



UNIVERSITY OF IOWA
HOLDEN COMPREHENSIVE
CANCER CENTER

University of Iowa Health Care

Autologous Blood & Marrow Transplant Guidebook

UIHC Adult Blood & Marrow Transplant Program

Approved by the Office of Patient Education, 2014

Autologous Blood and Marrow Transplant (BMT)

Guidebook

The goals of this book are to:

- Help you plan for your transplant
- Answer your questions
- Help you understand your treatment
- List ways to lower the risk of complications, such as infections

You will hear and read these terms throughout the transplant process:

- Bone Marrow Transplant
- Blood and Marrow Transplant
- BMT
- Stem Cell Transplant
- Hematopoietic Stem Cell Transplant

This Guidebook will use the term BMT to include all the above listed terms.

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Section 1: Getting to Know Us

Your BMT Team

It takes many health care staff to help you and your family through transplant. The BMT team works together to take care of you. You and your family are **key** members of this team. The table below lists some of the BMT team.

Health Care Staff	What they do
BMT Doctor	<ul style="list-style-type: none">-Gives your medical care before and after transplant.-Choose your treatment plan.-Teaches and supports you before and after transplant.-Conduct research to improve transplants.-Teach doctors in training.-Talk with your Attending Doctor during transplant.
Attending Doctor	<ul style="list-style-type: none">-Gives your medical care during transplant.- Teaches and supports you before and after transplant.-Teach doctors in training.-Talks with your BMT Doctor during transplant and before you go home.-Talk with your Referring Doctor as needed.
Referring Doctor	<ul style="list-style-type: none">-Gets information from your BMT Doctor and Attending Doctor.-May give some of your after-transplant care. Such as lab draws or platelet/blood transfusions.-Talk with your BMT Doctor after transplant.- Teaches and supports you before and after transplant.
Physician Assistants & Nurse Practitioners	<ul style="list-style-type: none">-Take your history and do physical exams.-Order medicines.-Order tests and check the results.

- Assess and treat your medical problems.
- Do bone marrow biopsies and lumbar punctures.
- Teach you about your treatment plan and symptom management.
- Give support for you and your family.

Nurse Coordinator

- Arrange the needed tests to see if you are ready for transplant.
- Arrange and schedule your appointments leading up to transplant.
- Talk with your BMT Doctor to prepare you for transplant.
- Give support and teaching to you and your family.
- Arrange care with your Referring Doctor.

Social Worker

- Help you find housing.
- Help with work related issues, disability, and leave programs.
- Help you complete an Advanced Health Care Directive and Durable Power of Attorney.
- Give you information about your insurance.
- Give support to you and your family.

Nurses

- Teach you about your treatment plan, symptom management and hospital stay.
- Give you chemotherapy, antibiotics, and transfusions. Infuse stem cell transplant.
- Check on you often to spot changes in your health during transplant.
- Give supportive care to you and your family.

Pharmacist

- Talk with your doctors to provide the medicines ordered for you. They will do this before, during, and after transplant.
- Teach you and your Caregiver about your medicines. This is done before transplant, and before going home after transplant.

Nursing Assistants

-Take your vital signs.

-Help with your laundry, setting up your shower, and changing your linens each day.

-Talk with you and your nurse about your care.

-Offer support for you and your family.

Physical Therapist

-Assess your baseline activity, strength, and stamina.

-Give you an exercise plan to follow during transplant, and when you go home.

Recreational Therapist

-Give you things to do during your transplant stay.

-Talk with you about your interests and give support through activities.

Dietician

-Teach you about food guidelines for transplant.

-Assess the amount of calories you are eating to help with recovery and stamina.

Financial Coordinator

-Help you know your BMT insurance coverage.

-Help you talk with the right financial staff member

Section 2: Who to Contact

Call us directly anytime day or night

Monday through Friday, 8 a.m. – 5 p.m.

Blood and Marrow Transplant Program 319-384-8828

Holden Clinical Cancer Center 319-356-4422

Weekdays after 5 p.m., weekends and holidays

Call the main UIHC number 319-356-1616. Ask the operator to page the Hematology-Oncology Fellow on call for BMT.

Contacts for Dr. Tricot & Dr. Abbi Patients

Prescription refills, questions about clinic, to report symptoms

Nurse, Paula McCue

paula-mccue@uiowa.edu 319-356-4200

Patient Coordinator:

Sonya Behrends sonya-behrends@uiowa.edu 319-353-6326

Dr. Abbi:

Kamal-abbi@uiowa.edu

Social Worker (family support, resources, lodging, service referrals)

Tammy Temple tammy-temple@uiowa.edu 319-356-3994

Pharmacist:

Susan Fajardo susan-fajardo@uiowa.edu 319-356-2577

Financial Coordinator:

Kathy Moser Katherine-moser@uiowa.edu 319-384-7364

Questions about our research study:

Research Coordinator, Annick Tricot

Annick-tricot@uiowa.edu 319-467-5830

Mailers for multiple myeloma kits:

bmt@uiowa.edu 319-356-3337

Medical Records Request

319-356-1719

Patient and Caregiver Education

Shannon Hunger Shannon-hunger@uiowa.edu 319-384-9102

Contacts for Dr. Silverman & Dr. Farooq Patients

Prescription refills, questions about clinic

Nurse, Karen Roode

Karen-roode@uiowa.edu 319-356-4200

Patient Coordinators:

Julie Aschenbrenner (Patient last names beginning with A through J)

Julie-aschenbrenner@uiowa.edu 319-353-6798

Beth Kaufman (Patient last names beginning with K through Z)

Lizbeth-kaufman@uiowa.edu 319-384-9562

Social Worker:

Tammy Temple tammy-temple@uiowa.edu 319-356-3994

Financial Coordinator

Kathy Moser Katherine-moser@uiowa.edu 319-384-7364

Medical Records Request

319-356-1719

Questions about our research study:

Research Coordinator, Karen Parrott karen-parrott@uiowa.edu

319-353-6347

Patient and Caregiver Education

Shannon Hunger Shannon-hunger@uiowa.edu 319-384-9102

What Doctor Takes Care of You?

Your BMT Doctor will take care of you before and after transplant. While you are in the hospital the doctors caring for you will rotate monthly. Your care will always be led by an Attending Doctor. It may not be **your** BMT Doctor. The BMT Attending Doctors have special training in the care of transplant patients. They will be helped by fellows and residents. Fellows are medical doctors who have finished residency. They are doing extra training in hematology-oncology. Residents are medical doctors who are training in a chosen area.

The BMT team will visit you each morning in the hospital (in-patient). They will check to see how you are doing. Your BMT Doctor and your Attending Doctor talk with each other often.

Where will you receive care?

During Transplant:

[Adult Stem Cell Transplant Unit](#)

7 Roy Carver South (7RCS)

Located in the Roy Carver Pavilion, between elevators D and E

Unit phone number (319) 356-3330

15 bed unit

Before and After Transplant:

[4JPE](#)

Located in the John Pappajohn Pavilion, Elevator I, 4th floor

Unit phone number (319) 356-3327

10 bed unit

[Holden Clinical Cancer Center](#)

Outpatient appointments & Labs

1st floor Pomerantz Family Pavilion, by Elevator M

Phone number (319)356-4422

[Holden Clinical Cancer Center – Infusion Suite](#)

Outpatient infusions & Blood product transfusions

2nd floor Pomerantz Family Pavilion, by Elevator M

Phone number (319) 356-4422

Terms

Term	What it is
Allogeneic transplant	Often called “Allo”. The use of donor stem cells for your transplant. Donor stem cells are gotten from a genetically matched person.
Anemia	A state in which you have less than normal red blood cells. Signs of anemia are feeling tired, weak, and short of breath.
Apheresis	The collection of stem cells from the blood using a machine that can separate the blood cells.
Autologous transplant	Often called “Auto”. Your own stem cells are used for your transplant.
B lymphocyte	A cell of the immune system that helps protect you from infection.
Bone marrow	A liquid that looks like blood. It is the spongy tissue found inside large bones, such as the hip bones.
Bone marrow biopsy	A procedure used to get a sample of bone marrow for testing.
Central venous catheter	An IV tube placed in a vein under the collarbone. The tube is used to give fluids, medicines, and take blood samples.
Consent form	A form that lists your treatment plan and the risks and benefits of transplant.
Differential	A lab test. It shows the numbers of different types of white blood cells in the blood.
Donor	The person who is the source of stem cells used in transplant. <ul style="list-style-type: none">• You can be your own donor.• The donor can be a genetically matched person. Types of donors include brothers, sisters, and unrelated volunteer donors.• In some cases the donor may be a partial match, or ‘mismatched’.

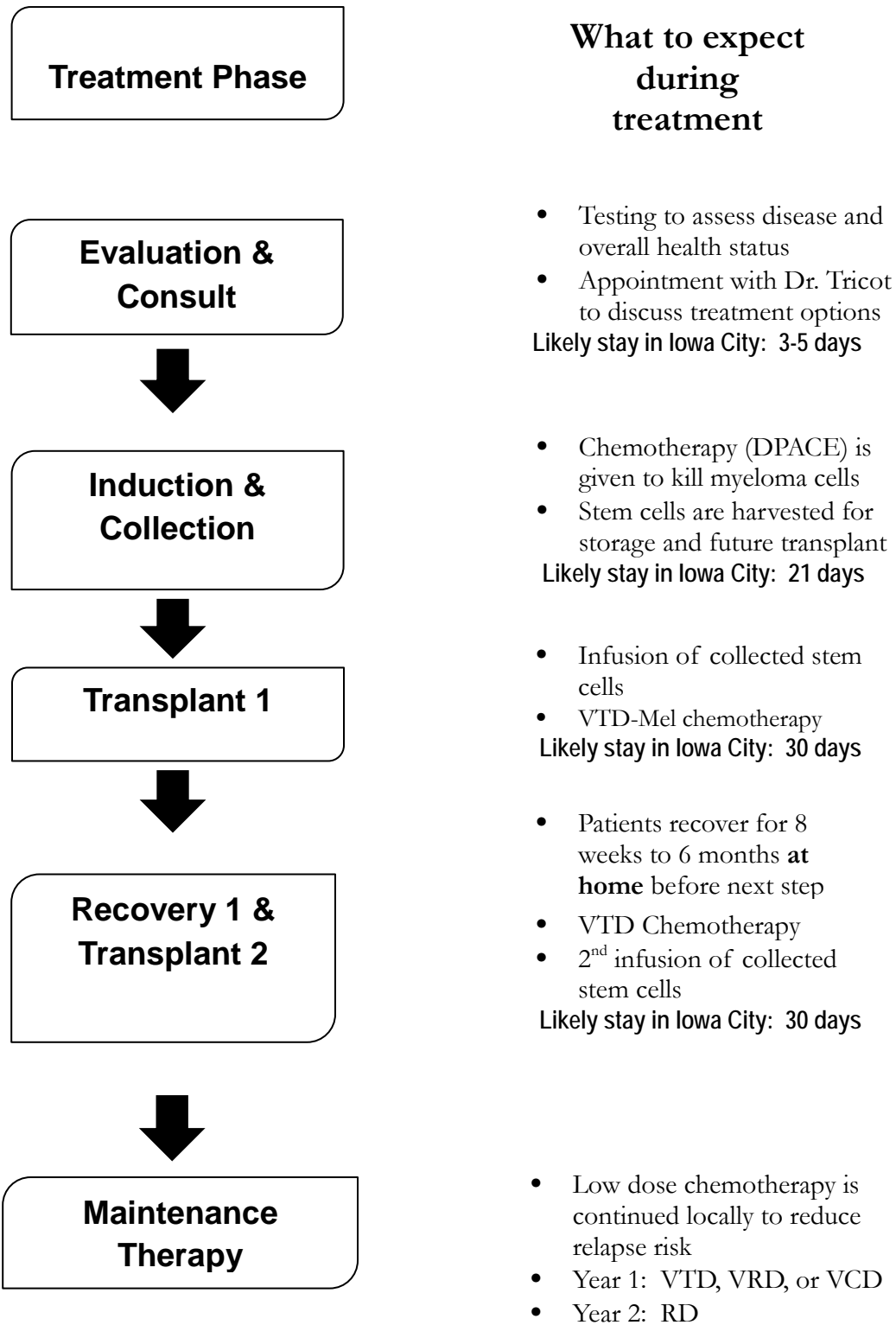
Eligibility	A series of tests to see if you are healthy enough for transplant. These tests check: <ul style="list-style-type: none"> • organ (heart, lung, kidney, and liver) function • blood counts • bone marrow • the status of your disease.
Engraftment	The recovery of the blood cells after the stem cells are transplanted.
Graft	A collection of stem cells that is infused. The graft may be your own stem cells or donor stem cells.
Hemoglobin (Hgb)	The part of the red blood cell that contains iron. Iron binds to oxygen and carries it to tissues throughout the body. Normal range for females: 11.7-15.7 g/dL Normal range for males: 13.2-17.7 g/dL
Holden Clinical Cancer Center (HCCC)	Also referred to as “Clinic”. This consists of your Outpatient Doctor’s clinic, its lab, and Infusion Suite. It is found on the 1 st and 2 nd floors of the Pomerantz Family Pavilion at UIHC.
Human leukocyte antigen (HLA)	A group of markers on the surface of cells of the immune system. They are inherited from your parents. They are used to find a donor from your family or the unrelated volunteer donor registries.
Immune system	A system made of specialized cells of the body. It protects you from germs in the environment that cause infections.
Immunosuppressants	Medications given to weaken the immune system. They are given to prevent or treat graft versus host disease.
Inpatient	A person who gets care in the hospital.
Microorganisms	Small organisms that can cause infections. This includes bacteria, virus, parasite, or fungus.

Mobilization	A process to raise the number of stem cells in the blood. Stem cells are moved from the bone marrow into the blood. The stem cells can be collected from the blood. This can be done by using chemotherapy combined with a growth factor. This causes the bone marrow to make more stem cells. You may get growth factor alone.
Monoclonal antibody	A protein that is designed to destroy one type of cell. For example, rituximab can destroy lymphoma cells.
Mucositis	Inflammation of the mucous membranes in the mouth, throat, GI tract, or rectum. Symptoms are redness, swelling, sores, dry mouth, thick saliva, pain.
Myeloablative	A program of high dose chemotherapy with or without radiation. It will completely destroy your body's ability to make blood cells.
Neutropenia	A state in which you have a low number of neutrophils. They are one type of white blood cell. They are vital for fighting bacterial infections. Normal range is 40-60% of the total number of white blood cells.
Non-myeloablative	Low or standard doses of radiation, chemotherapy or immune suppressing medications. The purpose is to suppress your immune system. This lets the donor's cells grow and function.

Platelets (Plts)	<p>A blood cell that helps with clotting to prevent or stop bleeding after injury. When the platelet count is low there is a risk of bleeding.</p> <p>Normal range: 150-400 thousand/MM3</p> <p>You will often hear this number without the “thousand” stated.</p>
Preparative Regimen	<p>High dose chemotherapy, with or without radiation, given before transplant.</p> <p>This has a multi-purpose:</p> <ol style="list-style-type: none"> 1. Destroy remaining cancer. 2. Knock out your immune system. This prepares the bone marrow to receive the stem cell transplant. 3. Create space in the bone marrow for the donor’s cells. This allows your donor’s cells to grow and the transplant to engraft.
Red blood cells (RBC)	<p>A blood cell that carries oxygen throughout the body.</p> <p>Normal range for females: 4.0-5.2 million/uL</p> <p>Normal range for males: 4.4-5.9 million/uL</p> <p>You will often hear this number without the “million” stated.</p>
Safe Zone	100 mile radius of UIHC.
Stem cells	<p>Stem cells make all blood cells and cells of the immune system. They are one of the human body's most complex cells. Stem cells can renew themselves. They make new cells of whatever tissue they belong to. Bone marrow stem cells are the most immature cells in the marrow. All the different types of blood cells are made by them.</p>
Stomatitis	Inflammation of an opening in the body. Redness, swelling, sores in the mouth or anus.
Thrombocytopenia	A low platelet count. A low platelet count raises the risk of bleeding.
T lymphocyte	An immune system cell that protects your body from infection and foreign tissue.

Transfusions	The infusion of different parts of the blood to treat specific problems. Red blood cells are given to treat anemia. Platelets are given to lower the risk of bleeding.
White blood cells (WBC)	<p>White blood cells protect the body from infection. There are many types of white blood cells:</p> <ul style="list-style-type: none"> • neutrophils • eosinophils • basophils • monocytes • macrophages • lymphocytes <p>Normal range: 3.7-10.5 thousand/MM3 You will often hear this number without the “thousand” stated.</p>

Plasma Cell Disorder Plan



Section 3: The Steps of Autologous Blood or Marrow Transplantation (BMT)

The steps of transplant are:

1. Disease treatment (chemotherapy)
2. Harvesting (collecting) your stem cells
3. Giving the preparative/conditioning regimen
4. Infusing the stem cells (Transplant)
5. Recovery

Disease Treatment

By the time you reach BMT you have received treatment for your disease. Part of this treatment is getting chemotherapy. Some patients need surgical procedures. Some need radiation. Multiple Myeloma patients may get months-to-years of disease treatment before transplant. You have been through a lot. The BMT team respects all you have done.

Consent Forms

You will be given consent forms to read and study. The consent form for your transplant will list a lot of details. It will review the risks and benefits, the side effects, and long-term complications.

The BMT program wants to improve outcomes and advance the science of transplants. Improvements in BMT are assessed and refined using clinical trials, research, and studies. Many patients are happy to help improve cancer treatments by taking part in:

- Databases
- Research
- Clinical trials.

You will be asked to consider a consent for data.

We are part of a research database for the Center of International Bone Marrow Transplant Research. This research puts some of your medical data into a worldwide database. If you want to allow this, you will need to give permission. The purpose is to compare outcomes.

The data will not reveal your identity. Taking part asks two things of you:

1. Allow us to collect blood research samples at the same time of routine collection. We use this blood to study and improve transplants.
 2. The chance to follow your health status throughout your life. What we learn from your transplant can help us treat other patients.
- Research for the UIHC-BMT database. We look for ways to improve transplants.

Harvesting (Collecting) Your Stem Cells

What is a Stem Cell?

Stem cells are immature cells that contain basic genetic information.

There are stem cells for skin, liver, intestines, ova, sperm, heart, brain, and blood.

The blood-forming or hematopoietic stem cell is the most basic blood-forming cell. It is the "parent" cell of the blood supply. It can mature into a red blood cell, white blood cell, or platelet. These stem cells make an endless supply of blood cells. A small number of stem cells make an ounce of new blood each day. This is about 260 billion new cells.

Where Are Stem Cells Found?

Most blood stem cells are found in the bone marrow of large bones. Only a small number are found in the blood stream.

How Are Stem Cells Harvested?

There are two ways to collect stem cells: a bone marrow harvest and apheresis. Most stem cells are now collected through peripheral blood apheresis. The process is like donating blood. Moving stem cells from the bone marrow into the blood is called **mobilization**. We need to increase the number of stem cells in the blood. You may be given a growth factor shot. The growth factor used most often is G-CSF, granulocyte colony stimulating factor (Neupogen). The growth factor is given for 4-5 days.

When your lab work shows there are enough cells to collect, apheresis starts. Your blood can be removed in one of two ways. An IV line in a neck vein or IVs in your arms can be used. The blood is spun through a machine which will collect the stem cells. Your blood is transfused back into your system through the tube. This stem cell collection occurs in the DeGowin Blood Center at UIHC. A nurse will stay with you throughout the collection. It will take about 5 hours. There are recliners, a television, and the staff will order lunch for you. If you like, you are welcome to bring your own. After the 5 hour collection, the stem cells are tested, processed, and frozen until transplantation. It may take more than one day to harvest the stem cells for your transplant.

The Preparative/Conditioning Regimen

You will get a few days of high dose chemotherapy before your transplant. This time period is called the Preparative Regimen. The treatment you are given is based on your disease and general health. The medicines will be specific to your medical condition. You will be given

information about the medicines and their side effects. Transplants can be done in two ways:

- Outpatient through the Holden Comprehensive Cancer Center or
- Inpatient on 7 RCS or 4JPE at UIHC.

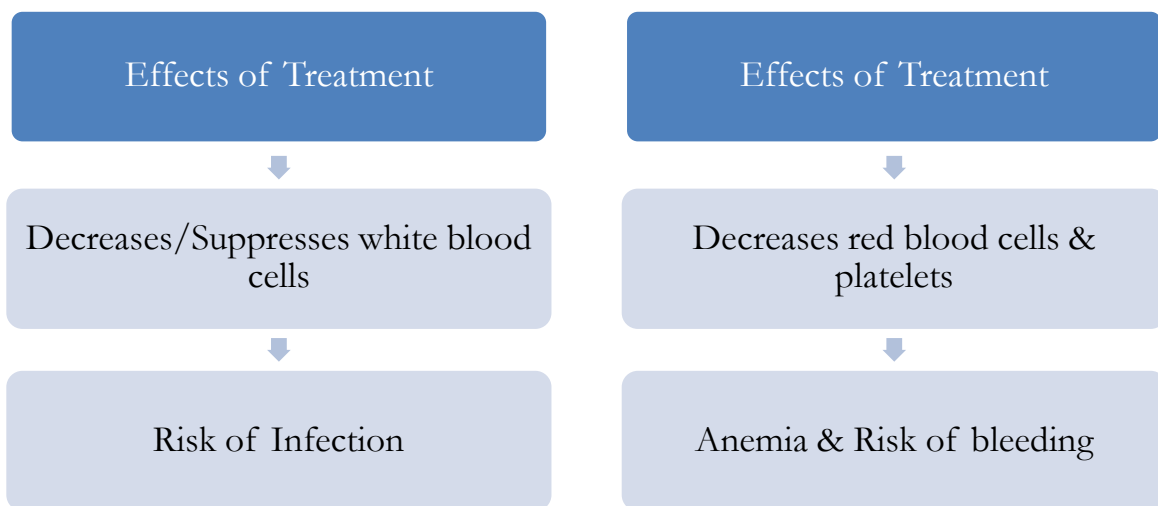
This will depend on your treatment protocol, insurance carrier, or both.

You will receive the stem cells after the right treatment is finished. The treatment medicines need to clear from your body. Some of the first tests you had may be repeated. This is to make sure you are ready for the transplant.

This treatment can cause:

- Nausea
- Low energy
- Loss of appetite
- Taste changes
- Diarrhea

Please talk with the BMT team. We can help lessen, get rid of, or manage these symptoms!



Possible Side Effects & Complications

Side effects and complications are due to many factors. They can be from:

- High doses of the chemotherapy

- Radiation
- Long period of neutropenia
- Medicines you were given

Side effects can be treated on the transplant unit. Some complications may be life-threatening. We will use the Medical-ICU if needed.

You need to understand the risks for side effects and complications. Sign the consent for transplant only after you understand.

Possible Side Effects

- Pain (mainly Stomatitis/Mucositis)
- Feeling sick to your stomach or throwing up
- Confusion/seeing or hearing things that are not there
- Vision changes
- Feeling light-headed or dizzy
- Diarrhea or constipation
- Sleep problems
- Bleeding
- Skin changes

The Caregiver's Role

A transplant is not possible without the support of Caregivers. They assume **24-hour responsibility for the BMT patient during collection and out-patient transplant.** During in-patient transplant the healthcare team is also responsible. The Caregiver needs to maintain an active role. The role includes many important aspects of your recovery and care. **A Caregiver may be needed 24 hours per day, seven days per week. The time commitment after discharge from inpatient transplant is 1-2 weeks.** Sometimes a Caregiver is one person. Often several people share the responsibility.

Please consider this list of duties when choosing a Caregiver:

1. Make Arrangements

Provide or arrange transportation.

Make and keep appointments at BMT Clinic and hospital.

Arrange home health care

Set clear guidelines while communicating with homecare staff.

2. Give Emotional Support

Give encouragement and be a good listener!

3. Give Physical Care

Care for the patient's central line. This may include flushing lines and changing dressings.

Organize the patient's oral medicines and keep an updated list.

Make sure medicines are taken and keep accurate records.

Set up supplies and pumps for needed IV care. Home care nurses will help.

Watch for changes in the patient's condition. Report them to the BMT team right away.

Make sure the patient is getting out of bed daily and exercising.

May possibly be asked to give shots.

4. Clean and Maintain the Home or "Home Away from Home"

Keep the home (or the "home away from home") clean.

Prepare food for the patient.

5. Be a Patient Advocate

Help the patient with decision-making.

Protect the patient from others who may be sick.

Gather health, support, financial aid, and other information.

6. Give Assistance and Support to Patient's Family and Friends

Serve as a contact link between the patient, family, and friends.

Support the patient's children as needed.

Preparing to be a Primary BMT Caregiver

The Caregiver is there to help and support. The primary BMT Caregiver is a partner with the patient. You will help to see that the patient's wishes and concerns are properly addressed. Most transplant centers require transplant patients to have a Caregiver. You will provide emotional support and act as an advocate for the patient. You may also be asked to help with medical, financial and social needs. You may be needed before, during, and after the hospital stay. A primary Caregiver may be a close relative or a friend.

Before Entering the Hospital

You and the patient may need to travel away from home for the transplant. Deciding how to run a household away from home requires planning. Discuss these tasks with the patient before going into the hospital:

- Learn about the patient's insurance coverage. Contact the transplant case manager at the patient's insurance company. Find out what will and will not be covered by the insurance plan. Ask what expenses for the Caregiver (lodging, food, and transportation) may be covered.
- Discuss and decide on medical directives and medical powers of attorney. Most hospitals will want a written medical directive from the patient. This is the time to develop these forms. They will clearly spell out the patient's wishes.
- Plan for how monthly bills (utilities, rent, etc.) will be paid. Consider on-line bill paying or the help of a trusted friend or family member.
- Develop a plan to share updates. Friends and family will want to know how they can help. Name a friend or family member as a "gatekeeper". This person can help organize offers of help and share information.

During the Hospital Stay

Patients often act as their own medical advocates. They rely on Caregivers for support. At times patients may be too tired, sick, or overwhelmed to advocate for themselves. You need to work with the patient. This helps you meet their needs and wishes as well as possible. You may need to act as the patient's medical advocate. Get the patient's consent. Tell the medical team that you want to be involved. Have them tell you about important results and decisions.

Caregivers...

- **Help make known the patient's treatment goals and needs if the patient cannot do so.**
- **Keep a notebook of lab results, meetings with the medical team, and treatment plans.** Use your notebook to list any questions you have. Record the answers.
- **Report any new symptoms to the health care team.** You know the patient better than anyone else on the team. Do not be afraid to speak up. You are an active member of the patient's health care team.
- **Reach out to the nurses.** Nurses are excellent resources. They can give caregiving tips and information.
- **Make use of the BMT social workers, chaplains, and other support services.** They are here for you and your family. There are many professionals ready to give support to you and the patient.
- **Pace yourself.** You need to be physically, mentally, and emotionally healthy to care for the patient outside the hospital setting.

Leaving the Hospital and Returning Home

Leaving the hospital and its 24 hour expert care can be scary. The transplant team will prepare the patient and Caregiver for the change. The team will be on call for help. Most people go straight home to recover after leaving the hospital. But depending on how it goes, you may need to stay closer to the hospital.

The Caregiver needs to be available 24 hours a day for the first 100 days following transplant. The patient may need to make 1-3 clinic visits (or more) for the first four weeks. This means you should have a plan. You and the patient must ask the transplant team what time commitment will be needed. You may need to talk with your employer and the patient's employer. Ask about the Family Medical Leave Act and employment options.

Some activities the Caregiver may have to do include:

- **Oversee the daily needs of the patient.** You will need to:
 - Oversee medicines
 - Check for infections or any new symptoms
 - Get emergency care if needed.
 - Know who to contact and how at the transplant center.

Think of others who may be able to provide respite care for you. Online resources (listed on the following page) are available.

- **Arrange for the house to be cleaned thoroughly before the patient goes home.**
This includes:
 - Dusting
 - Vacuuming
 - Washing the floors
 - Changing furnace and air conditioning filters.

Keep the house as clean as possible when the patient comes home. Ask the patient to wear a mask while you are cleaning the home.

- **Provide transportation and go to medical appointments with the patient.**
- **Learn how to take care of the patient's central line catheter.** The patient's medical team will teach you. Do not be afraid to ask if you need more help with this.
- **Help keep the patient from being exposed to crowds, sick people, and small children.**

Caring for the Caregiver

This is not a job you can do alone. You will need emotional and physical support to care for your loved one. The transplant center's social workers can help you find local support groups. Be willing to ask friends and family for help with meals, transportation, and shopping. You need to develop a respite system for yourself and use it.

Please read the booklet **Caregivers' Guide for Bone Marrow/Stem Cell Transplant ~ Practical Perspectives**. We will give this to you. It will help you realize the importance of:

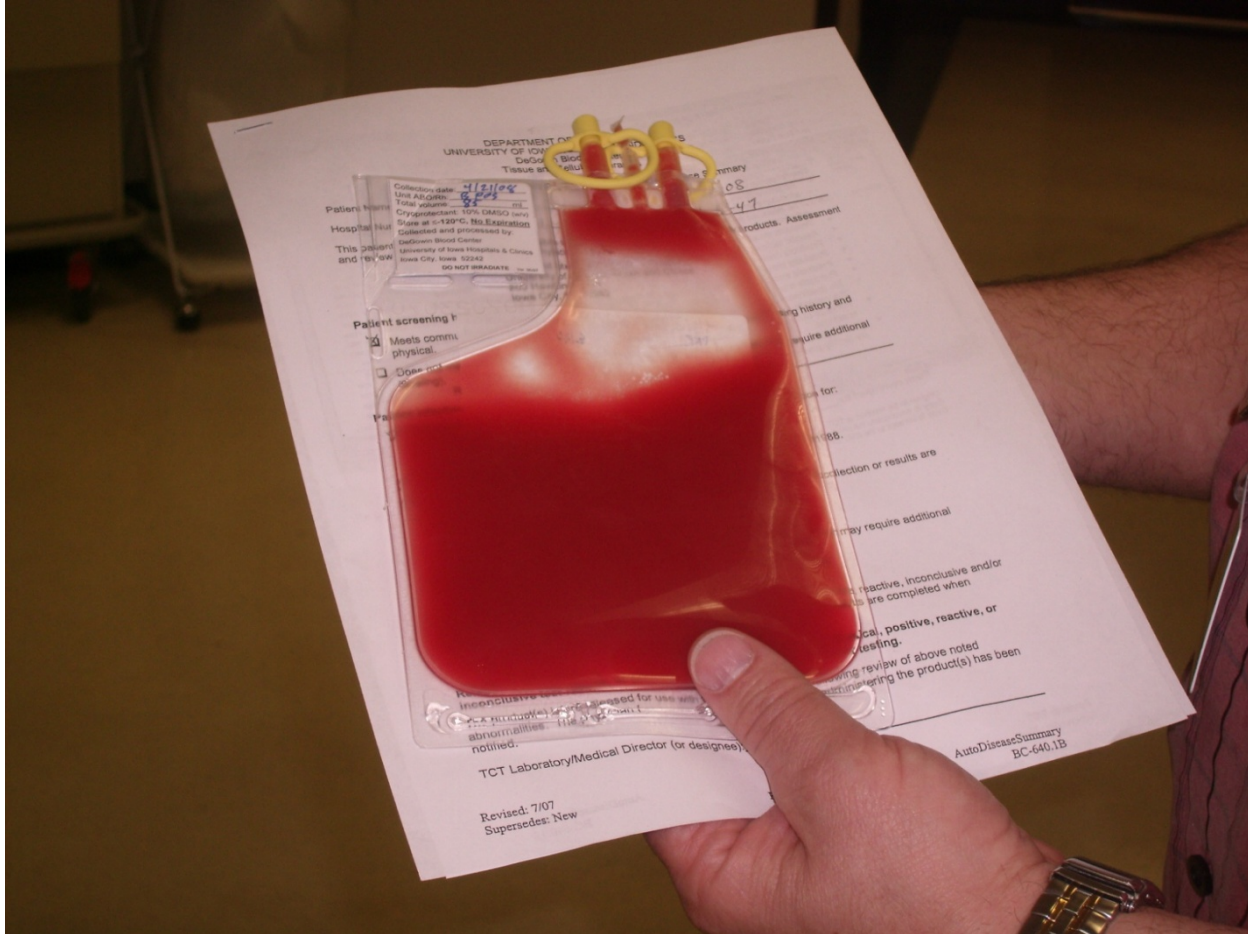
- Setting up a support system for yourself and accepting help
- Taking time to recharge
- Setting up a system for sharing updates
- Being politely assertive, flexible, and patient
- Taking one day at a time
- Keeping a positive outlook and sense of humor
- Long-term planning.

The following page of resources may help make your job as Caregiver a bit easier.

Blood and Marrow Transplant Caregiving Resources		
<i>Organization</i>	<i>Description</i>	<i>Contact Information</i>
National Bone Marrow Transplant Link	Has print materials on care-giving. They can be ordered for a fee or downloaded from the web site. It offers peer volunteer support to patients and Caregivers.	Web site: www.nbmtlink.org E-mail: info@nbmtlink.org . Phone: 1 (800) LINK-BMT (800-546-5268)
Blood and Marrow Transplant Information Network	Publishes books on caregiving, finances and BMT. The program facilitates a patient to survivor network. It links a potential transplant patient with a volunteer who has undergone BMT. Good information on transplant centers.	Web site: www.bmtinfonyet.org E-mail: help@bmtinfonyet.org Phone: 1 (888) 597-7674
Lotsa Helping Hands	This is an easy-to-use, web-based private group calendar. It is specially designed for organizing helpers. Helpers can pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during a crisis.	Web site: www.marow.lotsahelpinghands.com E-mail: support@lotsahelpinghands.com
Share the Care	This book (\$14.00) and Web site are aimed at providing the tools and resources for a group of people to care for someone seriously ill.	Web site: www.sharethecare.org Make contact with this organization through their Web site.
CaringBridge	This program offers free, easy-to-create Web sites. This helps connect friends and family when they need it most.	Web site: www.caringbridge.org E-mail: Submit requests via the Web site. Phone: (651) 452-7940
The Patient/Partner Project	Provides e-mail education on care giving with cancer patients. Also, a free online private progress reporting system to keep loved ones informed.	Web site: www.theppp.org E-mail: Submit requests via the Web site.
Well Spouse Association	A national, non-profit membership (\$25/yearly) organization. It gives support to family members of chronically ill and/or disabled. Features regional support groups, a national conference, bi-monthly newsletters and more.	Web site: www.wellspouse.org E-mail: info@wellspouse.org Phone: 1 (800) 838-0879
Family Caregiving 101	An online service of the National Family Caregivers Association and the National Alliance for Caregiving. It gives Caregivers the basic tools, skills and information they need to protect their own physical and mental health. Only accessible online.	Web site: www.familycaregiving101.org

You can access these resources & a variety of health topics on www.uihealthcare.org!

Transplant



Your transplant day, when your stem cells are infused, is called “Day Zero”. Your days will be counted up from there. The day after transplant is “Day +1”, and the next day is “Day +2”, etc.

On Day Zero your stem cells will arrive as frozen bags. The lab technician will bring the stem cells outside your room in a special container. One bag at a time will be thawed in a pan of warm, sterile saline. The bags of stem cells are handed to your nurse, one at a time. They will be infused through your Central Line (PICC, Double Port, or Hickman) Catheter. With the doctor on the unit, your nurse will infuse the transplant. She will stay with you the entire time. She will take your vital signs, chart, work with the infusion, and talk with you. You may have more than one bag to be infused. The number of bags does not matter. What matters is the actual cell count. This is determined by the lab, and confirmed by a doctor. The length of the transplant depends on number of bags, gravity, and how you are feeling. It can take 15 minutes to 2 hours.

There is a preservative called dimethyl sulfoxide (DMSO). It protects the cells during freezing. It may cause a strange taste and smell during infusion. Eating hard candy or popsicles may cover the taste. The DMSO can also cause these symptoms:

- A rise in blood pressure
- Feeling sick to your stomach
- Throwing up
- Very rarely it may cause blood pressure to drop
- Abnormal heartbeats
- An allergic reaction.

If this happens, your nurse will slow the infusion. The doctor will be there to make decisions. Most often patients feel good on the day of transplant.

Inpatient transplants. Benadryl and other medicines may be added, including a steroid. Your urine may have a pink hue for a few hours. This is caused by red blood cells that were broken during freezing and thawing. These effects often last only a short time.

Outpatient transplants. Benadryl will be given before the infusion to prevent reactions. A normal saline infusion will follow the stem cells. It will last for two hours after the stem cell infusion is complete. This clinic visit may last between 3 to 5 hours. It will depend on the number of stem cell bags infused. Your transplant may be more than ten bags. If so, the infusions will take place two days in a row.

Your blood system delivers the stem cells to the bone marrow. The body directs the stem cells to stay in the bone marrow. The stem cells begin to replace your blood cells.

Hospital Routines

Each morning the BMT Team will visit you and check your condition. Mornings are a busy time. You will have lab draws, nurse assessment, Physician Assistants and Attending Doctor assessments.

Every day the BMT Team expects you to:

- Talk openly.
- Take a shower.
- Exercise.
- Do your mouth care.
- Take your medicines on time.

Talking with the Team

We can do a lot to ease and manage symptoms. The BMT Team needs to know how you are really feeling. We need to know what you are thinking. This helps us give you the best care. Please talk openly with the BMT Team.

Protective Isolation

All BMT patients are in “Protective Isolation”. These restrictions are worth it!

What are BMT Protective Isolation restrictions?

- Shower each day. Protect your skin and keep it moisturized.
- Each person washes hands or uses hand sanitizer when entering and leaving your room.
- Your door will stay closed.
- You will wear a N95 particulate mask when out of your room.
- All visitors will stop at the nurses’ station each day for a health screening. They must be healthy enough to visit.
- Your own children or grandchildren may visit. They must be 5 years or older, healthy, and current on all childhood shots.
- Your visitors are limited to 3 in your room at a time.
- Each room has a Hepa-Air filter or a Laminar Airflow fan. This will provide the best air quality.
- You are the only person who should use your phone, bathroom, or sit on your bed.
- Your IV tubing should be kept off the floor.

Exercise

Daily exercise is vital. A Physical Therapist (PT) will assess your baseline activity, strength, and stamina. You will then be given an exercise plan for you to follow during transplant. You will maintain and build upon this when you go home. You must set this as a priority each day. You will do this by:

- Walking in the hall. (1 lap= down the hall & back; 17 laps=1 mile)
- Stationary bike
- NuStep, a recumbent stair stepper
- Wii Fitness or Wii Sports
- Exercise bands
- Incentive Spirometer (it exercises your lungs!)

Mouth Care

You will likely develop some sores in the mouth and throat. They will range from mild to severe. This is called **mucositis** or **stomatitis**. For many people, this can be the most painful part of transplant. Your BMT Team will work to ease the pain. **Your** job is to do frequent mouth care to prevent infections and help healing.

- Use your mouthwash after each meal and at bedtime. More often if you like.
- No flossing.
- Use a soft-bristle toothbrush.
- Report sore areas or pain to the BMT Team.

Lab Draws

Labs are drawn from your central line each morning between 4-6 am. Call your nurse anytime you wake up after 4 a.m. We can bundle your care and get you back to sleep. Why so early? We can get results and act on them before the day gets started. It is a good jump-start for the day!

Vital Signs

The nursing staff will take your vital signs every 4 hours, around the clock. Each morning they will weigh you. They will also take your blood pressure lying in bed, sitting, and standing.

Intake & Output (I & O)

Each day the nursing staff will keep track of your I & O. Everything that goes into your body and comes out will be written down. The nursing staff will measure and dispose of your urine and bowel output. You should not dump these yourself. This is an infection risk for you. Staff needs to make sure you are getting enough fluids for your recovery. You will also have days when your calories are counted for 24 hours. This is called a Calorie Count. All food and drinks will be written down. The dietician will then figure the nutrition you have received.

Central Venous Catheter

The central venous catheter will be used for:

- Giving fluids
- Medicines
- Blood products
- The stem cell transplant
- IV nutrition if needed
- Lab draws

The dressing will be changed once a week. It must be flushed once a day.

Making Your Stay Comfortable

There will be some items and activities that make your hospital stay more comfortable. Here are some ideas:

- Feel free to bring items from home. Many patients like to bring family pictures, a favorite blanket, or their own pillow. Use a colorful pillowcase to tell it apart from the hospital pillows.
- You may bring your own laptop, or other electronic devices. Your room has:
 - a TV
 - cable
 - wireless internet
 - DVD player.

You may use a hospital laptop throughout your stay if you like. We also have Wii Sports & Wii Fitness for you to use. The Patient Library has hundreds of movies and books. You are welcome to check-out and view these.

The next page is a list of things you may want to bring for your hospital stay. There is also a list of things to leave at home.

Things You May Want to Bring:

Clothing

- 5 or 6 changes of loose fitting clothing or lounge wear. There is a washer/dryer on the unit. The nursing assistants will wash your clothes when you ask.
- Bathrobe and slippers with non-slip soles
- Underwear and socks
- Comfortable nightclothes, pajamas or nightgown
- Comfortable walking shoes
- Sweater or sweatshirt that buttons or zips up the front (no hoodies)

Personal items

- Eyeglasses and case
- Electric razor
- Favorite blanket or throw; your own pillow if you like
- Photos of family and friends
- Address book, phone card, cell phone
- Favorite drinks or snacks. Your room has a small refrigerator

Things to do

- A notebook or journal to write down your experience
- Favorite books, crossword puzzles
- I-pod or CD player with favorite CDs
- Laptop computer, electronic games
- Stationery, envelopes, and stamps

Paperwork

- Current lists, doses, and schedule of medications
- Durable Power of Attorney/Living Will

- Health insurance card & This Guidebook



Things to leave at home:

- Contact lenses
- Live plants, flowers, anything with dry moss
- Medicines
- Straight edge razors
- Toothbrush/toothpaste/floss (these will be given to you)

Rooming Guidelines

Your Caregiver is welcome to stay in the room with you. The guidelines are as follows:

- One guest may sleep in your room. Each room has a chair that makes into a bed. We will give you linens.
- Nursing staff is here to give care to the patient only. Your Caregiver needs to be aware of their own health and well-being. They need to ‘pace’ themselves during the transplant process. Sleep will be disturbed by needed patient cares, IV pumps beeping, and other noise. Make plans accordingly. Many area hotels offer reduced rates if your Caregiver will be more rested elsewhere. The Helen Rossi Guest House may be available.
- Limit personal items. The room is small and must remain neat.
- Visitors and your Caregiver are welcome to bring food from home. **Do not** store used food or drink containers in your room.
- The unit has a small kitchen. It has:
 - A full-size fridge and freezer
 - Dishwasher
 - Coffeemaker
 - Toaster
 - Blender
 - Microwave.

You and your Caregiver are welcome to use these.

Potential Complications

It is important that you understand that complications can happen with transplant.

Infection

Infection is one of the biggest risks patients face during BMT. The high dose chemotherapy you received stops your immune system for a while. Each person carries many kinds of germs on the skin and inside the body. They do not cause problems unless you have a weakened immune system. We will give you medicines to prevent some infections while your body cannot fight them. The entire BMT plan takes steps to protect you from infection. Using good hand washing is the most important thing you can do. Also, follow the BMT Team instructions.

Infections of Concern:

Infection	Description	BMT Plan	What You Can Do
Lungs	Viral, bacterial, or fungal.	<ul style="list-style-type: none"> - Antibiotics to prevent infection -Antibiotics added as needed -Chest x-rays will be done as needed. -A CT Scan will be done if the x-ray is of concern. 	<ul style="list-style-type: none"> -Use your Incentive Spirometer! -Use good handwashing. -Exercise. -Follow BMT Team instructions.
Herpes Simplex Virus (HSV) Herpes Zoster Viruses (HZV)	Cold sore virus Chicken pox/Shingles virus	<ul style="list-style-type: none"> -Each patient is tested before transplant. -Anti-viral medicine. -Areas that look like HSV/HZV will be swabbed and sent to the lab. 	<ul style="list-style-type: none"> -Use good handwashing. -Follow BMT Team instructions. -Talk openly with the BMT Team.
Vancomycin Resistant Enterococcus (VRE)	Vancomycin is a strong antibiotic. The team may need to use it for you. Sometimes the germ (enterococcus) can become resistant to Vancomycin. This happens with weakened immune systems.	<ul style="list-style-type: none"> -All inpatients are checked for VRE when they arrive for their hospital stay. It is also done each Monday. -If you test positive: <ul style="list-style-type: none"> *You will need to wear a gown and gloves when out of your room. *Staff and visitors will wear gown and gloves to enter your room. 	<ul style="list-style-type: none"> -Perform the VRE check on yourself. Use the sterile swab given you when you arrive. Repeat each Monday. It is a gentle swab from your anus. -Tell your nursing assistant when you have finished. -Always use good handwashing.

Engraftment Syndrome

When the transplant stem cells engraft there may briefly overreact. This is called Engraftment Syndrome. It may include fever, rash, or breathing problems. It is treated with steroids.

Heart, Lungs, and Kidneys

You will receive heart, lung, and kidney testing before transplant. During transplant the BMT Team will continue to watch these systems. We will test as needed. These organs and body systems may have trouble tolerating the transplant. Many of the complications can be treated. In some cases they may need to be handled in the ICU. If this happens, the BMT Team uses the Medical-ICU. BMT patients will be followed by the BMT Team for transplant related needs. The ICU team will take care of critical care needs. The BMT Team will serve as a resource.

Recovery

After transplant and before engraftment, blood counts will fall. Patients often need blood products (red blood cells and platelets). You may feel weak, tired, and dizzy or light-headed with low blood counts. This is the time that you often get mouth sores and a sore throat. You may have a decreased appetite and maybe an increase in nausea. You can expect to feel poorly for about 7 days after transplant or until engraftment starts. This is the time you are neutropenic and most prone to infections. The worst days are most often days 7, 8, 9, and 10 after transplant. It is very important that you are protected from complications before and after engraftment. As your counts come up, you will start to feel better.

Engraftment occurs after the stem cell transplant when the bone marrow makes new blood cells. After the stem cells are infused, the bloodstream carries them to the bone marrow. The body's own chemical signals direct the stem cells to stay there. They start to make new stem cells and blood cells. White blood cells reach a certain level of recovery in 10 to 14 days. This level is measured through blood work, most importantly the segmented neutrophils (segs). The transplant is considered engrafted when the level is steady for three days in a row. Red blood cell and platelet counts become stable in another one to two weeks.

Your care is transferred back to your BMT Doctor after discharge from the hospital. Your doctor will see you in the clinic. You may need outpatient transfusions after discharge. Eventually, your care will transfer back to your local oncologist or hematologist. This happens roughly six to twelve months after transplant. How often your BMT Doctor will continue to see you will depend on:

- What medicines you are taking
- Your overall health
- If you are having any complications from your transplant.

Your hair will start to re-grow in about 3 months. Your taste buds will return to normal in about 4 months. Your energy and stamina may stay low for up to a year. It is not unusual to need rest periods or naps. The best way to regain your energy is to pace yourself and stay active.

Lodging Options for Patients and Families of the Adult Stem Cell Transplant and Multiple Myeloma Program

You may be asked by your doctor to stay close to UIHC for further care. The following is a list of options for lodging in the area. Please review the information. If you would like help, please call the BMT Social Worker at 319-356-3994.

American Cancer Society Hope Lodge -- 750 Hawkins Dr, Iowa City (319)-248-5400

- Rooms available on a first come, first served basis for all patients receiving cancer care.
- No charge.
- Private rooms and bathrooms, shared living and kitchen spaces.
- Patients must stay, not for Caregivers only
- Patients must meet eligibility criteria and live more than 40 miles from UIHC
- Referral must be made by the Social Worker
- Shuttle available to UIHC

<http://www.cancer.org/treatment/supportprogramsservices/hopelodge/iowacity/iowa-city-about-our-facility>

Heartland Inn -- 87 2nd Street, Coralville, IA 52241 (319) 351-8132

- Limited number of rooms are available to HSCT/ Multiple Myeloma patients at a rate of \$40+tax per night
- Contact the BMT Social Worker for availability and reservations
- 25 item breakfast buffet, Sun-Thurs light evening meal, microwave and refrigerator in each room, shuttle to the hospital

http://www.heartlandinns.com/loc_IowaCity.php

Suburban Extended Stay -- 2491 Holiday Road, Coralville (319) 625-2200

- Offers a hospital rate as well as a special rate of \$48 (\$85 on football weekends) through the American Cancer Society
- Kitchenette in each room
- No hospital shuttle
- Call the American Cancer Society Navigator, Sara Green-Otero at 319-356-4285 or the BMT Social Worker at 319-356-3994 if you would like the discounted rate
- Reservation made by pt/ family

<http://www.suburbanhotels.com/hotel-coralville-iowa-IA152>

Area Hotel/Motel Guide

- Many area hotels give hospital discount rates
- Assistance available from: UIHC Concierge Services (319) 356-1900
- Patients/ Families make own reservation
- The following link offers the list as provided by Concierge Services

[http://www.uihealthcare.org/uploadedFiles/UIHealthcare/Content/Your_Visit/While_You_Are_Here/Places_to_Stay/Hotel-Motel%20guide%20July%202012\(1\).pdf](http://www.uihealthcare.org/uploadedFiles/UIHealthcare/Content/Your_Visit/While_You_Are_Here/Places_to_Stay/Hotel-Motel%20guide%20July%202012(1).pdf)

Preventing Infections at Home

Good hand washing is the most important thing you can do to prevent infections. Use plenty of soap and warm water. **Scrub** your hands for at least 15 seconds (say the alphabet—that's about 15 seconds). The scrubbing removes the germs, and the soapy water washes them away. Rinse well and dry hands thoroughly. Paper towels are best. Turn off the water using the paper towel. Gel sanitizers are helpful when soap and water washing is not available.

Each person must wash or sanitize their hands when they come to visit. You and everyone in your home need to wash hands often.

Wash your hands at these times:

- Before eating, drinking, or taking medicine
- After using the bathroom
- Before making meals
- Before and after oral care, central line care, and connecting IV tubing
- After touching the eyes, nose, mouth, or any part of the face
- After touching things in your environment that others touch often
- After shaking hands
- After public outings

Personal Hygiene at Home

Your skin is the first line of defense against infection. These actions will decrease the number of germs on the skin:

- Shower each day.
- Shampoo hair or head each day.
- Check skin daily for rashes, bruising, redness, or swelling. Keep skin folds clean and dry, including genital and rectal areas.
- Change towels daily.
- Do not share towels with anyone.
- Brush teeth with a soft-bristled toothbrush after each meal and at bedtime.
- Ask your BMT team when it is okay to floss.

Avoid Dangerous Exposures

- Crowds of people increase exposure to harmful germs.
- In the first 3 months after transplant, avoid grocery stores, shopping, etc. Your Caregiver needs to do the shopping.
- Avoid construction sites. This includes homes or buildings being remodeled or repaired.
- The following activities involve close contact with harmful germs. **Do not** do any of the following:
 - touch human or animal feces
 - change baby diapers
 - touch bird droppings
 - clean the aquarium
 - clean up after pets
 - sit on grass, logs, or dirt
 - allow skin contact with dirt, lawn waste, leaves, or compost
 - change the water on flower arrangements
 - handle plants

Monitoring for Infection

Fever can be a sign of infection. You must check for a temperature daily. Do this even if you do not feel warm or sick. Here are some guidelines:

- Take your temperature at least twice a day. Once in the morning and around 4 p.m. Take it more often if it seems to be on the rise.
- Wash the thermometer with **warm** water and soap after each use. Another choice is to wipe it with alcohol after each use.
- Do not allow anyone else to use your thermometer.
- Do not take Tylenol, ibuprofen, or aspirin until you have talked a BMT team member. They will tell you if it is ok to take. Taking Tylenol when a temperature is rising affects true tracking of a possible fever.
- Always call the BMT clinic or hospital if you have a fever equal to or greater than 100.4°F or 38.0°C. **Talk directly to a member of the BMT team. You need to remember that steroids also may partially mask a fever.**
- Call the BMT team if chills occur, even without a fever.

See next page for Celsius to Fahrenheit temperature conversions.

CELSIUS TO FAHRENHEIT TEMPERATURE CONVERSIONS

Celsius	Fahrenheit
35	95
35.1	95.2
35.2	95.4
35.3	95.5
35.4	95.7
35.5	95.9
35.6	96.1
35.7	96.3
35.8	96.4
35.9	96.6
36	96.8
36.1	97
36.2	97.2
36.3	97.3
36.4	97.5
36.5	97.7
36.6	97.9
36.7	98.1
36.8	98.2
36.9	98.4
37	98.6

Celsius	Fahrenheit
37.1	98.8
37.2	99
37.3	99.1
37.4	99.3
37.5	99.5
37.6	99.7
37.7	99.9
37.8	100
37.9	100.2
38	100.4
38.1	100.6
38.2	100.8
38.3	100.9
38.4	101.1
38.5	101.3
38.6	101.5
38.7	101.7
38.8	101.8
38.9	102
39	102.2
39.1	102.4

Celsius	Fahrenheit
39.2	102.6
39.3	102.7
39.4	102.9
39.5	103.1
39.6	103.3
39.7	103.5
39.8	103.6
39.9	103.8
40	104
40.1	104.2
40.2	104.4
40.3	104.5
40.4	104.7
40.5	104.9
40.6	105.1
40.7	105.3
40.8	105.4
40.9	105.6
41	105.8
41.1	105.9

Frequently Asked Questions about Going Home

How long do I have to wear the N95-Particulate mask?

The mask protects you against airborne infections. Airborne infections develop when bacteria, viruses, or fungi are breathed into the lungs.

You must wear your mask when you come to the hospital for clinic appointments. Also wear it when you are in crowds or dusty places. You will wear it until your immune system is stable. For Dr. Silverman & Dr. Farooq patients, this is most often at least three months after your transplant. For Dr. Tricot & Dr. Abbi patients, this can be 2 years. Your BMT team will decide how long you must wear your mask. Their instructions are the final word. They will be watching your labs closely. They will know when the transition is best for you.

Do I need a Caregiver at all times?

If you are having an outpatient transplant- Yes. Through the weeks of outpatient transplant care. If you are having an inpatient transplant, you will need a Caregiver with you pretty much 24/7 for the first 1-2 weeks after discharge. Then we'll see how you're doing at that point.

After your discharge you will need a Caregiver available to help you:

- Remember scheduled medicines
- Make sure you eat and have the right foods
- Keep track of the water you drink
- Stay motivated
- Help build your stamina
- Provide transportation to and from clinic visits, etc.

Do I need to stay away from people with the flu or a cold?

Yes. Talk openly with friends and family. They do not need to visit you if they are not fully healthy. Your Caregiver should get a flu shot through their doctor or clinic. Caregivers should **not** get the nasal mist flu vaccine. It is a live-vaccine.

Do I need to stay away from people who have had vaccines?

You need to stay away from children who have had live-vaccines. Avoid people who have received the chickenpox vaccine for at least 2 weeks. Oral polio vaccines also carry a risk. They are no longer given in the United States.

If you are exposed to chickenpox or shingles, call the BMT team right away. You will receive vaccines after your immune system has recovered. You may get a tetanus or pneumonia

vaccine. You will need a flu vaccine each year. Talk to your provider at that time to confirm that you have received them.

Will a dog in the home increase my risk of infection?

Dogs are fine. In general, dogs do not carry organisms harmful to humans. If the dog licks you, wash the area with soap and water. You may pet or cuddle your dog. If your dog sleeps on your bed, it should not sleep by your head. Wash your hands after playing with the dog. Do not clean up dog feces. That will be a job for someone other than you. Avoid new puppies that bite or scratch, as infection could easily result. Talk to your BMT team for more details.

What about cats?

Cats pose more problems than dogs. Their sharp claws easily scratch your skin, exposing you to infection. The same general rules apply as for dogs. Take extra care to avoid being scratched. Cat feces can carry a germ that causes toxoplasmosis, a serious disease. Do not handle the feces or the litter box.

What about other animals?

Avoid birds, reptiles, fish tanks, and farm animals. They are more likely to carry harmful diseases.

Do I need to limit contact with plants or avoid doing gardening work?

Yes. Limit your contact with plants for at least 100 days. Plants may be present in your home. Do not work with their soil. Plant care should be done by your Caregiver.

What about going outside?

Once you're home you may go outside, **with your mask on**. There should be very little wind when you go out. If you live in the country avoid going outside while nearby farmers are working the fields. Skin may become more sensitive to soaps and detergents. If you have problems, use hypoallergenic, unscented soaps and laundry detergents. High-dose chemotherapy (such as what you received) predisposes you to skin cancer. You must avoid getting sunburned. Use a sun-protection factor equal to or greater than SPF 50 for UVB protection. It should contain zinc oxide for UVA protection. Both types of rays are dangerous. Apply sunscreen 20 minutes before going outside. Reapply often when in the sun. **Do not** sunbathe. It is best to avoid the sun, both in direct exposure and through windows. Riding in the car exposes you to UV rays. When you are in the sun wear:

- A wide-brimmed hat
- Long-sleeved shirt, long pants

When can I return to work?

This will be determined during your clinic visits with your BMT providers. The decision is based on:

- The type of work you do
- Contact with people
- Your labs
- Your well-being
- The state of your recovery
- What your doctor thinks is best

In general you will be waiting at least three months after your transplant. Your bone marrow is still recovering. It will take at least that long for your immune system to work normally. The risk of catching a contagious disease at school or work is too high. You must wait until your immune system is working as it should.

How much activity should I do at home?

Develop an exercise plan and set goals. Do not take part in strong exercise or contact sports. Walking and riding a stationary bike are very good exercise. Do not swim or use hot tubs. Have an exercise plan, and stick with it. You need a healthy level of activity.

What about sexual activity?

It is safe to resume normal sexual activity after chemotherapy and transplant. Your platelets must be 40,000 or higher. Discuss any concerns, problems, or discomfort with your nurse or BMT team. Remember that sex is a function of the mind and the body. It takes time for both to heal. Decreased sexual desire is normal after transplant. This is due to changes in hormone levels, anxiety, or depression. Hormone levels can change due to the chemotherapy you received. Some antidepressants can affect sexual function. Talk to your provider if you are having problems.

Latex condoms should be used by:

- Men who have had BMT
- Partners of women who have had BMT

This practice serves two purposes. It decreases the risk of infection and it prevents untimely pregnancies. **For men**, chemotherapy sometimes causes brown or orange semen. This condition is short-term. **For women**, chemotherapy can cause vaginal dryness. Use a water-soluble lubricating jelly to prevent trauma during intercourse. Do not use oil-based lubricants like Vaseline.

How tired will I be?

You may be more tired than you expect. Listen to your body and allow rest periods during exercise. Increase your level of activity slowly. Remember that your upper legs are most often the weakest. Good strength in your upper legs is vital to your stability. Weak upper leg muscles will lead to an increased risk of falling. Focus your activities on strengthening your upper leg muscles. Talk about this openly with your family and friends.

The fatigue from cancer and its treatments is different than other types of fatigue. It can be severe. It is not always relieved with rest. It does not always go away right after treatment ends. Others in your life may not be able to understand your fatigue.

You need to remember these facts about fatigue:

Feeling tired is normal during this time.

It does not mean the cancer is advancing.

It does not mean the treatment is not working.

It is not caused by lack of willpower. You need treatment and support for the fatigue.

Ways to Manage Fatigue

- Walking and other forms of exercise can help.
- Do not be discouraged if you are not able to walk very long. Simply start at a comfortable level. Ask your doctor for advice about what level of exercise is right for you.
- Choose an exercise that you enjoy, in a pleasant setting.
- Expand on an exercise activity you already do. It is easier than starting something new.
- Save energy. Set priorities for what you must do each day. Allow yourself to take a slower pace and to give tasks to others.
- Take short naps as needed. Do not sleep so much during the day that you cannot sleep at night.
- Distraction. Get together with small groups of friends and family for short periods of time. Play music you enjoy. Read short stories and news articles if you have trouble concentrating. Read longer books a chapter at a time.
- Keep in touch with friends by e-mail.
- Try healing activities. This could be bird watching or visiting a nearby park or natural area.

What about my diet?

Your appetite may decrease. Good nutrition is important to maintain your strength and sense of well-being. Food safety is critical for people with a low white blood cell counts (neutropenia). You can become seriously ill from food-borne illnesses.

Dr. Tricot and Dr. Abbi recommend a special diet. It will limit your risk of food contamination. It is called a Reduced Microbial Neutropenic Diet. This diet avoids foods that are likely to contain infection-causing organisms. It is used during transplant until your white blood cells and segs have recovered.

During this recovery, when you are not staying in the hospital, Dr. Tricot and Dr. Abbi recommend that the best options for your diet are in this order:

#1 Self-cooking

#2 Frozen meals

These should be the majority of your meals. These should be your choices before choosing a restaurant.

You can ask your dietitian or health care provider questions about the diet.

It is important to follow the guidelines from your doctor. Read the information listed here and avoid foods that may cause food-borne illness. All your food must be prepared with care and cooked to the proper temperatures.

General Guidelines

Fruits and vegetables

- Be certain all fresh fruit and raw vegetables are cleaned and well-washed.
- Do not eat pre-cut vegetables or fruits.
- Do not eat raw sprouts.

Meats and other proteins

- Cook all meat, poultry, seafood, egg, and tofu products until well done.
- Do not eat uncooked hotdogs or uncooked luncheon meats.
- Avoid aged and Mexican cheeses. Cheeses with blue mold, vegetables, peppers, or seasonings are not allowed.
- Avoid raw nuts.

Other food items

- Make sure all milk products, juice, and honey are pasteurized.
- Do not eat refrigerated cheese-based salad dressings.
- Avoid deli food items.
- Do not eat commercially made fresh salsa.

- Do not eat restaurant or convenience-store prepared food or drinks.
- Do not take herbal supplements.
- Do not eat outdated foods.

Here are a few ideas to help you increase your calorie and protein intake.

- Calories in any form are a priority after transplant. Adding margarine and oil freely to foods can add calories.
- Protein is also an important part of your diet. It helps your body recover from the stress it has been through. Chop eggs or grate cheese into soups, sauces, and casseroles.
- Your appetite may be low. Eat frequent, small meals. This will help you keep up your caloric intake.
- Fluid intake is highly important in hot, dry weather. The following liquids and semi-liquids add to your fluid intake.
 - Milk
 - Juice
 - Water
 - Jell-O
 - Ice cream
 - Puddings
 - Yogurt
- Most patients need at least 2 liters (about 68 ounces) of fluid daily. Your BMT Doctor may limit your salt intake. This happens if you are having trouble with swelling or edema. Your lab work may also show you need to limit salt.

When Should I Call?

It is important to know when to call the BMT staff. Call for help when any of the following things occur:

- Rapidly worsening general fatigue
- An oral or ear temperature of **100.4 Fahrenheit (38.0° Celsius)** or greater **Call right away**. Do not take Tylenol, ibuprofen, or aspirin. Buy a thermometer if you do not have one.
- Any episode of shaking chills or intense sweating
- Coughing, sneezing, runny nose, chest tightness with breathing, chest pain, or shortness of breath
- Frequent or burning urination
- New redness, swelling, or tenderness at the central line catheter
- New rashes, blisters, or cold sores anywhere on the body
- Headache or stiff neck
- New onset of nausea or vomiting that keeps you from drinking your normal amount of fluid
- Large volume and increased rate of diarrhea
- Blood in urine, stool, sputum, or bleeding from gums or nose
- New or unusual bruising

Contact us with questions or concerns. Call us directly anytime day or night. Use the emergency room only for medical emergencies.

**Monday through Friday, 8 a.m. - 5 p.m.
Holden Clinical Cancer Center 319-356-4422**

**Weekdays after 5 p.m., weekends and holidays
Call the main UIHC number 319-356-1616. Ask the operator to page the Hematology-Oncology Fellow on call for BMT.**

Section Four: Other Helpful Information

Food Safety Instructions from Dr. Tricot: Food safety is important after your transplant. Your weakened immune system makes you more prone to food-borne illnesses. It also makes them more difficult to treat.

Food-borne illness is caused by eating food contaminated with bacteria, viruses, molds, or parasites. Improper food handling causes most food-borne illness. Follow these basic food safety guidelines to reduce your risk of food-borne illness.

Shopping

General guidelines

- Shop at food stores that maintain high sanitary standards for the store and staff.
- Shop for refrigerated and frozen foods last. This keeps them from warming up while you shop.
- Do not buy food with damaged packaging.
- Do not use foods after their **sell-by** or **best-used-by** date.
- Return home quickly to put away chilled and frozen foods. Carrying food around in the car can allow bacteria to grow to unsafe levels.
- Do not choose food displayed in an unsafe way such as:
 - Raw fish on the same bed of ice with cooked fish
 - Samples left out on a counter.
- Avoid foods in bulk containers like nuts, candies, or granola. You may buy them if you will be cooking them prior to eating.
- Avoid unpasteurized or raw honey. It may contain bacteria.

Fruits and vegetables

- Fruits and vegetables should look fresh.
- Cook precut vegetables or fruits before eating. **Do not** eat them raw.
- Avoid raw sprouts such as alfalfa, clover, and radish.
- Avoid unpasteurized, fresh-squeezed fruit or vegetable juices and cider. Use juices that are processed to eliminate harmful bacteria. This includes frozen concentrates, shelf-stable juice in airtight sealed containers, and canned juices.

Meats and dairy

- Use only pasteurized milk and cheese products. Look for the word **pasteurized** on the label.
- Avoid Camembert, Brie, feta, and blue mold cheeses.
- Place raw meat, poultry, and seafood in plastic bags. Keep them separate from other foods in your shopping cart and grocery bags.

Food Storage

- Keep refrigerated food at or below 40°F. Keep frozen food at or below 0°F. Use refrigerator and freezer thermometers to ensure proper temperatures. You can buy them at most kitchen stores and supermarkets.
- Keep raw meat, poultry, and seafood separate from other foods in your refrigerator. Keep separate while preparing and handling foods.
- Keep fresh eggs refrigerated in their original container.
- Store leftovers on the upper shelves of the refrigerator. Store raw foods on the lower shelves.
- Do not over-pack foods in the refrigerator or freezer. This will keep all items properly cooled.
- Do not keep raw meats or prepared foods in the refrigerator greater than three days. This includes casseroles and potato salad. If you will not be eating foods within this time, you can freeze them.

Food Handling

- Keep shelves, countertops, refrigerators, freezers, utensils, sponges, and towels clean.
- Use separate, labeled cutting boards for raw meat and for fresh fruits and vegetables.
- Throw out wood cutting boards if they have cracks or grooves.
- Wash produce with water and a brush before peeling, slicing, cooking, or eating.
- Wash leafy vegetables such as lettuce, spinach, and cabbage under lukewarm running water. Wash each leaf separately.
- Rinse prepackaged salads or vegetables even if labeled as **prewashed**.
- Wipe the tops of cans with a clean cloth before opening.
- Thaw frozen meats in the refrigerator or microwave. Do not leave out at room temperature.

Preparing Food

- Wash your hands before making meals or snacks.
- Cover cuts or open sores on the hand with a plastic sealing bandage. You may wear plastic gloves while making food.
- Use a kitchen thermometer to check food temperatures. You can buy them at most kitchen stores and supermarkets.
- Use a clean plate for cooked animal products. Do not use the same plate that held the raw meat.

- Never eat raw or undercooked eggs. Both yolk and white must be firm, not runny.
- Cook food items that contain eggs thoroughly. Do not use raw eggs in uncooked foods. Use a pasteurized egg product in homemade Caesar salad dressing, ice cream, and mayonnaise.
- Do not allow foods to stand at room temperature for more than two hours. When temperatures are above 90°F (32°C), shorten this time to one hour.
- Heat prepackaged deli meat and poultry products until they are steaming hot (165°F). This includes hot dogs, sliced roast beef, turkey, and chicken breasts.

Eating Out

General

- Ask your doctor when it is safe for you to dine out or eat take-out foods.
- Choose a restaurant with clean plates, utensils, glasses, staff, and restrooms.
- Dine during off-peak hours and ask for an out-of-the-way table.
- Avoid these places:
 - salad bars
 - potlucks
 - sidewalk vendors
 - delis
 - smorgasbords
 - Buffet-style dining.
- Follow the same food restrictions you follow at home. Ask about ingredients in a specific dish before ordering.

Food Preparation

- Ask for well-done meats, fish, eggs, and poultry. Check for doneness by cutting into the center of a piece of meat. If it is bloody or pink, send it back for more cooking. Fish should be flaky, not rubbery, when cut.
- Avoid raw meat, poultry, and fish such as oysters on the half-shell, raw clams, sushi, and sashimi. Foods made with raw fish are more likely to contain parasites or bacteria.
- Avoid raw fruits and vegetables.
- Make sure fruit and vegetable juices are pasteurized, not fresh-squeezed.
- Do not use public self-serve condiments. Ask for individual condiment packets or for an unopened container that you can open yourself.
- Ask that your food be prepared fresh in fast-food restaurants.
- Ask your server to deliver your meal promptly as soon as it is prepared.

- Select food with care when traveling out of the country. Any raw food can be contaminated. Cooked foods that are served hot are generally considered safe.

Leftovers and delivery

- Leave the leftovers at the restaurant if you will not be arriving home within two hours of being served. If you do take leftovers home refrigerate them immediately.
- Do not use restaurant delivery services. The food may be in transit too long.
- Select food with care when traveling out of the country. Any raw food can be contaminated. Cooked foods that are served hot are generally considered safe.

Water

- Do not use water that has not been treated with chlorine. If you have well water it should be tested before returning home from the hospital. The health department should test well water yearly for coliforms and cryptosporidium. Test more often if the well is at risk for contamination. Causes of contamination are:
 - Construction
 - Flooding
 - Spring runoff near the well
 - The well is shallow
 - The well is near a livestock herd
- Use bottled water if you are unsure about the quality of your tap water.
- Drink only bottled water when traveling out of the country. Do not use ice in any drink unless it was made from boiled or bottled water.

Food Safety during Power Outages

- The biggest challenge in an extended power outage is keeping temperatures in the safe range. The refrigerator must be below 40°F and the freezer below 0°F.
- Keep refrigerator and freezer doors closed to maintain cold temperatures. A full freezer will stay below 0°F for about 48 hours. A half-full freezer will stay below 0°F for about 24 hours.
- Use dry ice or block ice to help keep your freezer and refrigerator cold. Fifty pounds of dry ice will keep a full 18-cubic-foot freezer below 0°F for two days.
- Assess the safety of the food once the power is back on. Refrigerated foods are safe if the power was out less than four hours. Throw out all leftovers, meat, poultry, eggs, or fish that have been above 40°F for more than two hours. These foods can make you sick even after cooking.