediately implement any boil-water advisories that might be issued for immunocompromised persons by state or local governments. A boil-water advisory means that all tap water should be boiled for $\geq 1$ minute before it is consumed.

**Water Filters**

Water can be filtered to remove pathogens like Cryptosporidium oocysts and parasites like Giardia lamblia. Only filters labeled with an “absolute” (not “nominal”) pore size of one micron or smaller will remove all oocysts (viruses, however, can pass through a one-micron filter). The pore sizes used in reverse osmosis are too small for oocysts to pass through. These filters may be point-of-use and can treat your water to be used for drinking or preparing foods.
They may be either attached to a faucet or have a pour-through design.

To see if a certain filter can remove Cryptosporidium, you can contact NSF-International directly:

NSF International 1-800-673-8010 or 888-99-SAFER  
789 N. Dixboro Rd. 1-734-769-0109 (fax)  
Ann Arbor, MI 48113 Email: info@nsf.org  
Website: www.nsf.org/certified/DWTU

**Bottled Water**

Bottled water can be consumed if it has been processed by one of three processes: reverse osmosis, distillation, or 1 micron particulate absolute filtration. If the bottled water is tested and certified by NSF Standard 53 or NSF Standard 58 cyst removal/cyst reduction, this is also considered acceptable. To confirm that a specific bottled water has undergone one of these processes, you can contact the bottling company directly. Bottled water labeled “artesian well water”, “well water”, “spring water” or “mineral water” are not guaranteed that the water does not contain Cryptosporidium or other pathogens.

To verify that a specific bottled water brand has used one of the above processes, you can contact the International Bottled Water Association (IBWA) at 1-800-928-3711. You may also visit their website at www.bottlewater.org. If IBWA does not have the information you are looking for, contact the bottling company directly.

**Other Precautions**

Avoid fountain beverages and ice made from tap water at restaurants, bars, and theaters. This may include soda, juice, iced tea, or lemonade. Do not drink unpasteurized milk, fruit, or vegetable juices.
Safe drink choices would 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 (>175 F) tea or coffee; juices labeled as pasteurized; and nationally distributed brands of frozen fruit juice concentrate that are reconstituted with water from a safe source.

Fast Facts About: Food Safety after Autologous Transplant

Why are these guidelines important?

After transplant, your immune system still needs time to get stronger. A weaker immune system makes it difficult to fight off infection. Your risk is highest 1 to 6 months after transplantation. Food can cause an infection if proper food safety guidelines are not followed. The Food and Drug Administration has published these guidelines to keep everyone healthy, including those who have just had an autologous stem cell transplant, so they can be used for the whole family.

Safe Food at the Store

- Buy cans and jars that look perfect
  Dented or bulging cans, cracked jars, unsealed lids may mean food has germs that could make you sick
- Check for “use buy” dates — DO NOT USE IF THE DATE HAS PASSED
- Put refrigerated or frozen items in cart last and take home immediately
- Put raw meat and poultry into a plastic bag so meat juices won’t drip on other foods such as lettuce or fruit that will be eaten raw.
- Check eggs — open carton and do not buy if any are broken or cracked. Only buy refrigerated, pasteurized eggs
• Buy only pasteurized milk, cheese, juice and cider. Do not buy “gently pasteurized” juices. If the label does not say “pasteurized,” don’t buy it!

  • Be sure food is being stored at safe temperatures — hot food is steaming and cold food is cold
  • Make sure person behind the deli counter changes gloves
  • It is recommended to heat luncheon meats before consumption

**Quick Tips**

1. Drink & brush teeth from safe water supplies – NO well water, unless you boil it 1-2 minutes first and then cool.
2. Wash hands frequently when working with food
3. Do not eat raw or undercooked meats & eggs

**Storing Food Safely at Home**

• After shopping — go directly home and put food away immediately

• Refrigerator
  
  • Use a thermometer to ensure food is being kept at 40° F or below
  
  • Make sure thawing juices from meat and poultry do not drip on other foods
  
  • Leave eggs in carton and do not store in door
  
  • Keep refrigerator clean
  
  • Cook or freeze ground meat, poultry and fish with 2 days; other meats such as steaks or roasts made of beef or pork, within 3-5 days

• Freezer: Use a thermometer to ensure food is being kept at 0° F or below
Cooking/Preparing Food Safely

- Make sure that you and your kitchen are clean
- Always wash your hands for at least 20 seconds before and after you touch food.

- Cutting boards
  - Use only plastic or glass for cutting raw meat and poultry or have a cutting board you use exclusively for meat and poultry
  - Sanitize with solution of 1 tsp. chlorine bleach per quart of water by flooding surface and allowing it to stand for several minutes, then rinse and dry
  - Wash cutting board with hot, soapy water before using it to cut fresh fruits and vegetables.

- You are allowed fresh fruits and vegetables but they need to be clean. Rinse them under clean running water to wash dirt & germs away. Use a produce brush to scrub potatoes and carrots. Cut away bruised or damaged areas.
- Clean dish towels in hot water in the washing machine or use paper towels and throw them away.
- Thaw meat, poultry and seafood:
  - In the refrigerator — 1 to 2 days before you will cook
  - In the microwave — use the defrost setting
- Cook eggs until firm, not runny. Cook poultry to 180° (no red juices). Cook fish until white & flaky. Cook ground meat to 160° or until it is brown inside (no pink).
- Put leftovers in the refrigerator or freezer as soon as you finish eating. Put them in shallow dishes so they cool faster. Use refrigerated leftovers within 4 days
• Do not leave foods out more than 2 hours unless on a heat source or on ice if the air temperature is < 90°. If it is >90° where you are eating, put food away after 1 hour.

Eating Out Safely

• **Always order meat, poultry, and fish well done;** if the food arrives undercooked, it should be sent back.

• Ask how sauces and dressing are prepared; if raw or undercooked eggs or insufficiently cooked meat drippings are used, do not order those dishes. If the server does not know how the food is prepared, ask him or her to check with the kitchen. If still doubtful, order something else.

• **Be careful at salad bars** – others may have left germs behind; avoid wilted, brown or bruised fruits and veggies.

• Avoid some buffets. If dirty plates are used for second helping, avoid. If holding temperatures are questionable, avoid (is the hot food hot?). Avoid high-risk foods from buffets (e.g., undercooked eggs, rare or med. rare beef).

• At fast food restaurants, ask for food to be prepared freshly

• **Do not eat raw seafood** including oysters on the half shell, raw clams, sushi and sashimi; lightly steamed seafood, such as mussels and snails, should be avoided.

• Avoid homemade Caesar salad dressing if it contains raw eggs (ask your server).
<table>
<thead>
<tr>
<th>Type of Food</th>
<th>It’s okay to Eat: Low Risk Foods</th>
<th>Don't Eat: High Risk Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bread, grains, and cereals</td>
<td>All bread products that are not raw including muffins, pancakes, French toast, rolls, potato chips, corn chips, pretzels, popcorn, all hot and cold cereals that are ready-to-eat, cooked grain/pasta/rice dishes</td>
<td>Raw (not baked or cooked) grains products such as raw oats</td>
</tr>
<tr>
<td>Meat, Meat Substitutes, and Poultry</td>
<td>All meats and poultry cooked until they are well-done, canned meats (heated to steaming), commercially packaged luncheon meats and hot dogs that are cooked until steaming, pasteurized and cooked tofu, canned or shelf-stable pâtés or meat spreads</td>
<td>Raw or undercooked meats, poultry, hard cured salami in natural wrap, meats or cold cuts from delicatessens. Avoid undercooked tofu or tempeh products. Do not eat refrigerated pâtés or meat spreads, unheated hot dogs or luncheon meats.</td>
</tr>
</tbody>
</table>
| Seafood                      | All well-cooked seafood products, canned fish such as tuna and crab, canned and shelf-stable smoked seafood (refrigerate after opening), refrigerated smoked seafood if cooked to > 160 F or contained in cooked dish | Raw or undercooked fish including sushi, sashimi, and ceviche, refrigerated smoked/pickled fish, raw oysters, refrigerated smoked seafood - *unless it’s in a cooked dish*, such as a casserole. (Refrigerated smoked seafood is most often labeled as “nova-style,” “lox,” “kippered,” “smoked,” or “jerky”)}
<table>
<thead>
<tr>
<th>Type of Food</th>
<th>It’s okay to Eat: Low Risk Foods</th>
<th>Don't Eat: High Risk Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dairy</td>
<td>All <em>pasteurized</em> grade “A” milk products including yogurt, ice cream, processed cheese, cream cheese, cottage cheese, eggnog, pasteurized whipped topping, soft cheese that have been cooked, <em>homemade</em> milkshakes, sherbet, commercial nutrition supplements containing dairy and are pasteurized</td>
<td>Unpasteurized or raw milk or foods containing unpasteurized dairy, cheese, yogurt, or other milk products. Avoid soft and/or moldy cheeses like feta, brie, blue-veined (Blue, Roquefort, Stilton, Gorgonzola), queso fresco, camembert <em>unless it is made with pasteurized milk</em>, cheese containing chili peppers or other uncooked vegetables, milkshakes outside the home</td>
</tr>
<tr>
<td>Eggs</td>
<td>Well cooked, firm eggs, pasteurized egg substitutes cooked until they are well done</td>
<td>Raw or undercooked “runny” eggs</td>
</tr>
<tr>
<td>Vegetables</td>
<td>Well washed raw and frozen vegetables, all cooked fresh/frozen/canned vegetables, fresh herbs and spices if washed well, canned shelf-stable salsa that is refrigerated after opening</td>
<td>Unwashed raw vegetables or herbs, non-pasteurized vegetable juices, all raw vegetable sprouts (alfalfa, mung bean, clover, etc), salads from deli or buffets, fresh salsa in fresh produce section</td>
</tr>
<tr>
<td>Fruits</td>
<td>Well washed raw and frozen fruits, all cooked fresh/frozen/canned fruits, fresh or frozen juices that have been pasteurized (flash pasteurizing included), dried fruits</td>
<td>Unwashed raw fruits, fresh berries, spoiled fruits, non-pasteurized fresh or frozen juices, fresh fruit salsa found in produce section</td>
</tr>
<tr>
<td>Type of Food</td>
<td>It’s okay to Eat: Low Risk Foods</td>
<td>Don't Eat: High Risk Foods</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Nuts</td>
<td>Canned and bottled roasted nuts not in the shell, commercially packaged nut butters (cashew, sunflower, peanut, almond, etc), nuts baked into food products</td>
<td>Unroasted raw nuts, roasted nuts in their shell</td>
</tr>
<tr>
<td>Fats</td>
<td>Refrigerated butter/lard/margarine, cooked gravies and sauces, vegetable oils and shortenings, commercial/shelf stable mayonnaise and other salad dressings including blue cheese and creaser (refrigerate after opening)</td>
<td>Fresh salad dressing (sold in grocery produce section) containing raw eggs or cheese</td>
</tr>
<tr>
<td>Soups</td>
<td>All cooked soups</td>
<td>All miso products</td>
</tr>
<tr>
<td>Dessert</td>
<td>Refrigerated commercial and homemade cakes/pies/pastries/pudding, refrigerated cream-filled pastries, cookies, shelf-stable cream-filled desserts (twinkies®, ding-dong®, poptarts®, etc), commercially prepared pudding/jello, ices, popsicles, ice cream, candy, gum</td>
<td>Unrefrigerated cream-filled pastry products (not shelf stable)</td>
</tr>
<tr>
<td>Type of Food</td>
<td>It's okay to Eat: Low Risk Foods</td>
<td>Don't Eat: High Risk Foods</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Beverages</td>
<td>Boiled water, tap water, ice made from tap water, commercially-bottled water that utilizes reverse osmosis or distillation, commercially prepared or instant herbal teas and coffee brewed made from a safe water source, commercial nutrition supplement drinks that have been pasteurized, pasteurized juices/vegetable/milk products, commercially sterile ready-to-feed infant and tube feed formulas</td>
<td>Unboiled well water, cold brew tea NOT made with boiling water, non-pasteurized fruit and vegetable juices, mate tea, unpasteurized alcoholic beverages (NOTE: All alcoholic beverages should only be consumed with physician approval)</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>Commercially pasteurized Grade A honey, salt, granulated and brown sugar, jam, jelly, syrups, condiments, pickles, relish, olives (refrigerate after opening), vinegars</td>
<td>Raw honey, honey in the comb, herbal and nutrition supplements not approved by your physician, uncooked brewers yeast</td>
</tr>
</tbody>
</table>

**Discharge Nutrition Guidelines after Allogeneic Transplant**

Following discharge from the hospital after a matched related or unrelated transplant, you will need to continue to follow an immunosuppressed diet until Day 100 to reduce your risk of developing a food-related infection. If you need to stay on immunosuppressive medications, i.e. steroids, Tacrolimus, Cyclosporine, for longer than 100 days, your doctor will let you know if you need to also continue these nutrition guidelines.
Follow these guidelines for good food safety:

- Never leave perishable food out of the refrigerator for more than 2 hours.
- Leftovers should be placed into shallow containers for rapid cooling and placed directly into the refrigerator or freezer.
- Leftovers should be thrown out after 4 days.
- Keep food at safe temperatures; cook hot foods to a minimum internal temperature of 165°F and keep cold foods below 40°F.
- Luncheon meats and hot dogs must be pre-sealed and heated to steaming or > 165°F
- Thaw foods in the refrigerator, microwave, or under running water; not on the counter top. Use defrosted foods right away, do not refreeze.
- Keep kitchen surfaces clean and sanitized. Change dishtowels daily.
- Wash hands after handling raw meat or poultry.
- Do not allow cooked food to come in contact with raw products. Use separate cutting boards for meats and vegetables.
- Never taste food that looks or smells abnormal.
- Wash the tops of canned foods or beverages before opening.
- Cook eggs until whites are firm and yolk has thickened.
- Check expiration dates on perishable items. Do not consume if the product has expired.
- You may have fresh fruits and vegetables but they need to be washed thoroughly under running water. Cut off any bruised areas. Check for mold, bruising, or insect contamination.
Cooking/Preparing Food Safely

- Make sure that you and your kitchen are clean
- Always wash your hands for at least 20 seconds before and after you touch food.
- Cutting boards
  - Use only plastic or glass for cutting raw meat and poultry or have a cutting board you use exclusively for meat and poultry
  - Sanitize with solution of 1 tsp. chlorine bleach per quart of water by flooding surface and allowing it to stand for several minutes, then rinse and dry
- Clean dish towels in hot water in the washing machine or use paper towels and throw them away.
- Thaw meat, poultry and seafood:
  - In the refrigerator — 1 to 2 days before you will cook
  - In the microwave — use the defrost setting
- Cook eggs until firm, not runny. Cook poultry to 180° (no red juices). Cook fish until white & flaky. Cook ground meat to 160° or until it is brown inside (no pink).
Frequently Asked Questions

**Q: How long will I need to follow this diet?**

**A:** Patients who have received an Allogeneic transplant (from a someone related or unrelated) should follow these guidelines for at least 100 days after transplant. If patients stay on immunosuppressive agents (ie: Tacrolimus, Medrol, Cellcept, Cyclosporine) longer than this, they may need to continue this diet. They will be advised by their BMT doctor and/or nutritionist.

**Q: Can I eat raw fruits and vegetables now?**

**A:** It is okay to eat raw fruits and vegetables after you are discharged from the hospital. These foods should be cleaned thoroughly under running water and bruises or bad spots should be removed. Fruits and vegetables that cannot be cleaned well should not be eaten raw. Examples of these foods would include broccoli, cauliflower, alfalfa sprouts, bean sprouts, raspberries, or strawberries.

**Q: Should I use soap or a cleaning detergent to clean my produce?**

**A:** It is best not to use soap or cleaning detergents on produce. This is because these products can linger on foods and are not considered safe from consumption. Actually, using clean running water is your best way to wash produce safety.

**Q: Can I use pepper and other dried seasonings?**

**A:** Pepper and other dried herbs may be added to foods that are going to be baked, or heated to a steaming temperature in the microwave. You should not add pepper to foods that have already been heated, or will be eaten raw.
Q: Can I eat in restaurants?

A: It is okay to eat food that is hot, freshly prepared and fully cooked. Uncooked or stir-fried fruits, vegetables, and salads should be avoided. Avoid salad bars, smorgasbords, and potlucks since these foods are often left at improper holding temperatures and are served to many people. Ask that food be prepared fresh, and order food without toppings or condiments (lettuce, tomato, mayonnaise). You can add your own condiments with individual shelf-stable packets. Meats and fish must be cooked thoroughly. Do not eat raw seafood including oysters, sushi, sashimi, lightly steamed seafood like mussels, clams, and snails.

Q: What about holidays or banquets, can I eat what everyone else is eating?

A: If you are having a family style dinner, ask to be first in line so that food will be at the proper temperature. If you go back for seconds, food should be heated to a steaming temperature in the microwave. Do not eat foods that have been sitting out for more than 1 hour.

Q: My muscles feel very weak and I don’t have a lot of energy, how can I feel stronger?

A: You may have lost some muscle mass during your hospitalization. Eating enough protein is important to restore lean body mass and avoid fluid retention. Try eating more of these foods: beef, poultry, fish, cheese, eggs, dairy products, peanut butter, and beans. If you do not have an appetite for these foods following transplant, ask your Registered Dietitian for some high protein drink recipes and samples.
Q: Do I need to use bottled water?

A: City water is safe for drinking. However, if you have a well, you will need to find an alternate source of water. You should not use well water for drinking, brushing your teeth, making ice cubes, or making juices from concentrate. If you need to use well water for any of these activities, it should be boiled at a roiling boil for at least 1 minute. Otherwise, you can purchase bottled water. When selecting a bottled water, it is suggested that you select a water that has been purified through distillation, or reverse osmosis or water that has been National Sanitation Foundation (NSF) certified. There is much variation in the source of origin, the types of microorganisms, and the treatment of water before it is bottled. Bottled water can vary considerably among brands of water and the companies that make them. Some examples of certified safe bottled water brands are: Aquafina, Ice Mountain, Zephyr Hills, Poland Spring, Calistoga, Arrowhead, and Aberfoyle.

For further information on bottled water, contact:

The National Sanitation Foundation (NSF)
Phone: 1-800-NSF-8010 / Web Site: http://www.nsf.org

The International Bottled Water Association (IBWA)
Phone: 1-800-WATER11/ Web Site: http://www.bottledwater.org
Q: How do I know if I am drinking enough fluid?

A: It is very important to take in enough fluids to prevent dehydration. Anything that is caffeine free and liquid at room temperature can be counted towards meeting your fluid goal. Remember: 240 ml = 1 cup = 8 ounces. Here are some examples of common fluids:

<table>
<thead>
<tr>
<th></th>
<th>Cups</th>
<th>Milliliters</th>
<th>Ounces</th>
</tr>
</thead>
<tbody>
<tr>
<td>Popsicle</td>
<td>½</td>
<td>120</td>
<td>4</td>
</tr>
<tr>
<td>Milk Carton</td>
<td>1</td>
<td>240</td>
<td>8</td>
</tr>
<tr>
<td>Ensure/Boost Can</td>
<td>1</td>
<td>240</td>
<td>8</td>
</tr>
<tr>
<td>Jello</td>
<td>½</td>
<td>120</td>
<td>4</td>
</tr>
</tbody>
</table>
Frequently Asked Questions

Employment

1. Am I eligible for paid time off from my job? If so, for how long?
   If eligible, you would likely first exhaust any unused sick and/or vacation time. Your employer's Human Resource (HR) representative will be able to provide this information; along with how long your position will be held and what pay rate you will be offered while receiving both short and/or long term disability. If you are paid only a portion of your income, you may want to consider applying for Social Security Disability (see Social Security section).

2. What if I am ineligible for paid time off from my job (i.e. self-employed)?
   You may be eligible to apply for Social Security Disability and/or Medicaid (see corresponding sections for detail).

3. When can I return to work?
   Most autologous transplant patients are able to return to work 100 days after transplant.
   Most allogeneic (donor) transplant patients are able to return to work 1 year after transplant. Speak to your BMT doctor should you have specific concerns regarding above time frames. Depending on your recovery and the type of work you will be returning to, you may be eligible to discuss options of returning on a part-time basis or to work from home sooner.
Disability

1. Am I eligible for short-term and/or long-term disability through my employer?

Your employer’s Human Resource (HR) representative will be able to provide this information; along with how long your position will be held and what pay rate you will be offered while receiving both short and/or long term disability. You will also want to inquire regarding health insurance coverage options while collecting short and/or long-term disability.

2. Should I apply for Social Security Disability (SSD)?

Please see “Social Security” section for information.

Social Security

1. Should I apply for Social Security Disability (SSD) / Supplemental Security Income (SSI)?

If you are undergoing an allogeneic transplant, you will meet 12 month disability criteria for SSD/SSI. The choice of if/when to apply is a personal decision based on whether or not you are in need of the income. For example, if your employer is maintaining your full income, or most of it, you may want to defer applying for SSD/SSI, which offers approximately 60-65% of your regular income.

If you are undergoing an autologous transplant, whether or not you meet 12 month disability criteria for SSD/SSI will depend on your disease process and anticipated recovery. As a result, the
application process can include a 5-month waiting period, which can further be discussed with a SSA representative.

2. **How do I go about initiating the social security application process?**

By contacting the Social Security Administration (SSA) on-line at www.ssa.gov, calling 800-772-1213, or by visiting your local SSA office. Your social security representative will eventually require medical documentation from UMHS, at which time you can make the request at a clinic visit with BMT medical staff. Please note: Information will likely be unavailable the day of request so you will want to provide advance notice.

3. **If I am approved for SSD, will I lose my medical insurance?**

No, SSD is income — completely separate from insurance.

4. **Is it true that I may be eligible for Medicare prior to the age of 65 if I am on SSD?**

See Medicare section for detail.

**Caregiver Needs**

1. **Will I need a full-time caregiver?**

   Autologous transplant patients — yes, for a minimum of 30 days post-transplant. Beyond that will be determined by your transplant doctor based on your medical status.

   Allogeneic (donor) transplant patients — yes, for a minimum of 100 days post-transplant. Beyond that will be determined by your transplant doctor based on your medical status.
2. **Does my caregiver need medical experience?**

   Most caregivers do not have medical experience. Patients and caregivers will be provided a brief training by one of the BMT nurses at the time of hospital discharge.

3. **If my caregiver is required to be with me 24/7, does that mean he/she is unable to take breaks?**

   Absolutely not. In fact, we encourage breaks for self-care. That said, we ask that no patient recovering from an allogeneic stem cell transplant is left alone for longer than a 4 hour block of time due to infection and other risks.

4. **Why am I required to have at least 2 caregivers?**

   Just as it is important for our patient’s to maintain self-care, we require the same of caregivers. By having one or more back-up caregiver(s), the primary person is allowed respite. Also, a back-up is necessary if the primary caregiver becomes ill.

---

**Lodging**

1. **Will I be able to return home after transplant?**

   If you are having an autologous transplant, barring any unexpected complications, you will be able to return home immediately following your hospital discharge. If you are having an allogeneic (donor) transplant and live within 1.5 hours of UMHS, barring any unexpected complications, you will be able to return home immediately following your hospital discharge.

   If you are having an allogeneic (donor) transplant AND reside more than 1.5 hours from UMHS, you will be required to secure temporary lodging within 1 hour of UMHS for a minimum of 100 days post-transplant (approximately 2 months after your hospital discharge).
2. **How do I go about finding Ann Arbor lodging?**

Patients/families are able to stay wherever they are comfortable, as long as the residence meets post-transplant criteria (i.e. within an hour of UMHS, free of new construction or renovations, etc.). Social work has included lists of “Extended Stay Hotels” and “Local Apartments” in this booklet for your reference. These are locations that other transplant patients/families have stayed. All are within a short distance of UMHS and offer flexible leasing options (i.e. month to month, flexibility of occupancy dates, etc.). If you wish to secure other options, you may consider talking with family/friends that live in the Ann Arbor area - or know of someone who does, church groups who may offer a host house, etc.

3. **How will I afford lodging expenses in addition to my regular living expenses?**

Potential options are listed below:

- **Medicaid** — pays $41.25/day toward lodging expenses when patient is present (approximately $1,200/month). Contact social work to fill out necessary paperwork to make the request.

- **National Marrow Donor Program (NMDP)** — once you have undergone an UNRELATED donor transplant, your social worker can apply for potential financial assistance of $200-$400 for up to 6 months.

- **Fundraising** — encourage family/friends to plan a spaghetti or fish dinner at work/church/a hall, take up a money collection, or hold a car wash/raffle/auction/golf-outing/bowl-a-thon to raise monies to be utilized toward temporary lodging expenses.
• **Private Insurance** — check with your insurance representative to see if you are eligible for a lodging/food stipend.

• **BMT Social Work** — Social Work is sometimes able to provide gift funds for a lodging stipend, based on individual financial need and depending on availability of donations.

### Insurance

1. **How do I know if my transplant is covered by my medical insurance?**

   The BMT billing and insurance specialist will contact you if there are issues with coverage prior to medical staff moving forward with your transplant care. However, if you have transplant specific coverage questions, you may contact her directly at 734-936-7804. If your questions are not transplant specific, contact your insurance company at the number on the back of your insurance card.

2. **What potential options do I have if I lose my medical insurance?**

   • **COBRA** — health plan sponsored by employers with 20 or more employees for a temporary extension of health coverage

   • **Medicaid** - a state funded insurance program for individuals who meet specific income/asset and disability criteria

   • **Medicare** - a federally funded insurance program for individuals who meet specific disability/disease and/or age requirements

   • **Purchasing a private plan** — privately paying for an individual vs. group plan
COBRA

1. **In what instance would I elect COBRA?**
   To maintain the insurance coverage you once had through your employer, continuing at a group rate, by paying the full monthly premium amount.

2. **How would I know about my eligibility and the associated costs?**
   Speak to your employer Human Resource (HR) representative for details.

Medicare

1. **Is it true I may be eligible for Medicare prior to the age of 65 if I am on Social Security Disability (SSD)?**
   Yes, SSD recipients under the age of 65 years become eligible for Medicare after 24 months of receiving SSD payments. You will receive a letter from the Social Security Administration to notify you of your upcoming Medicare eligibility.

2. **Where can I go for assistance with choosing a Medicare Part D plan?**
   Utilizing your current list of medications, you can contact 800-803-7174 and speak with a representative for assistance or visit www.medicare.gov. When selecting a plan, please keep in mind it is more important to find a plan that covers your most expensive medications vs. one that covers the most medications (i.e. choosing a plan that covers Cellcept, a costly medication, even though it does not cover Acyclovir, often a very affordable medication).

   **IMPORTANT NOTE:** if you choose to opt out of enrolling in a Part D plan once you become eligible, you will be charged a higher premium when you do enroll (a penalty of 1% of the national...
premium average for each month you are eligible for coverage, i.e. approximately $32/month additional). The only exception is if you have “creditable” (as good as or better than Medicare) coverage at the time you were eligible to enroll. Please contact Medicare with further questions at number/website above.

Medicaid

1. Should I apply for Medicaid?
   If you are anticipated to be disabled/unable to work any job for a 12 month duration (as are ALL allogeneic/donor transplant patients) AND you have $2K or less (single individual) or $3K or less (married) in all liquid assets (checking, savings, IRA’s, etc.) you may qualify for Medicaid assistance. If you are not anticipated to be disabled/unable to work any job for 12-month duration, you can contact your county Department of Human Services (DHS) office to inquire regarding other potential options for coverage (i.e. for those who have minor children under the age of 18 residing in the home).

2. Where do I apply for Medicaid?
   At your local Department of Human Services (DHS) office, on-line at www.michigan.gov, or via an application obtained from the UMHS Guest Assistance Program (GAP) office (800-888-9825).

3. How long will my Medicaid application take to process?
   Applications can take up to 90 days to process, however if approved will offer retroactive coverage for 90 days prior to the date the application was submitted.

4. If I am approved for Medicaid, will I lose my private and/or Medicare insurance?
   No, your private and/or Medicare policy coverage will remain and Medicaid will act as secondary coverage for the costs not covered by your primary insurance(s).
5. If I am approved for Medicaid, will I also be approved for cash and/or food assistance?

Not necessarily. If you are newly applying for Medicaid, you can include such requests in your initial application. If you are already a Medicaid recipient, you will need to contact your DHS worker to inquire regarding eligibility.

6. Will I be denied Medicaid based on my monthly income even if I meet all other criteria?

Not necessarily. You may qualify for Medicaid after meeting an assigned deductible each month. The DHS caseworker determines such eligibility and calculates the deductible amount.

7. What is covered by Medicaid?

If you do have a primary insurance, Medicaid will cover most medical and prescription charges not covered by your primary insurance. If you do not have a primary insurance, Medicaid will cover most medical and prescription charges.

8. What if I am uninsured and denied Medicaid?

You may be eligible for M-Support through UMHS. Please contact Linda Zywicki, Cancer Center financial counselor, to be screened for eligibility at 734-647-5120.

Prescriptions

1. What if I do not have prescription coverage?

Patients with limited or no prescription coverage may apply for potential assistance through various drug companies. Please contact the UMHS Guest Assistance Program (GAP) office for assistance at 800-888-9825 or visit www.needymeds.com to obtain applications.
2. Are there any resources available to assist with prescription expenses?

In addition to the above, patients are sometimes eligible to apply for discount cards and/or reimbursement through community agencies (see “Community Assistance Organizations” sheet). You may also talk with family/friends regarding fundraising options, and/or speak with your social worker about placing the charges on your hospital bill/setting up a monthly/interest-free payment plan.

3. Where can I go for assistance with choosing a Medicare Part D plan?

See “Part D” under Medicare section.
Glossary

**Absolute Neutrophil Count (ANC) also called “absolute granulocyte count”** – amount of white blood cells present in the blood that are able to fight infection.

**Allogeneic Transplant** – a transplant using a human donor who has bone marrow that is a genetic match to the recipient.

**Antibiotics** – a group of medicines used to prevent or treat infections.

**Antibody** – a protein that helps the body fight foreign substances (antigens) in the body, such as bacteria, fungi and viruses.

**Antigens** – a foreign substance that stimulates the formation of antibodies in the body.

**Apheresis** – a blood-separating procedure in which blood is removed from a patient, sent through a special machine (where cells are separated and some are removed) and the remainder are returned to the patient.

**Aplastic Anemia** – a blood disorder in which the bone marrow is deficient in producing red blood cells, white blood cells and platelets.

**Aspiration (of marrow)** – the removal of marrow from the cavities in large bones by suction through a needle.

**Autologous Transplant** – a transplant in which a patient’s own blood stem cells are collected, frozen and then returned to the patient at a later date.

**Blood Cells** – cells formed in the bone marrow that make up blood.
**Red Blood Cells (erythrocytes; RBCs)** – cells that carry oxygen throughout the body (measured by the hematocrit or HCT)

**White Blood Cells** – cells that help the body fight foreign substances; Neutrophils (ANC) are the front line of defense against infections. Neutrophils are the main infection fighting cell in our body.

**Platelets** – cells that help form clots. This can stop or prevent bleeding.

**Bone Marrow Harvest** – a procedure in which bone marrow is taken from the pelvic bone (hip area) for use in a transplant.

**Bone Marrow Transplant** – a process in which a patient’s bone marrow is destroyed by chemotherapy and/or radiation therapy and then replaced by previously harvested stem cells from a donor or the patient.

**Central Line Catheter** – semi-permanent intravenous catheter that is inserted into the large blood vessels that enter into the heart. It can stay in you for many weeks — months often.

**Chemotherapy** – drugs used to treat cancer, either by destroying abnormal (cancer) cells or by slowing their growth.

**Complete Blood Count** – a blood test that determines the number of red blood cells, white blood cells and platelets in the blood.

**Conditioning** – a combination of chemotherapy drugs, and sometimes radiation, given a few days prior to transplant to eliminate cancer cells and destroy the immune system.

**Cytomegalovirus** – a virus that can cause flu-like symptoms in patients with normal immunity, and more severe problems (lung infections, liver problems and intestinal problems) in patients with suppressed immune systems.
DMSO – a preservative used in the freezing of marrow and blood stem cells.

Engraftment – growth of transplanted (donor) stem cells in the patient’s (recipient’s) marrow spaces.

Granulocyte – one of the major groups of white blood cells. Includes three types of cells: neutrophils (segs and bands), eosinophils and basophils.

Graft – the infused or transplanted bone marrow and blood stem cells.

Growth Factor (Colony Stimulating Factor) – an injectable drug used to stimulate the development of blood cells (Leukine, Neupogen, Filgrastim, Mozobil).

Harvesting – term used for the collection of stem cells from the bone marrow or peripheral blood.

Hematology – a division of medicine that studies and treats diseases of the blood and blood-forming tissues.

Herpes Simplex – a virus that can produce small, painful, fluid-filled blisters on the skin and mucous membranes. Very common in transplant patients.

Herpes Zoster – a virus that can produce shingles (painful skin eruptions that follow the underlying nerve routes inflamed by the virus)

Hemorrhage – a general term for a large loss of blood brought about by injury to blood vessels or by a lack of necessary cells (platelets) to clot blood.

Hyperalimentation – see Total Parenteral Nutrition (TPN).

Immunoglobulin – proteins made by the body that attack infections. They are usually given intravenously, but in rare cases may be given orally.

Immunosuppression – a state of decreased immunity or a lowering of the body’s immune response. This can occur after receiving chemotherapy.
Intravenous – within or through a vein.

Irradiation – high-energy rays used to kill cells before or during transplant.

Leukocytes – a general term for all the types of white blood cells.

Lymphocytes – a type of white blood cell. B-lymphocytes make antibodies against bacteria. T-lymphocytes attack virus infected cells directly.

Lymph Node – a gland in the body that produces lymph (the clear fluid that circulates through the body and contains white blood cells and antibodies).

Lymphoma – cancer of the lymph nodes

Malignant – cancerous; abnormal growth of cells.

Microbial – minute forms of life such as bacteria, fungi, or viruses.

Mucositis – inflammation of the mucous membranes in the lining of the mouth

Neutropenia – a lack of neutrophils

Neutrophil – a type of white blood cells that fights bacteria (also called segs and bands).

Oncology – the study of treatment of cancer

Platelets – blood cells that promote blood clotting

Peripheral Blood Stem Cell Harvest – a procedure in which stem cells are collected from the circulating blood for use in a transplant.

Petechiae – small red spots under the skin caused by a low platelet count

Protocol – a precisely timed and organized approach to treatment of disease

Relapse – the reappearance of a disease after a period of remission
Remission – the decrease or disappearance of a disease and its symptoms

Stem Cells – parent or seed cells in the bone marrow or peripheral blood that produce blood cells.

Syngeneic Transplant – transplant in which the donor is an identical twin.

Transfusion – the infusion of a product derived from blood cells.

Total Parenteral Nutrition – intravenous feeding consisting of IV fluids high in calories and essential nutrients.

Titer – a blood test that assesses the levels of antibodies against various germs, such as bacteria or viruses.
Community Assistance Organizations

The following information may help patients and families experiencing financial stress, as well as when seeking information or support regarding a diagnosis or transplant issue. Each organization provides assistance for both children and adults with blood disorders. Applications are available through the Cancer Center Patient Education Resource Center (PERC) on Level B2, directly from the agency, or from the transplant social worker.

<table>
<thead>
<tr>
<th>Agency Name/Location</th>
<th>Contact Information</th>
<th>Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children’s Leukemia Foundation (CLF)</strong></td>
<td>Local: 248-530-3000</td>
<td>• up to $1,000/yr for patient/caregiver travel, Rx’s, head coverings, etc.</td>
</tr>
<tr>
<td><a href="http://www.leukemia.foundation.org">www.leukemia.foundation.org</a></td>
<td>Toll Free: 800-825-2536</td>
<td>• a separate/one-time maximum of $500 special needs assistance can also be requested (for insurance premium assistance, etc.)</td>
</tr>
<tr>
<td></td>
<td>Fax: 248-530-3042</td>
<td></td>
</tr>
<tr>
<td><strong>Leukemia &amp; Lymphoma Society (LLS)</strong></td>
<td>Local: 248-582-2900</td>
<td>• $150/yr for misc. assistance (i.e. insurance, gas, prescriptions)</td>
</tr>
<tr>
<td><a href="http://www.lls.org">www.lls.org</a></td>
<td>Toll Free: 800-456-5413</td>
<td>• application must be signed by a doctor &amp; original copy submitted</td>
</tr>
<tr>
<td></td>
<td>Fax: 248-581-3901</td>
<td></td>
</tr>
<tr>
<td><strong>National Marrow Donor Program (NMDP)</strong></td>
<td>National: 612-627-5836</td>
<td>• assistance for UNRELATED donor</td>
</tr>
<tr>
<td><a href="http://www.marrow.org">www.marrow.org</a></td>
<td></td>
<td>• transplant patients only applications accepted post-transplant only/ submitted via</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• social work</td>
</tr>
<tr>
<td>Agency Name/Location</td>
<td>Contact Information</td>
<td>Assistance</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Medicaid (Department of Human Services / DHS)</td>
<td>n/a</td>
<td>• if you are a Medicaid recipient, contact your caseworker to inquire re: eligibility for lodging and/or transportation assistance, mileage reimbursement, chore provider benefits, and food/cash assistance.</td>
</tr>
<tr>
<td>Medicaid (Department of Human Services / DHS)</td>
<td>n/a</td>
<td>• if you are a Medicaid recipient, contact your caseworker to inquire re: eligibility for lodging and/or transportation assistance, mileage reimbursement, chore provider benefits, and food/cash assistance.</td>
</tr>
</tbody>
</table>
| American Cancer Society                             | Toll Free: 800-ACS-2345       | • for a large variety of support and other services  
“Road to Recovery” volunteer program available in some counties to assist with patient transportation to/from treatment appointments |
| Prescription Assistance Programs                     |                              | • for those with limited or no prescription coverage to apply for potential prescription assistance through various drug companies                      |
| Patient Advocate Foundation                         | Toll Free: 866-512-3861       | • financial & prescription assistance based on diagnosis and need                                                                                                                                 |
| Patient Access Network                               | Toll Free: 866-316-7263       | • financial & prescription assistance based on diagnosis and need                                                                                                                                 |


<table>
<thead>
<tr>
<th>Agency Name/Location</th>
<th>Contact Information</th>
<th>Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>HealthWell Foundation</td>
<td>Toll Free: 800-675-8416</td>
<td>• financial &amp; prescription assistance based on diagnosis and need</td>
</tr>
<tr>
<td><a href="http://www.healthwellfoundation.org">www.healthwellfoundation.org</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lymphoma Research Foundation</td>
<td>Toll Free: 800-500-9976</td>
<td>• help-line and clinical trial information service for all types lymphoma</td>
</tr>
<tr>
<td><a href="http://www.lymphoma.org">www.lymphoma.org</a></td>
<td></td>
<td>• Healthcare Provider Grant Program - assist with unpaid medical bills</td>
</tr>
<tr>
<td>CancerCare</td>
<td>Toll Free: 800-813-4673</td>
<td>• $100/yr for financial assistance w/ transportation/home care/child care</td>
</tr>
<tr>
<td><a href="http://www.cancercare.org">www.cancercare.org</a></td>
<td></td>
<td>• counseling, support, and informational resources</td>
</tr>
<tr>
<td>Pardee Cancer Fund</td>
<td>Local: 989-832-3691</td>
<td>• financial assistance for those residing in the following counties:</td>
</tr>
<tr>
<td><a href="http://www.pardeecancerfoundation.org">www.pardeecancerfoundation.org</a></td>
<td>Fax: 989-832-8842</td>
<td>Bay, Clare, Gratiot, Isabella, Midland/ Gladwin</td>
</tr>
<tr>
<td>Lotsa Helping Hands</td>
<td></td>
<td>• free, easy to use private group calendar website for organizing caregiver</td>
</tr>
<tr>
<td><a href="http://www.lotsahelpinghands">www.lotsahelpinghands</a></td>
<td></td>
<td>schedules</td>
</tr>
<tr>
<td>My Friends Care</td>
<td>Local: 586-783-7390</td>
<td>• to provide expertise/ support for individuals regarding fundraising all</td>
</tr>
<tr>
<td><a href="http://www.myfriendscare.org">www.myfriendscare.org</a></td>
<td></td>
<td>funds funneled through them are tax deductible</td>
</tr>
<tr>
<td>Agency Name/Location</td>
<td>Contact Information</td>
<td>Assistance</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>National Children’s Cancer Society</td>
<td>Toll Free: 800-532-6459</td>
<td>• Provide assistance with meals during treatment, transportation, phone cards and medical expenses not covered by insurance</td>
</tr>
<tr>
<td>National Transplant Assistance Fund</td>
<td>Toll Free: 800-642-8399</td>
<td>• help to organize communities to fundraise on patient’s behalf</td>
</tr>
<tr>
<td><a href="http://www.transplantfund.org">www.transplantfund.org</a></td>
<td></td>
<td>• short-term, one-time emergency financial grants may be available</td>
</tr>
</tbody>
</table>
Lodging

UM Transplant House

Address: 1011 Cornwell Place  
Ann Arbor, MI 48109  
Guest Phones: (734) 930-0754 or 0755  
Reservations: 1-800-544-8684

The Michigan Transplant House is for patients and families who are having an organ or stem cell transplant at the UM Medical Center. To qualify for staying at the Transplant House, transplant patients and/or families must meet the following criteria:

- Live 50 miles or more one way from the UM Medical Center
- Age 18 years or older (companions may be 16 and older)
- Non-wheelchair dependent and do not require more assistance than their companion can provide
- Can perform activities of daily living with assistance or has accompanying guest to help perform such activities

The Transplant House has six bedrooms (each with two twin beds). Each bedroom can accommodate only one patient and one companion. Five bedrooms are on the second floor and one is on the first floor. Linens are provided. **Guests are expected to clean their room and change their own linens.** Patients who have difficulty with walking may be placed on the first floor; however there is no guarantee that a first floor room will be available. There are three bathrooms, one on the first floor and two on the second floor, which guests share. Television and stereo are available in the large living room. In addition a television with cable is located in each bedroom. Transplant House is air-conditioned. The Transplant house is not a nursing care facility. If a guest cannot perform activities of daily living and has no companion to assist them, alternative lodging accommodations must be made.
Cleaning products, dishes, cookware, utensils and staples are provided in the kitchen, which also has a dishwasher, microwave, blender, oven, refrigerator and separate drawers for individual food storage. Guests are expected to bring their own food. Laundry facilities are also available at the house.

**Accessibility**

There are steps into the house. The house is not wheelchair accessible.

**Cost**

Patients may stay for the entire time of their outpatient treatment, including weekends. The cost is $22 per night for a patient/family member staying alone or $25 per night for a patient and companion together. Cash and checks are acceptable forms of payment.

**Check-in and Check-out**

When a room is available, check in materials will be left in a package for the patient/family in the mailbox, which will include a key and a parking pass. The resident manager will make contact with the guests within 24 hours to orient the guest to the house and make arrangements for payment. Notify the PVAP office with your approximate time of check in, so that we may notify the resident manager. All checkouts should be coordinated with the resident manager.

**Transplant House Staff**

The Transplant House resident manager has an apartment in the house and is available for emergencies 9 p.m. — 9 a.m. through the week and on weekends.

**Parking and Transportation for Transplant House**

There is free parking for guests in a lot one-half block from the house. The permit needed for entry to this lot is obtained in the check-in packet. Shuttle
service is available through Hospital Security; guests should call security themselves to arrange transportation. 936-7890

**General Use of the Transplant House**

The Transplant house may be used occasionally for family members or patients who are not receiving a transplant. Radiation Oncology patients may have access to the house if availability exists, but will be moved to the Wilmot House as soon as a room becomes available. Family members of other patients may stay at the Transplant House if there is availability and there is no waitlist. Accommodations for family members must be made prior to the check in date.

**General Rules of Transplant House**

Smoking, alcoholic beverages, illegal drugs, and firearms are NOT allowed.

Failure to comply with any of these rules will result in a guest's immediate eviction by the house manager who reserves the right to evict guests based on their behavior/non-compliance with house rules.

**Reservations and Cancellations**

Contact the Patient and Visitor Accommodations (PVA) office at 734-936-0135 or 1-800-544-8684 with your requested reservation dates to be placed on a reservation list. Contact the PVA again the day before checking-in to confirm your reservation. If rooms are unavailable at Transplant House, the PVA will assist you in locating other arrangements. Notify PVA if your schedule changes and you need to cancel or change your reservation.

**Extended Stay Locations**

A list of extended stay locations is included in the back pocket of this manual. It is furnished for your convenience utilizing information provided by the various businesses directly. The University of Michigan Health System (UMHS)
Local Apartments

A list of local apartments is furnished, for your convenience, in the back pocket of this manual. It was developed from information provided by the various businesses directly. The University of Michigan Health System (UMHS) assumes no responsibility for private rentals of these resources. All facilities listed are within 30 minutes of UMHS. Rental Rates and Terms subject to change. Pricing may vary based on length of stay and # of bedrooms. Please contact facility directly, identifying yourself as a patient at UMHS, for the most current information on pricing and amenities.
Walking Route between Children’s & Women's and the Cancer Center Pharmacy

The Cancer Center connects to University Hospital on Levels 2 & B1 only.

Level B1

The Cancer Center connects to University Hospital on Levels 2 & B1 only.

Level 2

The Cancer Center connects to University Hospital on Levels 2 & B1 only.
Floor 7

North

- Entry/Exit
- Public Pathway
- Elevators
- Stairs
- Information
- Restrooms
- Lactation Room

Pediatric Patient Rooms
7E-01 to 7E-14

Pediatric Patient Rooms
7E-15 to 7E-26

Pediatric Patient Rooms
7E-27 to 7E-32

Adult Patient Rooms
7W-33 to 7W-50

Adult Patient Rooms
7W-51 to 7W-64

Pediatric Patient Rooms
7E-01 to 7E-14
Important Phone Numbers
(all numbers are 734 area code unless noted)

Adult Physicians

Daniel Couriel, M.D. - Director
Steve Goldstein, M.D. - Associate Clinical Director
John Magenau M.D.
Attaphol Pawarode, M.D.
Brian Parkin, M.D.
Pavan Reddy, M.D.
Mary Riwes, D.O.

Pediatric Physicians

Sung W. Choi, M.D.
James Connelly, M.D.
James Ferrara, M.D.
Andy Harris, M.D.
Carrie L. Kitko, M.D.
John E. Levine, M.D.-Director
Gregory A. Yanik, M.D.

Pre-Transplant Nurse Coordinators

Mandy Heikka..................................................232-7596
Kimberly Kyro..................................................232-7568
Peggy Parker....................................................232-7593
Maureen Rose..................................................232-7567
Diane Klann.....................................................232-7594
Isabel Vial........................................................232-7564
Denise Mouro...................................................232-7565

Monday through Friday 8am – 5pm:
BMT Doctors can be reached at 936-9814

After 5pm on weekdays, and on holidays and weekends:
Call 936-6267 and ask the page operator to contact the bone marrow transplant doctor on call.
Research Nurse Coordinator ..............................................615-2858

Social Workers

**Adult Patients:**

Barb Rose (During Hospitalization) .........................232-7567
Toni Spano-English (Before & After Transplant) ..........232-5776

**Pediatric Patients:**

Katy Fasl. .................................................................232-8544
Beth Stuchell ............................................................232-8545

**Adult After Transplant Clinic Nurses** .......................936-9814
Becky Mammel Laura Walsh KarenDuby
Maria Kirk Cheryl McCullough

**Pediatric After Transplant Clinic Nurses** ...............936-9814
Teresa Bell Christie Byrne
Lori Keough Jenni Stull

**Appointment Schedulers.** ......................................232-8838 or 232-7591

**Patient Accounts Representative**

Joan Taylor .............................................................936-7804

**Outpatient Accounts Representative**

Linda Zywicki .........................................................647-5120
Desmon Embry .......................................................615-6798

**Dieticians**

Sandy Bouma ..........................................................763-2503
Kim Thomas ..........................................................615-6127
Pharmacy

Cancer Center Pharmacy..................................................647-8911
Taubman Center Pharmacy.................................................936-8260

Other Telephone Numbers at the University of Michigan:

Emergency Department - Adult (UH) ..............................936-6666
Emergency Department - Pediatric (MH) .........................936-4230
Guest Assistance Program (GAP) .................................800-888-9825
Inpatient Bone Marrow Transplant Unit .........................936-4688
(7 West C.S. Mott Children’s Hospital ) .........................232-7777
Inpatient Bone Marrow Transplant Unit .........................232-7700
(7 East C.S. Mott Children’s Hospital)
Medical Records .................................................................936-5350
Patient Relations Department .................................936-4330 or (877) 285-7788
PsychOncology Clinic (Cancer Center) .......................(877) 907-0859
Psychiatric Emergency .....................................................936-5900
Radiation Oncology ............................................................936-4300
Spiritual Care Offices (University Hospital) .....................936-4041

Information

Cancer Center Answer Line ...........................................(800) 895-1125
Hospital Information - UH ..............................................936-4000
Patient Education Resource Center (PERC) .................647-8626

Lodging

Patient and Visitor Accommodations ......................(800) 544-8684 or 936-0135
Transplant House ...............................................................764-6893
This document is not intended to take the place of the care and attention of your personal doctor or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education.

Questions about individual health concerns or specific treatment options should be discussed with your doctor.

©2011 The Regents of the University of Michigan
Document #0064 / Revised 10/2013