The Allogeneic Blood & Marrow Transplant Guidebook
Adult Blood and Marrow Transplant Program

Approved by the Office of Patient Education, 2014
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 One: Introduction

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.

<table>
<thead>
<tr>
<th>Health Care Staff</th>
<th>What they do</th>
</tr>
</thead>
</table>
| BMT Doctor        | - 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  | - 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  | - 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
- 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.

Donor Coordinator
- Arrange the donor search
- Lets the BMT team know about donor/patient match.
- Tells the BMT Team about the collection plan.

Social Worker
- Help you find housing.
- Help with work related issues, disability, and leave programs.
- 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.
<table>
<thead>
<tr>
<th>Role</th>
<th>Responsibilities</th>
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<tbody>
<tr>
<td><strong>Pharmacist</strong></td>
<td>- Give supportive care to you and your family.</td>
</tr>
<tr>
<td></td>
<td>- Talk with your doctors to give the medicines ordered for you. They will do this</td>
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<tr>
<td></td>
<td>before, during, and after transplant.</td>
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<tr>
<td></td>
<td>- Teach you and your Caregiver about your medicines. This is done before</td>
</tr>
<tr>
<td></td>
<td>transplant, and before going home after transplant.</td>
</tr>
<tr>
<td><strong>Nursing Assistants</strong></td>
<td>- Take your vital signs.</td>
</tr>
<tr>
<td></td>
<td>- Help with your laundry, setting up your shower, and changing your linens each</td>
</tr>
<tr>
<td></td>
<td>day.</td>
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<td></td>
<td>- Talk with you and your nurse about your care.</td>
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<td></td>
<td>- Offer support for you and your family.</td>
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<tr>
<td><strong>Physical Therapist</strong></td>
<td>- Assess your baseline activity, strength, and stamina.</td>
</tr>
<tr>
<td></td>
<td>- Give you an exercise plan to follow during transplant, and when you go home.</td>
</tr>
<tr>
<td><strong>Recreational Therapist</strong></td>
<td>- Give you things to do during your transplant stay.</td>
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<td></td>
<td>- Talk with you about your interests and give support through activities.</td>
</tr>
<tr>
<td><strong>Dietician</strong></td>
<td>- Teach you about food guidelines for transplant.</td>
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<tr>
<td></td>
<td>- Assess the amount of calories you are eating to help with recovery and stamina.</td>
</tr>
<tr>
<td><strong>Financial Coordinator</strong></td>
<td>- Help you know your BMT insurance coverage.</td>
</tr>
<tr>
<td></td>
<td>- Help you talk with the right financial staff member.</td>
</tr>
</tbody>
</table>
Who to Contact
(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 Class
Shannon Hunger Shannon-hunger@uiowa.edu 319-384-9102

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.
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

<table>
<thead>
<tr>
<th>Term</th>
<th>What it is</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Allogeneic transplant</strong></td>
<td>The use of donor stem cells for your transplant. Donor stem cells come from a genetically matched person.</td>
</tr>
<tr>
<td><strong>Anemia</strong></td>
<td>A state in which you have less than normal red blood cells. Signs of anemia are feeling tired, weak, and short of breath.</td>
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<tr>
<td><strong>Apheresis</strong></td>
<td>The collection of stem cells from the blood using a machine that can separate the blood cells.</td>
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<tr>
<td><strong>Autologous transplant</strong></td>
<td>Your own stem cells are used for your transplant.</td>
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<tr>
<td><strong>B lymphocyte</strong></td>
<td>A cell of the immune system that helps protect you from infection.</td>
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<tr>
<td><strong>Bone marrow</strong></td>
<td>A liquid that looks like blood. It is the spongy tissue found inside large bones, such as the hip bones.</td>
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<tr>
<td><strong>Bone marrow biopsy</strong></td>
<td>A procedure used to obtain a sample of bone marrow for testing.</td>
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<tr>
<td><strong>Central venous catheter</strong></td>
<td>An IV tube placed in a vein under the collarbone. The tube is used to give fluids, medicines, and take blood samples.</td>
</tr>
<tr>
<td><strong>Consent form</strong></td>
<td>A form that lists your treatment plan and the risks and benefits of transplantation.</td>
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<tr>
<td><strong>Differential</strong></td>
<td>A lab test. It shows the number of different types of white blood cells present in the blood.</td>
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<tr>
<td><strong>Donor</strong></td>
<td>The person who is the source of stem cells used in transplant.</td>
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<tr>
<td></td>
<td>• You can be your own donor.</td>
</tr>
<tr>
<td></td>
<td>• The donor can be a genetically matched person. Types of donors include brothers, sisters, and unrelated volunteer donors.</td>
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<tr>
<td></td>
<td>• In some cases the donor may be a partial match, or ‘mismatched’.</td>
</tr>
<tr>
<td><strong>Eligibility</strong></td>
<td>A series of tests to see if you are healthy enough for transplant. These tests check:</td>
</tr>
<tr>
<td></td>
<td>• organ (heart, lung, kidney, and liver) function</td>
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<tr>
<td></td>
<td>• blood counts</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
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<tr>
<td>• bone marrow</td>
<td>The recovery of the blood cells after the stem cells are transplanted.</td>
</tr>
<tr>
<td>• the status of your disease.</td>
<td>A collection of stem cells that is infused. The graft may be your own stem cells or donor stem cells.</td>
</tr>
<tr>
<td><strong>Engraftment</strong></td>
<td>A complication of donor stem cell transplant. It is an immune reaction of the donor’s cells against your body tissues.</td>
</tr>
<tr>
<td><strong>Graft</strong></td>
<td>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</td>
</tr>
<tr>
<td><strong>Holden Clinical Cancer Center (HCCC)</strong></td>
<td>Also referred to as “Clinic”. This consists of your Outpatient Doctors clinic, its lab, and Infusion Suite. It is found on the 1st and 2nd floors of the Pomerantz Family Pavilion at UIHC.</td>
</tr>
<tr>
<td><strong>Human leukocyte antigen (HLA)</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Immune system</strong></td>
<td>A system made of specialized cells of the body. It protects you from germs in the environment that cause infections.</td>
</tr>
<tr>
<td><strong>Immunosuppressants</strong></td>
<td>Medicines given to weaken the immune system. They are given to prevent or treat graft versus host disease.</td>
</tr>
<tr>
<td><strong>Inpatient</strong></td>
<td>A person who gets care in the hospital.</td>
</tr>
<tr>
<td><strong>Microorganisms</strong></td>
<td>Small organisms that can cause infections. This includes bacteria, virus, parasite, or fungus.</td>
</tr>
<tr>
<td><strong>Mobilization</strong></td>
<td>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.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Monoclonal antibody</td>
<td>A protein that is designed to destroy one type of cell. For example, rituximab can destroy lymphoma cells.</td>
</tr>
<tr>
<td>Mucositis</td>
<td>Inflammation of the mucous membranes in the mouth, throat, GI tract, or rectum. Symptoms are redness, swelling, sores, dry mouth, thick saliva, pain.</td>
</tr>
<tr>
<td>Myeloablative</td>
<td>A program of high dose chemotherapy with or without radiation. It will completely destroy your body’s ability to make blood cells.</td>
</tr>
<tr>
<td>Neutropenia</td>
<td>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.</td>
</tr>
<tr>
<td>Non-myeloablative</td>
<td>Low or standard doses of radiation, chemotherapy or immune suppressing medicines. The purpose is to suppress your immune system. This lets the donor’s cells grow and function.</td>
</tr>
<tr>
<td>Outpatient</td>
<td>Your medical care is provided while you are living at home or in local housing. You come to the Holden Cancer Center to receive care.</td>
</tr>
<tr>
<td>Platelets (Plts)</td>
<td>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. Normal range: 150-400 thousand/MM3 You will often hear this number without the “thousand” stated.</td>
</tr>
</tbody>
</table>
| Preparative Regimen                     | High dose chemotherapy, with or without radiation, given before transplant. This has a multi-purpose:  
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. |
<p>| Red blood cells (RBC)                   | A blood cell that carries oxygen throughout the body. Normal range for females: 4.0-5.2 million/uL. Normal range for males: 4.4-5.9 million/uL. You will often hear this number without the “million” |</p>
<table>
<thead>
<tr>
<th>Safe Zone</th>
<th>100 mile radius of UIHC.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stem cells</td>
<td>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.</td>
</tr>
<tr>
<td>Stomatitis</td>
<td>Inflammation of an opening in the body. Redness, swelling, sores in the mouth or anus.</td>
</tr>
<tr>
<td>Thrombocytopenia</td>
<td>A low platelet count. A low platelet count raises the risk of bleeding.</td>
</tr>
<tr>
<td>T lymphocyte</td>
<td>An immune system cell that protects your body from infection and foreign tissue. It is involved in graft versus host disease.</td>
</tr>
<tr>
<td>Transfusions</td>
<td>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.</td>
</tr>
</tbody>
</table>
| White blood cells (WBC)   | White blood cells protect the body from infection. There are many types of white blood cells:  
  • neutrophils  
  • eosinophils  
  • basophils  
  • monocytes  
  • macrophages  
  • lymphocytes  
Normal range: 3.7-10.5 thousand/MM3  
You will often hear this number without the “thousand” stated. |
Section Two:
Allogeneic Blood or Marrow Transplantation (BMT)

The 5 steps of transplant are:
1. Finding a donor
2. Giving the preparative/conditioning regimen
3. Collecting the stem cells from the donor
4. Infusing the stem cells (Transplant)
5. Recovery
Step 1: Finding a Donor

A donor may be a full or partial genetic match. The donor may be a sibling, or an unrelated volunteer donor from the volunteer registries.

A tissue typing blood test will first be done on you and your full siblings. This blood test is limited to full brothers and sisters. These are the people who the same mother and father as you. This test is called Human Leukocyte Antigen (HLA). This test looks at genetic codes on your white blood cells. The codes are from your parents. Half are from your father and half from your mother. Other relatives or friends are rarely asked to give a sample for HLA typing. The chance they will match is very slim. Most insurance companies will not cover typing persons outside your immediate family. Only about 25% of all patients have a matched donor within their families.

You may not have a family member whose HLA type matches yours. A Donor Coordinator will enter your HLA typing into the National Marrow Donor Program (NMDP) registry. This is done at www.BetheMatch.org. This registry tries to match your HLA type with a volunteer donor. The screening is free. This screening helps the transplant team find a donor.

Finding a donor in the registry could take several months. Your BMT doctor will continue to treat your disease. You can use this time to build your strength through a healthy diet and exercise. Your Nurse or Donor Coordinator will update you and your family with search results often.
Step 2: The Preparative/Conditioning Regimen

A central line catheter will be placed after your screening tests are done. You may have it placed before coming into the hospital. It can also be placed on the day you are admitted. You may already have a central line. Your Nurse Coordinator will make sure that it is the right type for the transplant. There is a chance that the line you have may need to be replaced.

You and your family will meet with your BMT Doctor before admission for your transplant. We will go over:
• the upcoming treatment
• the transplant itself
• side effects from treatment
• how we expect the treatment to help you
• how the treatment may affect you and your family

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. Signing the form means:
• the transplant has been explained to you
• you understand the risks and benefits
• you had a chance to ask questions
• you freely agree to take part

You will be asked to sign study consent. It is for a research database for the Center of International Bone Marrow Transplant Research. This research puts some of your medical data into a worldwide database. You will need to give permission. Your name will not be used. The purpose is to compare outcomes. It helps doctors and researchers who are working to make transplants better. This may help those who have a transplant at a later time.

An Advanced Directive is a decision that you make now about your future medical care. You can state your wishes about the use of treatments to prolong your life. An Advanced Directive has two parts; a living will and a health care power of attorney. For more facts you can discuss this with your social worker. Copies are in the last section of this book.

Your Nurse Coordinator will call you and let you know your admission date. On the day of admission, you will come straight to the BMT Unit on 7 RCS or 4JPE. Your
The coordinator will tell you which unit. The BMT doctor or physician assistant or Fellow will do a brief physical exam. If you do not have a central line one will be placed. This will most likely be a PICC line. The line lets the nurses give you medicines and take blood samples. They will not need to poke your arms with needles. The catheter is placed under your skin into a large blood vessel. Part of the catheter will stay outside of your arm or chest. The PICC team will numb your skin before putting the catheter in. The skin may be sore but should not hurt after a couple of days. (If you have a port, it may stay in place during the transplant. You will need another catheter to be placed as well).

Next you will start your conditioning or preparatory regimen. This includes chemotherapy and maybe radiation. The chemotherapy is much stronger than any you may have had before. It has to kill any bad cells that are still in your body. It will destroy your bone marrow cells. This stops your cells from fighting off the new stem cells you will be given. Your transplant will take place 1-2 days after your conditioning is done. This will depend on your treatment plan.

**Preparative Regimens**

- **Myceloblatative**
  This is a combination of high dose chemotherapy with or without radiation. This treatment is given for three reasons:
  1) To destroy the diseased cells in your bone marrow
  2) Wipe out your immune system to let the donor’s cells grow
  3) Make space in the bone marrow for the donor’s cells
  The average time to finish treatment is one week.

- **Reduced Intensity**
  This is chemotherapy with or without immune suppressing medicine given before transplant. A mid-range dose of chemotherapy is given. The purpose of the treatment is the same as above.

- **Non-myceloblatative**
  Radiation and immune suppressing medicine is given before transplant. You may or may not get chemotherapy.
  This will weaken your immune system so the donor’s cells can grow and work. The healthy donor immune system will spot diseased cells and destroy them.
These treatments 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!
Step 3: Collecting the Stem Cells from the Donor

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 (Collected)?
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. Your donor may be given a growth factor shot. This is to raise the number of stem cells in the blood. The growth factor used most often is G-CSF, granulocyte colony stimulating factor (Neupogen). The growth factor is given for 4-5 days.

When lab work shows there are enough cells to collect, apheresis starts. Blood can be removed in one of two ways. An IV line in a neck vein or IVs in both arms can be used. The blood is spun through a machine which will collect the stem cells. The remaining blood is transfused back to the donor through the IV. This stem cell collection occurs in the DeGowin Blood Center at UIHC. A nurse will stay with the donor throughout the collection. It will take about 5 hours. After the 5 hour collection, the stem cells are tested and processed. It may take more than one day to harvest the stem cells for transplant.

The Donor’s Experience
Your donor will complete a health history screening form. He or she will have a physical exam done by a BMT Physician Assistant. The donor will have blood work, a chest X-ray, and an electrocardiogram (ECG) done. The donor will be taught about the bone marrow harvest and sign a consent. If the donor is cleared to donate, the bone marrow harvest will be scheduled. Some donors are also given an order for iron tablets. These are to be taken before and after the harvest. This can help the donor build up his or her red blood cells.
Frequently Asked Questions about the Donor’s Experience

- How are the stem cells collected?
The donor’s blood is removed through a catheter in a neck vein or an arm vein. The blood passes through an apheresis machine that separates out the stem cells. The stem cells will be ‘skimmed off’ in the cell separator. The rest of the donor’s blood will be returned to them. Only about 15 ounces of plasma and cells will be collected at each procedure. This is much less blood than is taken when a person donates blood.

- Will it hurt?
No, it does not hurt. Many patients watch TV, read, or sleep during the process. A nurse will be with you the whole time.

- Can someone stay with the donor?
Yes. The staff is happy to meet family and friends and answer questions. There is a waiting room and a snack area nearby.

- How long will it take?
The donor will spend between 4 and 7 hours in the DeGowin Blood Center. The collection time is most often 5 hours. A nurse will take the donor’s blood pressure and temperature. She will ask some brief questions about their health. Then the
donor will be connected to the machine. The nurse will draw another blood sample when the collection is done. Then the donor will be able to leave. The doctor will decide on the number of collections. It will depend in part on how many cells are collected each time. A Donor Coordinator will call the donor. She will let them know if they need to return for another collection the next day. Most often, a sibling donor will have only one or two collections done on back-to-back days. It would be rare to take 3 days to collect stem cells from a donor.

- **Are there any side effects?**
  Side effects from the collection are very rare. A donor may notice a slight “tingling” or “numbness” in the lips, nose or fingers. Citrate is used to keep the blood from clotting in the machine. Blood is returned to the donor where the citrate is broken down by the liver. This causes the “tingling”. It will not keep their blood from clotting normally. If any tinges are noticed, the nurse will give the donor TUMS (calcium) to chew on. If needed, an IV solution with calcium may be given.

- **What does the donor do during collection?**
  The donor will need to lie quietly but may turn over or sit up. Many patients watch TV or read. Some people sleep. The donor may not be able to bend their arms due to IV lines.

- **How do donors feel after the collection?**
  Most people feel fine. The donor will feel a little tired. Someone must drive the donor home or to their hotel. We advise the donor to eat and drink extra fluids. Your donor will receive teaching and instructions about their donation process.
Step 4: Transplant

The transplant is the infusion of the donated stem cells. This is done in your hospital room. The stem cells look like blood. They are given through your central line. It is not painful. You can visit with your family, rest, or watch TV. You will be given medicines before the transplant to prevent serious reactions. This medicine may make you feel sleepy. The nurse will watch you closely to treat any reactions. Reactions are not common. You may get chills, a mild fever, or a skin rash. Your urine may turn pink for a day. This is normal. Your body is getting rid of extra red blood cells from the transplant.

Day 0

When you finish the preparative regimen, you’re ready for your transplant. The transplant day is the day your donor’s stem cells will be given to you. You will hear your transplant team refer to your transplant day as “Day Zero”.
Your days will be counted up from there. The day after transplant is Day +1, the next day is Day +2, etc.

The Waiting Begins

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 donor stem cells will start making blood cells in about 14-21 days. White blood cells will recover first. Platelets and red blood cells take longer. You will need blood products (red blood cells and platelets) until your cells recover. This can take several months.

Antibiotics and Protective Isolation will help protect you while your white cell count is low. You will be at risk of getting an infection. Germs that would not bother you before can now make you very sick. You will be watched very closely and started on antibiotics to prevent infection. More antibiotics will be ordered if you have a fever or other signs of infection. You must tell the doctor or nurse if you notice any changes in your body. You will be on antibiotics until all signs of infection are gone.

All staff and visitors must scrub their hands before coming into your room. They can use a germ-killing soap or special foam. This helps keep you safe from infection.

Discharge from the hospital depends on how quickly your blood counts recover. The average length of hospital stay is 28 days. You may stay in the hospital longer if you have complications.
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 can range from 1 week to 3 months. This depends on the type of transplant you receive. Sometimes a Caregiver is one person. Often several people share the responsibility of providing 24 hour care.

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 care-giving 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. You may need to be available 24 hours a day for several months. You may need to find housing close to the hospital. This will be for the first month or longer post-transplant. The patient may need to make 1-3 clinic visits (or more) for the first four weeks. 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
• Cleaning window treatments
• 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

<table>
<thead>
<tr>
<th>Organization</th>
<th>Description</th>
<th>Contact Information</th>
</tr>
</thead>
</table>
| **National Bone Marrow Transplant Link**          | Organization has print materials on caregiving that 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, linking a potential transplant patient with a volunteer who has undergone BMT. Good information on transplant centers. | Web site: www.bmtinfonet.org  
E-mail: help@bmtinfonet.org  
Phone: 1 (888) 597-7674 |
| **Lotsa Helping Hands**                           | This is an easy-to-use, web-based private group calendar. It is specifically designed for organizing helpers, where everyone can pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during a crisis. | Web site: www.marrow.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 that help 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 and 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 which 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 provides caregivers with the basic tools, skills and information they need to protect their own physical and mental health while they provide high quality care for their loved one. **Only accessible online.** | Web site: www.familycaregiving101.org |

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

Sample Daily Schedule
8am: Breakfast, Nurse, Doctor, or PA will check you
9am: Shower, mouth care, linen change, use incentive spirometer
10am: Walk in hall with mask on, discuss daily plan with BMT Team
11am: Work with Physical Therapy, or activity with Recreational Therapist
Noon: Sit in recliner for lunch, mouth care
1pm: Quiet Time, nap
3pm: Visit with family and friends, use incentive spirometer
4pm: Exercise with mask on, email friends
5pm: Dinner, mouth care, watch TV
7pm: Read, watch a movie, call friends, play computer games or Wii
9pm: Walk hall one last time, mouth care, use incentive spirometer, get ready for bed
10pm: Bedtime

Research proves that patients who take an active part in their care recover faster!

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 you 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 this 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. Your BMT doctor will decide which central line you will have. It could be a PICC, double port, or Hickman.
Making Your Stay Comfortable
You are welcome to decorate your room to make you feel happy! 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
  - VCR
  - 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.

This 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

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 medicines
☐ Durable Power of Attorney/Living Will
☐ Health insurance card
☐ This Guidebook
Rooming Guidelines
Your Caregiver is welcome to stay in the room with you. They should be there during morning rounds. This gives your family the chance to hear updates and ask questions. 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’ themself 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.
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

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

Don’t be afraid to ask the same question more than once. Do not be afraid that your question will sound dumb. Transplant information is hard to understand. Most people need to hear things more than once before it is fully understood. It is important for you to understand.

Graft Versus Host Disease (GVHD)

Graft versus Host Disease is an immune reaction of the donor’s cells against your body tissues. It is a reaction of the donor’s immune system (the graft) versus you (the new host). GVHD occurs as the graft sees your body tissues as foreign. The purpose of the immune system is to spot foreign objects and destroy them. In GVHD, the donor’s immune system is doing what is supposed to do. In this case, destroying your body tissues.

There are four main ways to prevent GVHD:

1. **HLA Matching** - The HLA matching between you and the donor. The closer the HLA match the lower the risk of graft versus host disease. Even with a “perfect” match there is still a risk of GVHD.

2. **Immunosuppressive Medicines** - Medicines taken to weaken the patient’s immune system. There are many immune suppressing medicines. Your consent form lists the immune medicines you will be given.

3. **Preventing Infections** - You will be taking immune suppressing medicines to prevent GVHD. They increase your risk of infections. You will be taking medicines to try to prevent infections. You will be asked to follow rules to lower your risk of infection.

4. **Protection from Sunlight** – Sunlight can cause a reaction in the skin that causes GVHD. When you are outside wear sunscreen with an SPF of at least 30. Reapply often to help prevent GVHD. Wear clothing that protects your skin from sunlight such as hats and long sleeved shirts.
Acute and Chronic GVHD

There are two forms of GVHD: acute and chronic. 
**Acute GVHD** most often occurs within the first 100 days of transplant. It can happen quickly. It can range from a mild problem to a very serious and life-threatening problem. Acute GVHD most often affects the skin, stomach and intestines, and the liver.

- Acute GVHD of the skin can cause rashes. In severe cases it can affect the entire body.
- Acute GVHD of the liver can cause mild to severe changes in the liver. In severe cases it can cause liver failure.
- Acute GVHD of the stomach and intestines can cause nausea, diarrhea, and belly pain. In severe cases there are large amounts of diarrhea.

**Chronic GVHD** most often occurs within the first two years after transplant. It is a slower process. It can range from mild to life-threatening. In some cases, chronic GVHD can limit what you are able to do physically. Chronic GVHD is most often taken care of by your BMT doctor in the outpatient setting.

- Chronic GVHD can affect any tissue in the body.
- Symptoms of GVHD:
  - Skin rash or color changes on any part of the skin
  - Itching
  - Not feeling hungry
  - Weight loss
  - Dry, thick scaly skin
  - Watery, frequent, bloody or large volume stools
  - Belly pain or cramping
  - Long lasting nausea or vomiting
  - Dry mouth, thick plaques in the mouth
  - Dry eyes, crusting of the eyes in the morning
  - Burning or sandy feeling in the eyes
  - Burning or redness of the palms and soles
  - Tea colored urine
  - Low grade fevers: 99º-100ºF without chills
Treatment of GVHD involves medicines that weaken the donor immune system. This raises the risk of infection. Some infections can be life-threatening. If you get GVHD we will work with you on:

- treatment,
- ways to prevent infections
- taking care of your symptoms
- making your quality of life the best it can be

The acute form most often improves quickly with treatment, often within a few days. Since the chronic form comes on slowly, it also responds to treatment slowly. Symptoms may take days to weeks to resolve.

**Important Note:** GVHD can appear any time after transplant. You must talk about any of these symptoms with the BMT Team. Sooner is always better than later!

Medicines will be given to prevent and treat GVHD. One or more medicines will start the day before your transplant. You will have blood drawn to check the levels of these drugs. Sometimes your dose will need to be changed. You **must** take these medicines on a strict time schedule of every 12 hours. **Never** stop your medicine suddenly without the okay from your BMT Doctor.
## Immunosuppressive Medicines

These medicines are used to prevent and treat graft versus host disease:

<table>
<thead>
<tr>
<th>Name</th>
<th>Type of Drug</th>
<th>Given /Used</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tacrolimus (Prograf)</td>
<td>immunosuppressive</td>
<td>Orally, twice daily. Used to prevent GVHD</td>
<td>Increased blood pressure, tremors, kidney problems</td>
</tr>
<tr>
<td>Cyclosporine (Neoral, Gengraf)</td>
<td>immunosuppressive</td>
<td>Orally, twice daily. Used to prevent GVHD</td>
<td>Increased blood pressure, tremors, kidney problems</td>
</tr>
<tr>
<td>Sirolimus (Rapamune)</td>
<td>immunosuppressive</td>
<td>Orally, once daily, used to prevent and treat GVHD</td>
<td>Liver problems, increased triglycerides</td>
</tr>
<tr>
<td>Mycophenolate mofetil (Cellcept)</td>
<td>immunosuppressive</td>
<td>Orally, twice daily, used to prevent and treat GVHD</td>
<td>Low blood counts, nausea</td>
</tr>
<tr>
<td>Prednisone (Deltasone)</td>
<td>Anti-inflammatory immunosuppressive</td>
<td>Orally, once or twice daily. Used to treat GVHD and other inflammatory states during transplant</td>
<td>Not able to sleep, increased blood sugar, bone effects</td>
</tr>
<tr>
<td>Infliximab (Remicaid)</td>
<td>immunosuppressive</td>
<td>Used to treat GVHD of the GI tract</td>
<td>Infection risk</td>
</tr>
<tr>
<td>Etanercept (Enbrel)</td>
<td>immunosuppressive</td>
<td>Used to treat GVHD of the GI tract and some lung problems</td>
<td>Infection risk</td>
</tr>
<tr>
<td>Alemtuzumab (Campath)</td>
<td>immunosuppressive</td>
<td>Used to treat GVHD</td>
<td>Fevers, rigors, allergic reactions, infection risk</td>
</tr>
<tr>
<td>ATG (Thymoglobulin)</td>
<td>immunosuppressive</td>
<td>Used to prevent and treat GVHD</td>
<td>Fever, chills, rigors, allergic reactions</td>
</tr>
</tbody>
</table>
Possible Complications (continued)

Interstitial Pneumonitis
The lungs are sensitive to some chemotherapy drugs and total body irradiation. These treatments are sometimes used before your bone marrow transplant. A reaction called interstitial pneumonitis (IP) can occur. It can keep your lungs from using oxygen as they should. The symptoms are:

- shortness of breath
- cough
- fevers
- feeling more tired than normal

Always tell your doctor if you have any of these symptoms.

Veno-occlusive Disease (VOD)
Chemotherapy and radiation can cause deposits of thread-like material in the tiny blood vessels of the liver. This can block the blood flow out of the liver. This is known as veno-occlusive disease (VOD). Symptoms include belly pain, sudden weight gain and poor liver function. Your skin and eyes may become yellow (jaundice). You may have swelling of the belly. Your stool color may get lighter and your urine darker. Always tell your doctor if you have any of these symptoms.

Graft Failure
Graft failure can occur your body rejects the donated marrow or stem cells. This results in very low blood counts and an increased risk of bleeding and infection. A second infusion of donor bone marrow or peripheral stem cells may be done.

Infection
Infection is one of the biggest risks patients face during transplant. The chemotherapy or radiation you receive before the transplant turns off your immune system. You will be given medicines to prevent some common infections. Everyone carries many kinds of germs on the skin and inside the body. They do not cause problems unless a person has a weakened immune system. Transplant patients are at high risk for infections caused by these germs. You will be given medicines to prevent some common infections. The BMT plan works to protect you from infection. Good hand washing is the most important thing you can do to prevent infections. Follow the BMT Team instructions.
### Infections of Concern:

<table>
<thead>
<tr>
<th>Infection</th>
<th>What is it?</th>
<th>BMT Plan</th>
<th>What You Can Do</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lungs</strong></td>
<td>Viral, bacterial, or fungal.</td>
<td>- Antibiotics to prevent infection &lt;br&gt;- Antibiotics added as needed</td>
<td>- Use your Incentive Spirometer! &lt;br&gt;- Good handwashing. &lt;br&gt;- Follow BMT Team instructions.</td>
</tr>
<tr>
<td><strong>Cytomegalovirus (CMV)</strong></td>
<td>Inactive virus that many people carry. It may become active after transplant. Can cause infections of the lungs, stomach, intestines, liver, and other organs.</td>
<td>- Each patient is tested before transplant. &lt;br&gt;- If you or your donor carry the inactive virus you will be have blood drawn often. &lt;br&gt;- If CMV becomes active, you will receive anti-viral medicine.</td>
<td>- Use good handwashing. &lt;br&gt;- Follow BMT Team instructions.</td>
</tr>
<tr>
<td><strong>Herpes Simplex Virus (HSV)</strong></td>
<td>Cold sore virus (HSV)</td>
<td>- Each patient is tested before transplant. &lt;br&gt;- Anti-viral medicine. &lt;br&gt;- Areas that look like HSV/HZV will be swabbed and sent to the lab.</td>
<td>- Use good handwashing. &lt;br&gt;- Follow BMT Team instructions. &lt;br&gt;- Talk openly with BMT Team.</td>
</tr>
<tr>
<td><strong>Herpes Zoster Viruses (HZV)</strong></td>
<td>Chicken pox/Shingles virus</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Cytomegalovirus (CMV):
Antibiotics and other medicines are given to prevent and to treat infections.
A very common and severe infection is from a virus called the Cytomegalovirus or CMV. CMV is a virus that most of us have been exposed to at some time. It remains silent in our body because our immune system protects us. After transplant the CMV virus can become active or ‘turn back on’. We will protect you with antiviral medicines to help prevent this. If not treated, it can cause pneumonia or other very serious complications.

Vancomycin Resistant Enterococcus (VRE):
All patients on the BMT Unit are tested for VRE. This takes place when you are admitted and every Monday.

-What is VRE?
Enterococcus is a germ normally found in the intestines. Vancomycin Resistant Enterococcus, or VRE, means vancomycin will not kill this germ. It may cause infection anywhere in the body. Some people can be colonized with VRE. This means it is present in the body without signs of infection. Colonized people can still spread VRE.

-How is VRE spread?
VRE is spread from person to person by dirty hands. It also comes from contact with dirty objects.

-What if I am positive for VRE?
You will be placed on Contact Precautions while you are in the hospital. A sign will be placed at the door. All visitors and staff who enter your room must wear a gown and gloves. They will remove and throw out the gloves and gown when they leave the room. Gowns and gloves are thrown out inside the patient’s room. You must wear a clean yellow gown and gloves when you are outside your room. This will protect other patients. Staff, caregivers and visitors must wash hands before entering the room and when leaving. They can use soap and water or an alcohol based hand rub.
# Common antibiotics used during and after transplant

<table>
<thead>
<tr>
<th>Name</th>
<th>Type of Drug</th>
<th>Given /Used</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cefepime</td>
<td>antibacterial</td>
<td>IV, Used to treat fevers and bacterial infections</td>
<td>Nausea, rash</td>
</tr>
<tr>
<td>Vancomycin</td>
<td>antibacterial</td>
<td>IV, Used to treat fevers and bacterial infections</td>
<td>Skin becomes red</td>
</tr>
<tr>
<td>SMX/TMP (Bactrim, Septra)</td>
<td>antibacterial</td>
<td>Oral, Used to prevent bacterial pneumonias</td>
<td>Rash, electrolyte disturbances, low platelets</td>
</tr>
<tr>
<td>Fluconazole (Diflucan)</td>
<td>antifungal</td>
<td>Oral or IV, Used to treat and prevent fungal infections</td>
<td>Belly pain, liver problems</td>
</tr>
<tr>
<td>Posaconazole (Noxafil)</td>
<td>antifungal</td>
<td>Oral, Used to treat and prevent fungal infections</td>
<td>Liver function may not be normal</td>
</tr>
<tr>
<td>Voriconazole (Vfend)</td>
<td>antifungal</td>
<td>Oral or IV, Used to treat and prevent fungal infections</td>
<td>Liver function may not be normal, changes in sight</td>
</tr>
<tr>
<td>Valacyclovir (Valtrex)</td>
<td>antiviral</td>
<td>Oral, Used to treat and prevent HSV viral infections</td>
<td>Nausea, kidney problems</td>
</tr>
<tr>
<td>Acyclovir (Zovirax)</td>
<td>antiviral</td>
<td>IV, Used to treat and prevent HSV viral infections</td>
<td>Nausea, kidney problems</td>
</tr>
<tr>
<td>Valganciclovir (Valcyte)</td>
<td>antiviral</td>
<td>Oral, Used to treat CMV and other viral infections</td>
<td>Low white blood count, nausea</td>
</tr>
<tr>
<td>Ganciclovir (Cytovene)</td>
<td>antiviral</td>
<td>IV, Used to treat CMV and other viral infections</td>
<td>Nausea, low white blood count</td>
</tr>
</tbody>
</table>
**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.
## Other Medicines

There are many medicines that may be used during your transplant. They may manage side effects or other problems that arise. Here is a list of some of the common medicines and their uses.

<table>
<thead>
<tr>
<th>Name</th>
<th>Type of Drug</th>
<th>Given /Used</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promethazine (Phenergan)</td>
<td>Anti-nausea agent</td>
<td>Used to treat and prevent nausea</td>
<td>Drowsiness</td>
</tr>
<tr>
<td>Ondansetron (Zofran)</td>
<td>Anti-nausea agent</td>
<td>Used to treat and prevent nausea</td>
<td>Constipation, headache</td>
</tr>
<tr>
<td>Lorazepam (Ativan)</td>
<td>Anti-nausea agent</td>
<td>Used to treat and prevent nausea</td>
<td>Feeling sleepy, feeling dizzy</td>
</tr>
<tr>
<td>Amlodipine (Norvasc)</td>
<td>Antihypertensive</td>
<td>Used to control high blood pressure</td>
<td>Low blood pressure, leg swelling</td>
</tr>
<tr>
<td>Furosemide (Lasix)</td>
<td>Antihypertensive and diuretic</td>
<td>Used to control blood pressure and to help get rid of edema and excess water</td>
<td>Low blood pressure, dehydration, kidney effects</td>
</tr>
<tr>
<td>Oxycodone (Roxicodone)</td>
<td>Narcotic pain medicine</td>
<td>Used to treat pain</td>
<td>Sedation, constipation, itching, nausea</td>
</tr>
<tr>
<td>Morphine (numerous brand names)</td>
<td>Narcotic pain medicine</td>
<td>Used to treat pain</td>
<td>Sedation, constipation, itching, nausea</td>
</tr>
<tr>
<td>Hydromorphone (Dilaudid)</td>
<td>Narcotic pain medicine</td>
<td>Used to treat pain</td>
<td>Sedation, constipation, itching, nausea</td>
</tr>
<tr>
<td>Levetiracetam (Keppra)</td>
<td>Anti-seizure medicine</td>
<td>Used to prevent seizures. Patients getting busulfan as part of their chemotherapy receive this.</td>
<td>Feeling dizzy or confused</td>
</tr>
<tr>
<td>Filgrastim (Neupogen, GCSF)</td>
<td>White blood cell growth factor</td>
<td>Used to increase white blood cell counts</td>
<td>Bone pain</td>
</tr>
</tbody>
</table>
Step 5: Recovery

Taking Care of Yourself during Recovery

Discharge from the hospital will depend on:

- how fast your blood counts recover
- not having a fever or infection
- how well you are eating and drinking.

We will start to make plans for your discharge as you recover. When you are discharged you will need a caregiver 24 hours a day.

The first 3 months after your transplant is a critical time. It will take that long to build up your immune system. During this time, you are at risk for complications. A longer stay may be needed if there are complications. We do not want you to return home until it is safe for you to do so! You may need to stay locally if your home is beyond the Safe Zone. The Safe Zone is within a 100 mile radius of the UIHC. Your BMT Doctor will see you in the clinic after discharge from the hospital.

About 6-12 months after transplant your care will transfer back to your local oncologist or hematologist. 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.

Recovery can take up to a year or more. Your hair will start to re-grow in about 3 months. Your taste buds will slowly return to normal. Your energy will improve. It is not unusual to need rest periods or naps. The best way to regain your energy is to pace yourself and stay active.

Follow-up Appointments

- Wear your mask at all times while on hospital property. This is vital in the waiting areas.
- After discharge you will be seen in the outpatient clinic often.
- You will have blood drawn at each clinic visit.
- Sometimes you may feel too sick to sit in the waiting room. Tell the staff at check-in. They will let the clinic nurses know.
- Know what medicines need to be refilled. Tell the nurse or PA during your clinic visit.
- It’s easy to forget your questions during your clinic visit. Write them down as they come up at home. Bring them with you to each visit.
Many clinic visits can turn into long days. You may need IV fluids or transfusions. Come ready to stay for a long time. Please bring your daily medicines, something to read, and snack foods.

**Medicines**
A BMT pharmacist will review your discharge medicines with you and your Caregiver. It is **very important** that you take your medicines as ordered. You must not miss any doses. Call the clinic if you have questions or problems with any of your medicines. Call if you need to speak with one of the BMT pharmacists.

**Bleeding Precautions**
You may have a low platelet count after being discharged from the hospital. Platelets are often the last blood cell to start growing in your new bone marrow. Platelets help form blood clots that control bleeding. During this time you might need platelet transfusions as an outpatient. That is fine, and not a set-back. Below are some of the signs of a low platelet count and bleeding.

- Petechiae - tiny pinpoint purplish red spots on the skin
- Nosebleeds
- Easy bruising, bruising more than normal
- Black or tarry stools
- Blood in your stools
- Blood in your urine or vomit
- Blood seen anywhere on your body
- Bleeding from your gums during your mouth care

Please call the clinic if you suddenly have any of the above symptoms. If the doctor knows about your symptoms, call if there they become worse.
What about my diet?
You may not feel hungry. Good nutrition is very important after your transplant. It gives your body the needed energy to heal. Eat small frequent meals or healthy snacks six to eight times per day. It is a good way to fight a lack of appetite. It will help you meet your diet needs. It is important to include foods from all the basic food groups.

Change in taste is a common complaint from transplant patients. Foods that you enjoyed may no longer taste good. Some medicines may leave a metallic taste in your mouth. Rinse your mouth often. Using gum or hard candy can also help with the strange tastes. This will get better in time. Do not give up on your favorite foods too soon. Your tastes will keep changing. Tempting your taste buds will help the healing process. Keep trying!

Some Tips:
- When your mouth and throat are sore try:
  - Chilled pudding
  - Jell-O
  - Popsicles
- Protein, vitamins, and calories are needed to build new cells. Try high calorie drinks such as:
  - Milkshakes
  - Carnation Instant Breakfast
  - Ensure
  - Boost
- Soups, eggs, and dairy products are good sources of protein and are easy to eat.
- Any food that is too hot or too cold may cause pain.
- Some foods may cause your throat and mouth to hurt. Spicy foods, citrus, and tomatoes are some you may want to avoid.
- Greasy foods can be hard to digest and lead to diarrhea.
- Keep servings small. Divide meals into many smaller ones throughout the day.
- Drink 2-3 liters of fluids each day.
- Do not drink alcohol.
- Choose your foods wisely, and go slow.
**Food safety** is critical for people with a low white blood cell counts (neutropenia). You can become seriously ill from food-borne illnesses. 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, sea food, 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.
**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.

Make an exercise plan and set goals. Do not take part in heavy exercise or contact sports. Walking or riding a stationary bike is very good exercise. Do not swim or use hot tubs.

**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
Preventing Infection at Home

Infection is one of the biggest risks patients face during transplant. The chemotherapy or radiation you receive before the transplant turns off your immune system. You will be given medicines to prevent some common infections. You and your caregiver must make every effort to keep infections away.

Everyone carries many kinds of germs on the skin and inside the body. They do not cause problems unless a person has a weakened immune system. Transplant patients are at high risk for infections caused by these germs.

Do not touch the patient after touching your nose or mouth. This may pass germs to the patient. This is most important after coughing or sneezing. Touching a surface that the patient touches later can spread harmful germs.

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:
  o touch human or animal feces
  o change baby diapers
  o touch bird droppings
  o clean the aquarium
  o clean up after pets
  o sit on grass, logs, or dirt
  o allow skin contact with dirt, lawn waste, leaves, or compost
  o change the water on flower arrangements
  o 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.

**Celsius to Fahrenheit temperature conversions**

<table>
<thead>
<tr>
<th>Celsius</th>
<th>Fahrenheit</th>
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<td>102.4</td>
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</table>
Frequently Asked Questions about Going Home

How long do I have to wear the N95-Particulate mask?
Plan to wear the mask for 3 months. You must wear it anytime you are out of your home. 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. This is most often at least three months after your transplant. 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?
Yes. After your discharge you will need a Caregiver to help you:
• Remember scheduled medicines
• Make sure you eat and have the right foods
• Help build your stamina
• Provide transportation to and from clinic visits, etc.
Your BMT team will tell you how long you will need a Caregiver.

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. 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.

**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

You will need to wait for 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.
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.
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 3: Other Helpful Tips