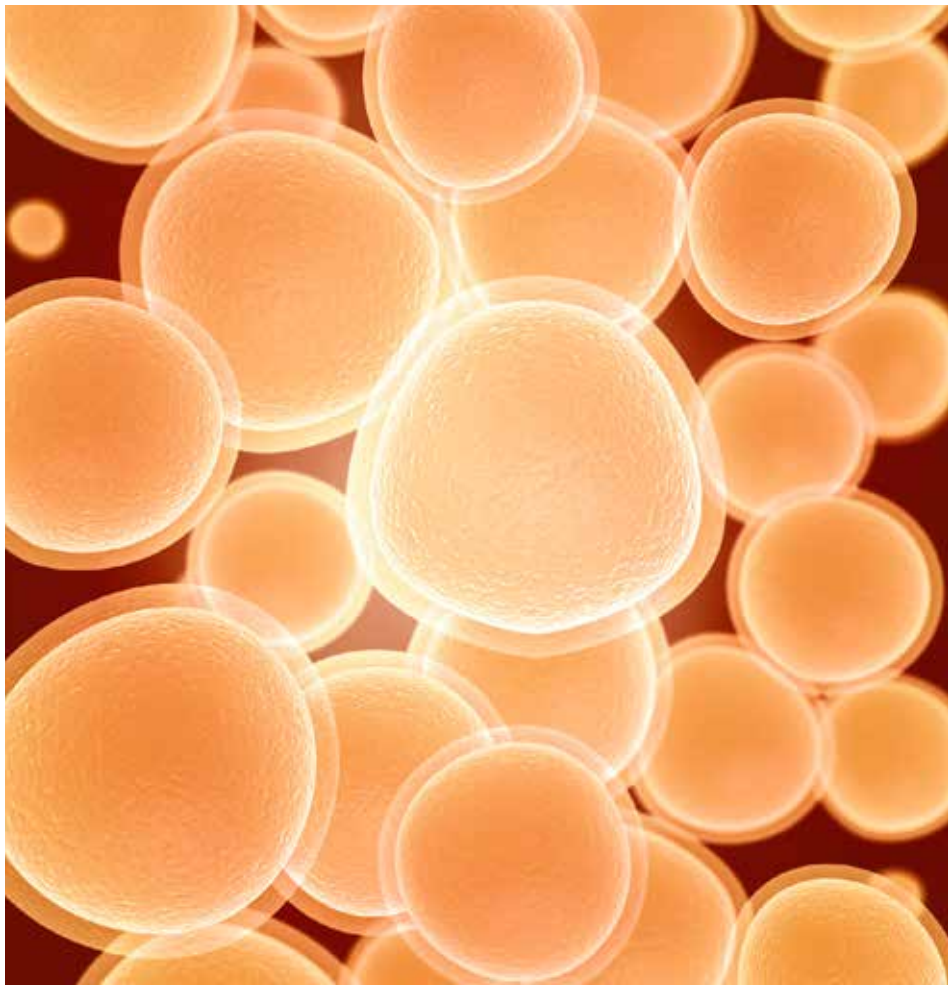




University of Colorado Hospital
UNIVERSITY OF COLORADO HEALTH

Blood & Marrow Transplantation



To Our Patients and Their Families:

Welcome to the University of Colorado Hospital Blood and Marrow Transplant Program. As you prepare to undergo a stem cell transplant, the Blood and Marrow Transplant Team would like you to know that we are dedicated to providing you and your family with excellent care. We are committed to a team approach and consider you and your family to be a part of our team.

The transplant process can be overwhelming. This book will help you and your family understand what to expect before, during, and after transplant. We ask that you and your family take the time to read and understand this information. If you need more information or have questions, concerns, or comments, please speak with one of your team members.

We look forward to caring for you at University of Colorado Hospital.

Sincerely,

Your Blood and Marrow Transplant Team



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The Blood and Marrow Transplant Team Members

There are many members of the transplant team that will assist you and your family throughout your transplant.

ATTENDING PHYSICIANS

Each physician or doctor on the transplant team specializes in stem cell transplantation and hematological malignancies (leukemias, lymphomas, multiple myeloma, and other malignant blood disorders). The doctors work in both the Blood and Marrow Transplant inpatient unit and the Cancer Center outpatient clinic. The transplant doctors, as well as the rest of the transplant team, meet frequently as a group to discuss your care and progress.

NURSE PRACTITIONERS (NP)

The NPs help manage your transplant care and work very closely with the attending physicians. You will see the NPs on the inpatient unit (should you be admitted for your transplant) and in the outpatient clinic. The NPs are nurses with advanced degrees (master's or doctoral level) who work with the physicians to carry out your treatment plan.

TRANSPLANT NURSE COORDINATORS

The transplant coordinators are nurses who will work with you, your referring doctor, and members of the transplant team to coordinate all aspects of your transplant process. He or she will assist with the education process, order tests, arrange stem cell collections, and, if applicable, conduct donor searches.

PSYCHOLOGISTS

The transplant psychologists have doctoral degrees in clinical or counseling psychology and specialize in the needs of stem cell transplant patients. You and your family will meet with a transplant psychologist prior to transplant and your psychologist will "check in" frequently during your transplant process. The psychology team can assist with symptoms such as anxiety and depression, practical concerns such as how to sleep better at night, and ways to help you maintain motivation during the transplant recovery process.

SOCIAL WORKERS

Social workers may assist in a variety of ways, as they are experts at solving practical problems. Some of their fields of expertise include: financial assistance, insurance planning and coordination, planning for services when you leave the hospital, and helping with housing and transportation. There are two social workers assigned to the team; one is located in the inpatient hospital setting and the other is available to patients/caregivers in the outpatient/clinic setting.

CLINICAL RESEARCH NURSE COORDINATORS

The research coordinators are registered nurses with a specialized focus in the care of hematological malignancy and stem cell transplant research participants. If you choose to take part in a clinical research trial your research coordinator will initiate your study enrollment, help coordinate your clinical care, and ensure your safety throughout the course of the clinical trial.

FINANCIAL COORDINATORS

The financial coordinator works with you and your insurance company to ensure that you have insurance coverage for transplant.

PRACTICE MANAGER

The practice manager oversees the function of the Blood and Marrow Transplant Unit, Cancer Center clinic, and Infusion Center.

CHARGE NURSES

A charge nurse is an Oncology and Blood and Marrow Transplant inpatient nurse with leadership skills and responsibilities. Every shift has a charge nurse who coordinates the shift and unit activities. There is also a charge nurse in the Cancer Center outpatient clinic.

REGISTERED NURSES (RN)

The RN working on the unit has skill in caring for the complex needs of the hematological malignancies and stem cell transplant patients.

APHERESIS NURSE, APHERESIS TECHNICIAN

The apheresis technicians and nurses collect stem cells from the bloodstream.

CERTIFIED NURSING ASSISTANTS (CNA)

The CNAs assist you with showers, meal trays, and self-care needs. The CNAs also take your vital signs. The nursing assistants work closely with your nurse on the Blood and Marrow Transplant Unit.

MEDICAL ASSISTANTS (MA)

The MAs take your vital signs, give injections, and assist you while you are in the outpatient clinic or infusion center.

REGISTERED DIETITIANS (RD)

The dietitian monitors your nutritional status and needs. You will meet with the dietitian several times to learn about your special diet needs. Dietitians work in the Cancer Center outpatient clinic and on the Blood and Marrow Transplant inpatient unit.

PHARMACISTS

The inpatient and outpatient pharmacists provide you with drug information and education.

PHYSICAL AND OCCUPATIONAL THERAPISTS (PT & OT)

The physical and occupational therapists may work with you to evaluate your physical abilities and your ability to engage in basic life tasks. If needed, they may develop an exercise program to maintain or help you regain your strength.

CHAPLAIN

The chaplain helps provide care for your spiritual and religious needs. The chaplain can help assist with ethical decisions, prayer and religious rites such as Holy Communion, and arranging for a priest, rabbi, or other denominational representative to visit you.



CARE TEAM ASSISTANTS (CTAS)

CTAs schedule your doctor, NP, labs and test appointments and provide support to the transplant team.

PATIENT SERVICE COORDINATOR (PSC)

The PSC provides secretarial support for the Oncology and Blood and Marrow Transplant inpatient unit.

Important Phone Numbers

ATTENDING PHYSICIANS

Clay Smith, MD

Professor

Director, Hematologic Malignancies and Blood and Marrow Transplant Program

Phone: 720-848-0300

Han Myint, MD

Professor

Phone: 720-848-0300

Jonathan Gutman, MD

Assistant Professor

Director of Cord Blood and Allogeneic Stem Cell Transplant Services

Phone: 720-848-0300

Daniel Pollyea, MD

Assistant Professor

Clinical Director, Leukemia Services

Phone: 720-848-0300

Vu Nguyen, MD

Assistant Professor

Phone: 720-848-0300

NURSE PRACTITIONERS

Patricia Dey, DNP, NP-C

Shannon Fonger, MS, NP-C

Carrie Parkinson, MS, NP-C

Glen Peterson, MS, ACNP-BC, OCN

Karley Trautman, MS, ANP-BC

Joanna Zakrocki, MS, ANP-C, OCN

Kelly Kales, MS, ANP-C, OCN

Marisa Ditullio, MS, PA-C

PSYCHOLOGISTS

Benjamin Brewer, PsyD

Assistant Professor

Director, Clinical Psychology and Counseling Services

Phone: 720-848-1611

Email: Benjamin.Brewer@ucdenver.edu

Jennifer Caspari, PhD

Assistant Professor

Clinical Health Psychologist

Phone: 303-848-0300

SOCIAL WORKERS

Outpatient: Amy Malcom, LCSW

Phone: 720-848-0461

Pager: 303-266-1246

Inpatient: Michelle Dwors, MSW, LSW

Phone: 720-848-1502

Pager: 303-266-1744

TRANSPLANT NURSE COORDINATORS

Chris Koch, RN

Phone: 720-848-0241

Pager: 303-266-1339

Email: Christine.Koch@uch.edu

Lindsey McMenimen, RN

Phone: 720-848-2606

Pager: 720-266-0913

Email: Lindsey.McMenimen@uch.edu

Kelly Pacic, RN

Phone: 720-848-1637

Pager: 303-266-1661

Email: Kelly.Pacic@uch.edu

CLINICAL RESEARCH NURSE COORDINATORS

Amanda Vyn, RN, BSN, MPH

Phone: 720-848-0656

Email: Amanda.Vyn@ucdenver.edu

Derek Schatz

Phone: 720-848-0628

Email: Derek.Schatz@ucdenver.edu

TRANSPLANT FINANCIAL CASE COORDINATOR

Jennifer Mays

720-848-0829

For non-urgent needs, please leave a message for your designated transplant nurse coordinator and she will return your call as soon as possible. For urgent assistance Monday through Friday from 8 am to 6 pm, you may page your designated transplant coordinator.

CARE TEAM ASSISTANTS (SCHEDULERS)

Donna Thompson

Phone: 720-848-0941

Phone: 720-848-0695

*For scheduling follow-up appointments and tests, please contact a care team assistant.

REGISTERED DIETITIANS

Jacklyn (JJ) Barten, RD, CSO

Phone: 720-848-8086

Email: Jacklyn.Barten@uch.edu

Katie Harper, MS, RD, CSO

Phone: 720-848-8086

Email: Katie.Harper@uch.edu

PHARMACISTS

Outpatient: Jenni Tobin, PharmD

Phone: 720-848-0615

Pager: 303-266-2500

Email: Jennifer.Tobin@uch.edu

Inpatient: Jeff Kaiser, PharmD

Email: Jeff.Kaiser@uch.edu

BONE AND MARROW TRANSPLANT INFUSION CENTER (BIC)

Phone: 720-848-2207 or 720-848-2208

How to Reach Us

CONTACTING THE MEDICAL TEAM AFTER HOURS:

1. Call the hospital operator at **720-848-0000**.
2. Give your phone number and ask for the BMT on-call nurse practitioner to be paged.
3. If no response after 30 minutes, call the hospital operator again and ask to have the on-call BMT physician paged.

Blood and Marrow Transplant Infusion Center (BIC) (2nd floor, Anschutz Outpatient Pavilion)

Phone: 720-848-2206, 720-848-2207, or 720-848-2208

Cancer Center Infusion Center (2nd floor, Anschutz Cancer Pavilion)

Phone: 720-848-0300

Blood and Marrow Transplant Inpatient Hospital Unit (11th Floor, Anschutz Inpatient Pavilion)

Phone: 720-848-4275

TO SCHEDULE ALL NON-URGENT APPOINTMENTS:

Donna Thompson

Phone: 720-848-0941

Phone: 720-848-0695

HOW TO PAGE TEAM MEMBERS

1. Dial pager phone number.
2. After three beeps are heard, enter your phone number carefully and then hang up.
3. The team member will return your call as soon as possible.

Understanding Stem Cell Transplant

Stem cells are immature cells that grow into mature red blood cells, white blood cells, and platelets. Stem cells can come from bone marrow, the bloodstream (peripheral blood), or umbilical cord blood. As a result, you may hear many terms that describe the transplant process such as:

blood and marrow transplant,

peripheral blood stem cell transplant,

bone marrow transplant,

or umbilical cord blood transplant.

After you, the patient, are treated with high dose chemotherapy and/or total body irradiation, stem cells (previously collected from the donor source) are transplanted intravenously. In general terms, and regardless of the source of the donor stem cells, we will refer to this process as a stem cell transplant.

There are two types of stem cell transplants:

1) autologous

Autologous stem cell transplants use your own stem cells. After your disease is in remission or has been treated, stem cells are collected and then returned to you at a later time.

2) allogeneic

An allogeneic transplant uses stem cells from an HLA (human leukocyte antigen) matched sibling, an unrelated HLA matched donor, or umbilical cord blood units. Unrelated donors and cord blood units are found through a donor registry such as the National Marrow Donor Program (NMDP). In the case of a sibling or unrelated adult donor, the stem cells are collected within a day or two of when you receive them. Cord blood units have been previously collected and are stored frozen and shipped to University of Colorado Hospital before your transplant.

AUTOLOGOUS STEM CELL TRANSPLANT

The term “auto” means self. An autologous stem cell transplant uses the stem cells collected from you, the patient. This type of transplant can be used to treat many diseases such as Hodgkins lymphoma, non-Hodgkins lymphoma, multiple myeloma, amyloidosis, and germ cell tumors.

Stem Cell Collection

Your stem cells can be collected from the bloodstream for a peripheral blood stem cell transplant, or from the bone marrow for a bone marrow stem cell transplant. Your doctor will decide which collection method will be right for you based on your disease and health status. The more common method is the peripheral blood stem cell collection. Because the high-dose chemotherapy and/or total body irradiation is so strong, it destroys your stem cells along with the cancer cells. Thus, your stem cells are removed before your transplant.

Apheresis, or Peripheral Blood Stem Cell Collection: Collecting stem cells from the bloodstream is called apheresis. In order to collect your stem cells using apheresis, our team may give you a dose of chemotherapy to motivate your body to produce more stem cells. Whether or not you receive chemotherapy, you will have daily injections of a growth factor (called G-CSF, filgrastim, or Neupogen®). These injections will be given daily for 4 to 10 days before apheresis and during the apheresis procedure. This injection can be given by you or a family member; you will be instructed on how to give the injection correctly. If you are not comfortable with this, arrangements can be made to have your injections given by a nurse or a medical assistant at the BMT infusion center. In some instances, your insurance company may require you to come to the infusion center for the injections. You will continue to take the growth factor until stem cell collection is completed.

The side effects of the growth factor commonly include bone pain and mild nausea. You may use Tylenol® as instructed on the container. **Do not** take ibuprofen (Motrin®, Advil®), naproxen (Aleve®),

aspirin, or aspirin-containing products as they can interfere with clotting and cause bleeding. If nausea is severe, contact a member of the Blood and Marrow Transplant team for instructions.

You will come in for frequent blood draws while you are taking the growth factor so we can closely monitor your white blood cell count. The white blood cell count is an indicator of whether the stem cells have *mobilized* (entered into the bloodstream). When your white blood cell counts are high enough, we will begin apheresis.

On the day of your stem cell collection you will be asked to come to the Apheresis Center. During the apheresis process you will sit in a recliner and the apheresis technician or nurse will connect your central venous catheter to the tubing that runs through a cell separator machine. One lumen (tube) will be used to draw your blood into the apheresis machine and the other lumen will be used to return your blood back into your body. The machine will separate your blood and remove your stem cells while returning the remaining blood to you. The apheresis procedure normally takes four to six hours per day and may take up to five days for an adequate collection of stem cells. Most people collect in one to three days. Occasionally we can't gather enough cells in the first attempt at collection and will need to try the process again.

Patients typically tolerate the apheresis procedure well. During the procedure an anticoagulant mixes with your blood to keep it from clotting while it is circulating through the machine. The anticoagulant lowers the calcium level in your blood and can occasionally cause cold sensations, numbness and tingling of your lips and fingers, or nausea. These side effects are temporary but it is important that you let your apheresis technician or nurse know if you are having any of these symptoms during the procedure as we may need to give you calcium.

To make the apheresis procedure go smoothly:

- » take your daily growth factor injection
- » eat breakfast before you arrive for the procedure

- » bring snacks and a lunch- your family members can also bring food in for you
- » arrive on time for your appointment
- » call the Cancer Center Clinic at 720-848-0300 if you are running late for your appointment
- » bring something to do- patients commonly bring reading material, a personal stereo with headphones, a laptop computer, or DVDs to watch on our DVD player in the Apheresis Center
- » bring any pain medications or other prescription medicines with you if you think that you may need them during the day



Bone Marrow Harvest: Collecting stem cells from your bone marrow is called a bone marrow harvest. This type of stem cell collection is used for only a small percentage of transplants. The bone marrow is collected in the operating room and requires general anesthesia. The bone marrow is collected from your hip bones. This procedure usually takes about one to two hours. The surgery is done outpatient (you will not be admitted to the hospital). After the procedure you are usually able to go home in the late afternoon. Your hips will be sore and stiff and you may need to take pain medication for a few days.

After Your Stem Cells are Collected:

After your stem cells are collected through either apheresis or a bone marrow harvest, they will be cryopreserved (frozen) and stored in a laboratory freezer. Your cells will remain frozen until you are ready for your transplant, a week to months after the stem cell collection. Factors that determine when your transplant will occur include your health status and whether further chemotherapy is needed.

Extra stem cells may be collected and frozen. They would be used in the case of relapse (your cancer comes back) or in the unlikely event that your stem cells do not begin to engraft (grow) after your transplant. Stem cells are stored in our stem cell laboratory for five years at no cost to you. After that time, you will be asked if you would like to continue to store the cells for a fee, discard the cells, or donate the cells to research.

ALLOGENEIC STEM CELL TRANSPLANT

An allogeneic stem cell transplant uses stem cells from someone other than the patient. This type of transplant can be used to treat many diseases such as leukemia, lymphomas, myelofibrosis, myelodysplastic syndrome (MDS), and aplastic anemia.

The allogeneic stem cell donor can be:

- » the patient's full brother or sister (matched related allogeneic stem cell transplant)
- » unrelated to the patient (matched unrelated allogeneic stem cell transplant)
- » umbilical cord blood units

Identifying a donor can take several weeks or months. The patient and potential donors undergo a blood test (human leukocyte antigen or HLA testing) to determine if they have similar antigens (specialized immune system proteins) that would be compatible with your HLA.

Identifying a Stem Cell Source or Donor

HLA (Human Leukocyte Antigen)

Once it is determined that you are eligible for an allogeneic transplant, your nurse coordinator will begin looking for a suitable donor. Your coordinator will be looking for the best HLA (human leukocyte antigen) match possible. HLA are proteins, or markers, found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not.

Your nurse coordinator first determines your HLA typing and then tests your full biological brothers or sisters. HLA testing requires several tubes of blood to be drawn. Your siblings can come to our center or we can send them a special kit and they can have their blood drawn where they live and then have it sent to our stem cell processing lab. Because of the way you inherit genetic material from your parents, your full brothers and sisters have a 25% chance of matching your genetic material. Your parent, half-sibling, or other family members and friends are not typically tested because they are unlikely to match.

Seventy percent of patients do not have a suitable family donor. If your siblings are not a match for you or you do not have any siblings, your nurse coordinator begins searching the donor registry (National Marrow Donor Program) for a suitable donor. Donor sources on the registry include adult bone marrow and peripheral blood as well as umbilical cord blood units. Adult donors on the registry have already been partially HLA typed. If the partial HLA typing matches your HLA typing, we request blood samples to be sent to us to complete the typing. With umbilical cord blood units the number of stem cells collected from the umbilical cord is usually small, so you will likely require stem cells from two different cords. The HLA typing from these cords may or may not be identical to you or each other. If you have several donor matches we will look at their age, gender, and weight to determine the best donor for you.

Obtaining Stem Cells from the Donor Registry

The registry works with us to schedule a collection date when stem cells come from adult unrelated donors. The date depends on your health and when you will be ready for transplant as well as on the donor's schedule. On the scheduled date, the marrow or stem cells are collected; a trained courier then brings them to University of Colorado Hospital 24 to 48 hours after collection.

If cord blood is chosen for your transplant, the cord blood units are shipped to us. Cord blood is stored frozen. The registry and our stem cell processing lab arrange the shipment of the cord. When you are ready for transplant, the cord blood is thawed and you receive your new cells.

Evaluation of Registry Donors

Regardless of your donor source, the donor undergoes several blood tests to look for the presence of infectious diseases (HIV, hepatitis, and others). For umbilical cord blood, the mothers and babies were tested before the cord blood units were collected and frozen. Donors also undergo testing to insure that they are healthy and can tolerate donating stem cells.



Patient and Donor Confidentiality

You will not know who your donor is at the time of your transplant. The NMDP follows strict confidentiality standards to protect the privacy of both you and your donor. According to these standards, you and your donor cannot learn each other's identities until at least one year after your transplant. Some international donor centers require a two-year waiting period, and some do not ever allow you and your donor to learn each other's identities. If you have a cord blood transplant, you will never learn who donated the cord blood.

Donor stem cell collection

Donor stem cells can be collected from:

- » the bloodstream, for a peripheral blood stem cell transplant
- » the bone marrow, for a bone marrow transplant.

Umbilical cord blood comes to our stem cell processing lab cryopreserved, or frozen.

Apheresis, a technique used to collect stem cells from the blood stream, is preferred as it is less invasive. However, if we are unable to collect stem cells through apheresis, a bone marrow harvest may be necessary.

Donors for unrelated allogeneic stem cell transplants are usually from other states or countries. For donations occurring outside of University of Colorado Hospital, procedures for apheresis and bone marrow harvest may be different than those described here.

Apheresis, or Peripheral Blood Stem Cell Collection

Apheresis is the collection of stem cells from the blood stream. In order to collect the donor's stem cells using apheresis, it is necessary for the donor to receive daily subcutaneous injections of a growth factor (called G-CSF, filgrastim, or Neupogen). These are given daily for four days before apheresis. A sibling donor or a family member can give this injection after receiving instructions on how to give the injection correctly. Or, if the donor prefers, the injections can be given by a nurse or medical assistant in the BMT Infusion Center (BIC).

Side effects of the growth factor most commonly include bone pain and mild nausea. The donor may use Tylenol for pain as instructed on the container. Ibuprofen (Motrin, Advil), naproxen (Aleve), aspirin, or aspirin-containing product should NOT be used since these can interfere with clotting and cause bleeding. If nausea is severe, your donor should contact a member of the Blood & Marrow Transplant team for instructions.

The related donor comes to the Apheresis Center in the morning on the day of stem cell collection. The donor receives two intravenous (IV) catheters in the arms. The donor sits in a recliner and the apheresis technician or nurse connects the two IVs to the tubing that runs through a cell separator machine. One IV draws the donor's blood into the apheresis machine and the other IV returns the blood back into the body. The donor's blood flows continuously through the machine. The machine separates the blood and removes the donor's stem cells while returning the remaining blood to them. This is normally a four to six hour procedure and needs to be done an average of one to two days for an adequate collection of stem cells.

Donors usually tolerate the apheresis procedure well. During the procedure, an anticoagulant mixes with the donor's blood to keep it from clotting while it is circulating through the machine. The anticoagulant can occasionally cause the donor to feel cold, have numbness and tingling around their lips or in their fingers, or have nausea. These side effects happen because the anticoagulant lowers the calcium level in the donor's blood. These effects are temporary but it is important that the donor tell the apheresis technician or nurse if they are having any of these symptoms during the procedure.

To make the apheresis procedure go smoothly the donor should:

- » take their daily growth factor injection
- » eat breakfast before they arrive for the procedure
- » bring snacks and a lunch -family members can also bring food in for them

- » arrive on time for the appointment
- » call the Cancer Center Clinic at 720-848-0300 if they are running late for the appointment
- » bring something to do -donors commonly bring reading material, a personal stereo with headphones, a laptop computer, or DVDs to watch at the Apheresis Center, using our DVD player
- » bring any pain medications or other prescription medicines they need during the day

Once the stem cells have been collected, either through a bone marrow harvest or apheresis, they will be directly given to you. They will not be cryopreserved, or frozen. Umbilical cord blood that comes frozen will be thawed and given to you.

Extra stem cells may be collected from your donor. The extra stem cells will be frozen and may be used if you relapse (your cancer comes back) or in the unlikely event that the stem cells do not begin to engraft (grow).

Bone Marrow Harvest

Bone marrow harvest describes the collection of stem cells from the donor's bone marrow. This is done in the operating room and requires the donor to have general anesthesia. The bone marrow comes from the donor's hip bones. This procedure usually takes about one to two hours. The surgery is done as an outpatient (the donor will not be admitted to the hospital). After the procedure, the donor is usually able to go home in the late afternoon. Your donor's hips will be a sore and stiff and they may need to take a pain medication for a few days.

CHEMOTHERAPY AND TOTAL BODY IRRADIATION (TBI)

Chemotherapy

When it is time for your transplant, you will be given chemotherapy. This chemotherapy is usually stronger than the chemotherapy received during your regular treatment. This is also called *conditioning therapy* or your *preparative regimen*. It is used in both allogeneic and autologous transplants.

In autologous transplant, high-dose chemotherapy is given with the goal to destroy any remaining cancer cells. This chemotherapy is usually stronger than the chemotherapy received during your regular treatment. It also destroys the stem cells in your bone marrow. Once the conditioning therapy is done, you will receive an infusion of your previously-donated stem cells. If we did not give you these cells, you would be unable to grow back any of your own stem cells. Because of this, an autologous stem cell infusion is also called a stem cell "rescue".

In allogeneic transplant, chemotherapy is given to reduce your immune system so the donor cells will not be rejected as well as to destroy any remaining cancer cells.

Conditioning therapy is given over several days with the exact number dependent on your treatment plan. The chemotherapy will be given intravenously through your central venous catheter. During the chemotherapy you may receive intravenous fluids and be connected to a heart monitor. You will also receive medications to alleviate any uncomfortable symptoms you may experience during this time.

The specific chemotherapy drugs you receive depend upon:

- » your disease
- » the source of your stem cells
- » how you have responded to chemotherapy in the past
- » what treatment regimen you received before your transplant

Your consent forms will describe in detail the treatment regimen decided to be best for you. Your doctor and transplant coordinator will review this information with you.

Total Body Irradiation (TBI)

You may receive chemotherapy alone or in combination with total body irradiation (TBI). TBI is the treatment of your entire body with radiation. The lungs may be protected from the radiation depending on the dose you receive. You will meet with the

radiation oncologist before your hospital admission. This visit allows the radiation oncologist to get to know you and develop a treatment plan specific to your medical needs. You will receive this treatment while you are in the hospital. You will be taken to the Radiation Oncology department for your treatments. You receive TBI once or twice on a single day or over several days depending on your treatment regimen. Each treatment lasts less than 30 minutes and you will be given medication to prevent and control uncomfortable side effects you may experience while receiving your TBI.

Whether or not you will receive TBI depends upon:

- » your disease
- » the source of your stem cells
- » how you have responded to chemotherapy in the past
- » what treatment regimen you received before your transplant

The intensity of TBI you will receive, and the expected side effects, are highly variable. Your doctor and transplant coordinator will review this information with you. Your consent forms will also describe in detail the treatment regimen decided to be best for you.

STEM CELL TRANSPLANT

About 24 to 48 hours after completing chemotherapy, you will receive your own (for autologous transplant) or your donor's (for allogeneic transplant) stem cells through your central venous catheter. The process is similar to a blood transfusion.

You will receive Tylenol, Benadryl®, and other pre-medications before the stem cell infusion to prevent a reaction. Allogeneic transplant patients will have also been started on immunosuppressant medications to prevent rejection and graft-versus-host disease (explained in more detail later in this book).

The stem cell lab technicians will bring the bag(s) of peripheral blood stem cells or bone marrow to your nurse. If you are receiving your own stem cells or umbilical cord blood, the stem cell lab technicians thaw the bags of stem cells one at a time in a sterile water bath. Once thawed, the stem cell lab technicians give the bag to your nurse. The bags of stem cells look similar to bags of red blood cells or platelets.

The nurse connects the bag of stem cells to tubing connected to your central venous catheter. Each bag of stem cells infuses over 10 to 20 minutes. The number of bags of stem cells you will receive depends on the dose of cells that the doctor ordered and the number of cells in each bag. During the stem cell infusion and for some time afterward, your nurse monitors your blood pressure, heart rate, respirations, oxygen saturation, and heart rhythm.

There are very few immediate side effects of the stem cell infusion. If you receive your own stem cells or umbilical cord blood, you may notice an unusual odor or bad taste in your mouth. This odor or taste is from the substance dimethylsulfoxide (DMSO) used to cryopreserve (freeze) the stem cells. Some individuals may cough or feel slightly nauseated when they receive their cells.

Once infused, the stem cells travel to the bone marrow space and slowly begin to engraft (grow). Engraftment usually occurs in 9-14 days in peripheral blood stem cell transplants and in 14-21 days in bone marrow

What is Day 0?

Day 0 is the day you get your stem cells. Negative numbers refer to days before transplant and positive numbers refer to days after transplant.

For example:

Day -3 is three days before transplant

Day +14 is 14 days after transplant

transplants. Umbilical cord blood stem cells usually take 17-24 days to engraft. The amount of time expected until your stem cells engraft varies significantly depending on your conditioning regimen and donor source. Your doctor will discuss expectations for your case with you. You will receive many treatments such as:

- » intravenous fluids
- » red blood cell and platelet transfusions
- » medication to control nausea, vomiting, and diarrhea
- » antibiotics to prevent and treat infections
- » blood tests to monitor blood counts
- » daily injections of a growth factor (called G-CSF, filgrastim, or Neupogen)

Since you are at risk for infection you will need to:

- » follow an immunocompromised diet (see pages 60-64)
- » not leave the Blood and Marrow Transplant inpatient unit



When your white blood cell count returns to normal, you will no longer be neutropenic and will have engrafted. However, your immune system is not as strong as it used to be. For both autologous and allogeneic transplants, it takes time for all of the cells of your immune system to recover. For allogeneic transplant patient, you are still immunosuppressed (at risk for infection) while taking immunosuppressant medications.

You will be discharged from the hospital when:

- » your white blood cell engraftment is complete
- » there is no evidence of emerging infection
- » you can tolerate oral medication, foods, and fluids
- » you are active enough to function outside of the hospital
- » you are medically stable
- » your discharge teaching is complete

In some cases, transplants may be done in an outpatient setting or with only a brief hospital stay. Our team will talk with you about this if it is appropriate based on your health status, your disease, and the type of transplant you require.

Some patients will have a nonmyeloablative or reduced intensity (lower dose chemotherapy/radiation) transplant. In this case, they may be discharged from the hospital a few days after their stem cell infusion.

DISCHARGE FROM THE HOSPITAL AND FOLLOW-UP IN THE OUTPATIENT CLINIC

Recovery after a stem cell transplant can be very complex. It may take six months to a year, and sometimes longer. The time it takes to get back to feeling “normal” after a stem cell transplant is different for each individual. It depends on the side-effects of your treatment and the specific complications that you may have after your transplant.

After discharge from the hospital, you must return to the outpatient clinic at least twice a week for three months or more (allogeneic patients). It is very important that you come to these appointments so that we can monitor how well your immune system is recovering.

As you recover from the transplant, you will need an adult caregiver to assist you during the recovery process. A caregiver can be a spouse, partner, adult child, sibling, parent, or friend willing to care for you. You can also have several caregivers helping you at different times throughout the process. Your caregiving will be different depending on the type of transplant you have.

An adult caregiver needs to be with you for at least 30 days after transplant for autologous transplant patients and for at least 80 days after transplant for allogeneic transplant patients (or until the doctor or nurse practitioner feels you are stable enough to safely take care of yourself). The caregiver will need to provide transportation to and from the hospital and assist you with daily activities, such as cooking and cleaning.

On average, patients return to their normal level of energy and activity 6-12 months after their transplant. Keep in mind, however, that every patient responds to their transplant differently. It may take less or more time for you to recover.

Depending on your disease, you may begin maintenance therapy after you recover from your transplant.

Preparing for Transplant

Your referral to our Blood and Marrow Transplant Program begins with much activity. An insurance specialist is communicating with your insurance company to confirm your benefit coverage. Your transplant physician and nurse coordinator are keeping in contact with your referring oncologist. Your transplant physician is discussing and designing your treatment protocol. Your part is to complete pre-transplant testing in preparation for stem cell transplant.

The next pages will specifically address:

- » your first visit with the Blood and Marrow Transplant Program
- » the role of your transplant nurse coordinator
- » financial considerations and insurance approval for transplant
- » work-up testing required before transplant
- » importance of maintaining your health before transplant
- » informed consent
- » clinical trials and research
- » advance directives
- » the need for an adult caregiver(s) after transplant
- » housing needs after transplant
- » preparation for admission to the hospital for transplant

The transplant team wants you and your family to know that we understand this is a difficult and stressful time. We are here to help you through the transplant process. Please do not hesitate to call upon any member of the transplant team with your questions or concerns.

YOUR FIRST VISIT WITH THE BLOOD AND MARROW TRANSPLANT TEAM

This section provides you and your family with a description of what to expect during and after your first visit to our transplant program. Ask as many questions as needed to better understand our program. We urge you to make notes of any questions that arise while reading through this book so that we can discuss them during your visits.

The initial visit can be overwhelming with the amount of information given to you. Do not expect to remember everything you hear. You will hear the information discussed at the initial appointment many times again as you prepare for the stem cell transplant process. You may find it helpful to audio record your meeting so that you and your family can listen to the information covered multiple times. Please notify your physician if you plan to record the visit.

Your first visit to our program is an initial consult appointment. There are several purposes for the initial consult appointment:

- » to provide you and your family an opportunity to meet several members of the Blood and Marrow Transplant Team
- » to allow the Blood and Marrow Transplant team an opportunity to meet you and learn about your medical and psychosocial history

- » to discuss why stem cell transplantation is an option to treat your cancer
- » to develop the proposed transplant plan to treat your cancer
- » to determine what type of transplant is right for you (autologous or allogeneic)
- » to begin identifying a donor for your transplant (you, a sibling, an unrelated donor or cord blood)

There are many members of our Blood and Marrow Transplant Team that you will meet during and after your visit. During your initial consult appointment, we will give you business cards that provide you with names and telephone numbers of team members. The members of the Blood and Marrow Transplant Team that you may meet on your first visit include:

- » transplant physician
- » nurse practitioner
- » transplant nurse coordinator
- » psychologist
- » transplant financial coordinator
- » care team assistant
- » dietitian

Before your initial consult appointment, we will ask you or your referring physician to gather your medical records to send to us.

YOUR TRANSPLANT NURSE COORDINATOR

After your initial consult appointment, your transplant nurse coordinator will contact you frequently. Your coordinator ensures that you have all the information needed to make a decision about undergoing transplant. He or she also coordinates testing to identify a stem cell donor (if necessary) and works with you to schedule the eligibility testing you must undergo. Once you are determined to be eligible for transplant, your transplant nurse coordinator works with you to schedule specific dates for your stem cell transplant.

Your coordinator acts as a link between you and the rest of the transplant team. If you have questions, do not hesitate to call your designated transplant coordinator.

FINANCIAL ISSUES

After your initial consult appointment, the Blood and Marrow Transplant Financial Coordinator begins the process of obtaining insurance approval for your transplant. Since this can be a very complex process, we ask that you let our financial coordinator communicate with your insurance company to obtain approval for your transplant. With that said, we want to make sure that you understand your transplant and drug benefits.

Confirmation of your insurance coverage is essential and must be completed before beginning the transplant process. The average approval process takes one to two weeks from the time we request it and send in your eligibility testing results. Insurance coverage for blood and marrow transplant depends on your individual policy and insurance carrier.

It is important to keep in mind two issues related to insurance coverage for a blood and marrow transplant: 1) Do not assume that your insurance company will automatically pay for a transplant just because you come to University of Colorado Hospital for other care and 2) Many insurance companies that initially deny transplant coverage may change their rulings during an appeal process. During and after your initial consult appointment, we will be happy to discuss financial or insurance concerns with you.

Once we have insurance approval, your nurse coordinator contacts you to discuss your treatment plan in detail. Your nurse coordinator then sets up an educational and consent session with you and your physician as well as a tour of the Blood and Marrow Transplant Unit. We encourage your family to attend this session and tour.

WORK-UP/ELIGIBILITY TESTING BEFORE TRANSPLANT

You will need to have some medical tests to determine if you are eligible for stem cell transplant.

The tests determine if your heart, lungs, kidneys, and liver are strong enough to undergo the stem cell transplant. These tests also give us a clear understanding of your cancer. Listed below are some of the tests you may undergo:

- » EKG (electrocardiogram): This looks at the electrical system of your heart and evaluates the rhythm of your heartbeat.
- » Chest x-ray: This evaluates the size of your heart and lungs and insures that you are infection free.
- » PFT (Pulmonary Function Test): This is a breathing test that determines how well your lungs function.
- » Echocardiogram: This evaluates the structures of your heart and how it pumps.
- » Blood tests: These measure your liver and kidney function and determine if you have had certain previous infections.
- » Bone marrow biopsy: This evaluates baseline functioning and shows if cancer is present inside the bone marrow.
- » PET/CT Scan, MRI, or CT Scan: These show where some cancers are in the body and can also assess for the presence of infection.
- » You and your caregiver will also have a meeting with one of our psychologists to talk about how you are coping with treatment, your understanding of the transplant process, and your support system during this time. Most insurance companies require that you meet with a psychologist before they approve your transplant.

There may also be other tests needed based on your medical history, current health status, and treatment plan.

If your transplant is postponed, you may have to repeat some or all of your testing. This is to ensure that you are still healthy enough to undergo high-dose chemotherapy and transplant.

MAINTAINING YOUR HEALTH BEFORE TRANSPLANT

It is important that you enter into transplant as healthy as possible.

- » You should eat a well-balanced diet that includes adequate calories and protein. If you have difficulty eating or maintaining your weight, you may make an appointment with one of the BMT dietitians.
- » With adequate nutrition you can:
 - * tolerate therapy with fewer side effects
 - * have more energy to help you recover
 - * help repair your body
 - * maintain your muscle strength
 - * prevent weight loss and maintain energy stores
- » You should remain as active as possible without overdoing it. Walking is a good way to build your strength and stamina.

- » *If you smoke, you must quit immediately.* This is necessary to prevent lung infections and lung damage. This restriction includes both tobacco and marijuana. You should also make every effort to avoid second-hand smoke. If you need help to quit smoking, contact your BMT psychologist for resources.
- » *If you use chewing tobacco, you must quit immediately.* This is necessary to prevent oral infections that can move into the bloodstream.

THE INFORMED CONSENT PROCESS

Before your transplant you will receive consent forms to read and sign. We require you and your caregiver to attend a scheduled consent review meeting with your transplant physician to formally discuss all aspects of the transplant process including the risks and benefits of this treatment, to answer any questions you may have, and to sign all consent forms.

CLINICAL TRIALS - RESEARCH

What is a clinical trial?

At some point during your treatment, you may have the option of taking part in a clinical trial. Hematological malignancy and stem cell transplant clinical trials are research studies in which doctors use innovative measures guided by specific protocols in order to more effectively treat cancer. If you are thinking about participating in a clinical trial, your physician and clinical research nurse coordinator will inform you of all available treatment options.

Why participate in a clinical trial?

Potential benefits of participating in a clinical trial include:

- » health care provided by leading physicians in the field of cancer research
- » access to new drugs and interventions before they are broadly available
- » a more active role in your own health care
- » close monitoring of your care and any side effects
- » an opportunity to make a valuable contribution to cancer research

What happens during a trial?

If you decide to participate in a clinical trial, the research team will check your health at the beginning of the trial, give you specific instructions for participating in the trial, monitor you carefully during the trial, and stay in touch with you after the trial is completed. To make the trial results as reliable as possible, it is important for you to follow the research team's instructions. This means coming to all doctor visits and lab appointments when scheduled and taking medicines as prescribed.

Blood and Marrow Transplant & Hematological Malignancies Research Program

The Blood and Marrow Transplant & Hematological Malignancy research program works to coordinate clinical research studies for a wide array of hematological malignancies at the University of Colorado. The team's group of physicians and research nurses offer expertise in leukemias, lymphomas, myelomas, and both autologous and allogeneic stem cell transplant, including umbilical cord blood transplant. The program is committed to providing patients access to novel and cutting edge therapies intended to improve outcomes for patients.

ADVANCE DIRECTIVES

You have the right to make decisions about your healthcare. Although you can make these decisions now, there may be a period of time during your transplant process that you will not be able to speak for yourself or communicate your decisions. As your healthcare providers, we want to be able to honor your wishes. A statement of your wishes is called a living will.

Not only do we encourage you to write down your wishes, but we encourage you to choose a family member, significant other, or a trusted friend to make your wishes known in the event that you are unable to communicate with the healthcare team. This type of statement is called a Durable Power of Attorney (POA) for Health Care. A medical POA is not the same as a legal POA.

Making such decisions ahead of time is called giving an "advance directive." Advance directives can either be given in writing or verbally. You are also encouraged to talk to your doctor or other members of the transplant team about your treatment choices.

We strongly encourage you to think about these decisions and your wishes before your stem cell transplant process begins. If you need any assistance in making these decisions or if you want to discuss advance directives options, feel free to ask any member of the blood and marrow transplant team. The team's psychologist, social worker, chaplain and/or your nurse coordinator are all available to discuss these issues with you.

ADULT CAREGIVER AFTER TRANSPLANT

The time spent in the hospital during transplant varies significantly. Some people may have their transplant outpatient and others will be in the hospital for a long time. When you are out of the hospital, PLEASE have an adult caregiver with you until day +30 (for autologous transplant

patients) or until day +80 for (allogeneic transplant patients) after the date of your transplant

A caregiver may be a spouse, partner, adult child, parent, sibling, or friend who is willing to care for you. Your caregiver does not always have to be the same person every day. You may have more than one.

The average amount of time a caregiver is needed, for transplants done in the hospital

Autologous Transplants- approximately two weeks after discharge from the hospital

Allogeneic Transplants- approximately two to three months after discharge from the hospital

This requirement is for your safety. At the time you are discharged, you will be fatigued and may need assistance with your daily activities. Your caregiver will drive you to and from your frequent clinic appointments, assist you with your medications, prepare your meals, and help you keep your home

clean. If an emergency arises, your caregiver will assist you in getting the help you need.

We will give your caregiver information and instructions and discuss his or her responsibilities before you are discharged from the hospital after transplant. We want you and your caregiver to feel comfortable and safe when you go home from the hospital.

HOUSING NEEDS AFTER TRANSPLANT

After discharge from the hospital, you will need to stay close to the hospital (within a 30 minute drive) and have two to three clinic appointments each week. During this recovery period you may stay at home if you live locally. If you do not live close but you have a friend or relative that does, you may choose to stay at their home. We know that finding low cost, short-term housing can be difficult. If you have any problems making housing arrangements, please talk to your nurse coordinator or social worker. The UCH lodging list is located in the Resource section of this book.

Some insurance providers as well as some state Medicaid plans (usually these are county specific) offer a travel and lodging benefit for patients who have to leave their metro areas for the care that they require. Your transplant financial coordinator usually

inquires about these types of benefits when verifying your transplant benefits. If you do have benefits of this type, your transplant financial coordinator will make you aware. It is then your responsibility to determine how to access them—i.e. what supportive documentation is required, how and to whom it is to be submitted for reimbursement of these costs to you.

If you are a veteran, you may be eligible for lodging at the (Denver) Fisher House. Please contact your social worker for more information. Your social worker can also discuss some other possible lodging options with you that are not necessarily listed on the UCH lodging list.

PREPARING FOR YOUR HOSPITAL STAY

During your hospital stay you will be in “protective isolation” on the Blood and Marrow Transplant Unit. Family and friends may visit if they are not sick or have not recently had close contact with someone who is sick. One person is allowed stay with you in your room at night. There is a couch in your room that can fold down into a bed. You will need to stay on the inpatient unit and may not go outside or leave the unit unless you are taken to another department for a test or procedure. You are welcome to bring items to decorate your room during your stay (such as photos, posters, quilts or blankets that have been washed) to make the room more comfortable for you. If there is something that you are unsure about bringing, please ask your nurse coordinator for clarification.

Passing the Time during your Hospital Stay

You may have a short attention span and decreased concentration for the first few weeks after the high-dose chemotherapy. We encourage you to bring items that may be helpful in passing the time while you are in the hospital. Below are some items that patients often bring in:

- » CD, MP3 player, or a radio
- » DVDs and videotapes. Each room has a TV/VCR/DVD player (We have some videos and DVDs that you can check out at no cost. Family members and friends are also welcome to bring rented DVDs and videos to you.)
- » handwork and craft projects (avoid projects that use sharp needles)
- » art or scrapbooking projects
- » puzzles, cards, and board games
- » laptop computers (rooms have a wireless connection available)
- » books or audio books

Clothing

The hospital provides gowns and pajamas that we recommended you use during your chemotherapy. However, after chemotherapy we suggest you bring your own clothes to wear during the day. Most patients feel comfortable wearing:

- ✓ t-shirts
- ✓ sweats
- ✓ loose clothing
- ✓ pajamas or gowns
- ✓ a bathrobe
- ✓ cotton underwear
- ✓ socks
- ✓ scarves, turbans, or hats
- ✓ washable slippers with grip bottoms (to prevent falls)
- ✓ Any clothing you bring in (even if it is new) must be washed before your hospital stay.

- ✓ To keep your clothes as clean as possible, bring your clothes from home in a plastic bag.

Miscellaneous Items

- » To decrease your risk of infection we do not allow any (dried or fresh) flowers or plants in the patient rooms or on the transplant unit. Friends and family can send non-latex balloons or silk flower arrangements instead. Remember to tell your friends and family about these restrictions if they are planning to send you flowers while you are in the hospital.
- » Because your skin will likely be more sensitive after the chemotherapy, you are welcome to bring in lotions, liquid soaps, and other skin products that are hypoallergenic and fragrance-free. These items must be new.
- » To reduce the risk of infection and skin irritation please do not wear a wig during your transplant stay.
- » We suggest you do not wear make-up. If you bring make-up it must be new. Specifically, we prefer you do not wear any eye makeup during this time because of the risk of infection and irritation.
- » In order to reduce your risk of bleeding and infection, you will not be able to use a regular toothbrush or dental floss. We will give you a very soft-bristled toothbrush and mouth antiseptic for you to use for your oral hygiene.
- » We do not allow shower net balls, sponges, or loofahs as they may carry bacteria.
- » In order to decrease your risk of infection, you will not be able to wear earrings or contact lenses. Make sure to bring a pair of glasses if you need them.
- » You may not use tampons.
- » You may bring your own pillow. Pillows must be new and may not be feather or down.
- » You may have stuffed animals if they are new or washable. Please wash them before bringing to the hospital.
- » Please remove artificial nails and nail polish before your hospital admission. Artificial nails commonly harbor fungus under them. Nail polish can interfere with the monitoring equipment.
- » During your chemotherapy infusion you may be given a large amount of intravenous fluid. This causes your hands and feet to temporarily swell. Please do not wear rings or jewelry during this time.

EMOTIONAL, SPIRITUAL AND FINANCIAL PREPARATION FOR TRANSPLANT

Our team values your psychological, emotional, and spiritual health. We have experience guiding many patients and their families through transplant and recovery and want to provide the best comprehensive care to your family. Please speak up if you are experiencing emotional, spiritual or financial distress.

Common feelings associated with preparation for transplant

Facing the prospect of transplant can be distressing. It can bring on feelings of dread, panic, and helplessness. It can be overwhelming to try to cope with the idea that you have a life-threatening illness, while at the same time having to deal with a tremendous volume of information.

What's "Normal"?

During this time, you are likely to experience feelings of anxiety, self-pity, frustration, and confusion. It is also normal to feel betrayed by your body and feel anger and jealousy towards others who do not have to face

the same challenges that you face. At times, you may find that your feelings undergo intense fluctuations, alternating between hope, anticipation, and fear or between high energy and extreme fatigue. Please note that some of the medications you will be prescribed may effect your emotions. Many people are also surprised at how well they cope with the demands of the transplant process and feel a sense of pride in their ability to “rise to the occasion”.

One Day at a Time

Most patients describe a coping strategy of taking things “one day at a time”. Breaking down the whole process of transplant into a series of small tasks to be accomplished and focusing mostly on just the next few steps is very helpful to our patients. If you start to feel overwhelmed by the number of things to learn and remember, know that many people have been through this process before and that our team can help you with whatever part of the process is next.

Avoiding Emotions

Another reaction you may have is that of avoiding emotions. You may find yourself responding to the situation by becoming emotionally numb and focusing on the specific task at hand. As you go through various emotional responses, try to be understanding and gentle with yourself. Avoidance can be an appropriate way to cope initially, but it is also important to discuss your thoughts and reactions to your current situation.

Hope

You may also see the transplant as a new lease on life and, as such, a source of great relief and hope, as well as a great challenge to overcome. Radical alterations in emotions and moods, as well as periods of relative calm, are all common ways of coping.

Connection

Many people find that their diagnosis of cancer or their need for transplant has a way of highlighting the things in their life that are most important to them. For many people this involves spending time with their close friends and family. Most patients report that during the transplant process their relationships with loved ones grow closer.

Pre-transplant: Meeting With A Psychologist

Every patient in our program meets with a psychologist before the process of transplant begins. You and the caregiver you choose will attend this appointment together and will have a chance to get to know one of our psychologists who will provide support as needed through the transplant and recovery process.

During this meeting the psychologist will get to know you and your family and will:

- » organize and document a caregiving plan to be used following transplant
- » provide simple coping skills for the emotional demands of treatment
- » address any existing mental health or social problems
- » offer tips that have been helpful to others going through transplant

The psychologists are available to you and your loved ones before, during and after transplant. They work in the hospital and also in our outpatient clinics. Psychologists provide psychotherapy as well as quick and simple recommendations to control immediate symptoms such as sleep problems, anxiety, or depression. Our psychologists can help with a wide variety of behavioral, emotional, and family concerns including:

Emotional Concerns:

- » adjusting to the “new normal” after transplant
- » managing stress and anxiety
- » fighting depression and loneliness
- » concerns about treatment decisions

Behavioral Concerns:

- » difficulties with sleep
- » pain control
- » persistent nausea
- » anxiety/panic attacks
- » managing fatigue

Family Concerns:

- » caregiver support
- » strengthen relationships (couples therapy)
- » how to talk to your children about transplant
- » asking for help from others
- » improve communication

Stress and Stress Management

Stress can be a positive or negative change to which you must adjust. Stress is a normal part of the transplant process and is not harmful as long as it is managed appropriately. Before the transplant, it will probably be helpful to think of ways that you can reduce stress in your life. Although you may not be able to avoid some of the factors that are stressful, such as your diagnosis of cancer, there are still things you can do to reduce the amount of distress you experience. Try the tips in the box on the right to reduce stress as you prepare for transplant.

Practice Relaxation Techniques

Practicing relaxation techniques that are calming such as muscle relaxation, meditation, breathing techniques, or imagery may be helpful to you as

you prepare for the hospital stay. Some people find that meditation reduces their level of anxiety and is helpful in combating depression as well as lowering their level of discomfort and pain. The blood and marrow transplant psychologists can assist you in learning these techniques.

Express Your Emotions

If you are experiencing a great deal of anxiety, fear, or sadness, give yourself permission to express these emotions. A common subject mentioned by almost every survivor is the importance of honest, open communication. Choose to express your emotions to people who are close to you and can be supportive. If certain people are not helpful, do not feel guilty about avoiding them and focusing on your own needs. Talking with the blood and marrow transplant psychologist or any professional therapist with psycho-oncology experience can also be helpful.

Tips to Reduce Stress

- » set clear priorities
- » develop a written list of short- and long-term goals
- » let go of less important obligations to reduce the amount of pressure you feel
- » delegate tasks to family and friends who want to help (Often the people who care about you are unsure of how to be of the most assistance. They will be grateful to you for giving them concrete suggestions. By doing this, you may not only help yourself but may also help your loved ones.)
- » keep a journal of your experiences (Write down questions, medications, comments, etc. from the beginning of the process throughout recovery.)
- » talk with a BMT psychologist

WHAT FAMILY MEMBERS CAN EXPECT FROM THE TRANSPLANT PROCESS

The transplant process is difficult for family members and other significant people in the patient's life. Family members may experience many of the stresses and feelings that the patient is experiencing. The transplant process places many demands on the family and on relationships. Sometimes when patients are not feeling well, they are more irritable and they direct their irritability toward loved ones. However, many families find that they pull together and become closer in ways that last long after their loved one has recovered.

Caregiving

The patient and our team rely heavily on caregivers so it is important that caregivers take care of themselves. This may mean scheduling some time away from the Blood and Marrow Transplant Unit to get a chance to relax. If possible, it is helpful to have multiple caregivers so that breaks can be arranged, even if they are only for an afternoon. It also can help to have friends or family assist with daily tasks such as meals, house cleaning, childcare, laundry, and phone calls. Keeping a list of things that need to be done and offering part of the list to family or friends that ask "how can I help" can be an easy way to get assistance with these tasks.

Mood Changes in Your Loved One

As caregivers, you may notice changes in the patient's mood or behavior. For example, you may notice that the patient shows less interest in life outside the hospital, their mood changes frequently, or they seem to focus only on "making it through the day." These mood changes are very common and may be caused by many things such as stress and medications. Although depression can occur, some emotional and social withdrawal is also normal for the patient. As a way of coping, patients become focused on their physical functioning and getting through the day. It is important for the caregiver to discuss their fears and concerns with the Blood and Marrow Transplant team members as they arise.

Although the psychosocial team is primarily concerned with the patient, we are also available to the patient's family and significant others. The BMT team encourages family members and caregivers to share their thoughts, feelings, and concerns with any member of the transplant team. Please do not hesitate to call upon any member of the transplant team at any time.

SPIRITUALITY AND RELIGION

Spirituality and faith can be an important source of comfort during this time. Many patients report that prayer and/or meditation can be a source of spiritual and psychological well-being. We encourage you to maintain a connection with your faith community throughout the transplant process if that is a source of support for you. Spirituality refers to the ways we seek and express meaning and life purpose. It also refers to the ways we experience feeling connected to what is happening to us, to our relationships with ourselves and others, and to the sacred. Some patients report an increased awareness of spiritual or existential needs, challenges, questions, and insights as they undergo treatment. Talking about these issues can be a helpful part of the healing process for some people.

Chaplaincy

A chaplain is available to provide support in coping with spiritual issues that arise during the transplant process. The chaplain is also available for family meetings or to meet individually with family members or children. The chaplain's role is to work with the religious, spiritual, and ethical issues that arise for patients and families. The goal is to help make use of your own spiritual resources in order to cope with your current situation. Our chaplain will respect your beliefs and will accommodate your needs in your spirituality or faith. Again, the chaplain's goal is to help you to draw on your own inner resources and to facilitate whatever external resources are available to you in order to help you cope with your illness, treatment, and healing.

Other services include pastoral conversation, prayer, and religious rites, such as the sacraments of Baptism and Holy Communion. Services of the chaplain

are available to all persons whether or not you are related to any faith group or denomination. Our chapel is available on the first floor of the hospital and provides a reflective atmosphere for prayer, meditation and worship. A weekly non-denominational chapel service is led by our chaplains every Wednesday at 11:00am. The chaplain can also assist you in contacting a particular faith group representative upon your request.

HOW TO LEARN MORE ABOUT YOUR CANCER AND TRANSPLANT

Seek Medical Information

Seeking medical information can sometimes reduce fear and help people regain a sense of control. This can be done through library and electronic research, talking to doctors, connecting with former transplant survivors, and by calling different transplant-related and cancer-related organizations that have knowledgeable people who can respond to your questions and concerns. The Blood and Marrow Transplant Program can provide you with a number of resources for up-to-date information about your cancer type, treatment, and long-term effects.

If you are seeking medical information on the Internet, please be aware that there are many sources of inaccurate and outdated information that appear to be legitimate. Always check that information is coming from a reliable source and ask a medical professional to help you evaluate the information, if needed. Also be aware that many people with the same type of cancer have very different treatments and outcomes based on the fine details of their diagnosis and other factors that are often not discussed in non-scientific information.

Contact a Survivor

Contacting someone who has undergone a transplant can be helpful. There are national organizations that can establish a peer support opportunity. You can also ask a member of the blood and marrow transplant team to put you in touch with one of the hundreds of people who have been through a stem cell transplant at University of Colorado Hospital.

Keren Stronach, who underwent two transplants, and 25 other bone marrow transplant survivors contributed to *"Survivors' Guide to A Bone Marrow Transplant"* (2002), published by NMBT Link. Ask the BMT Team if you would like a copy of your own or access <http://www.nbmtlink.org/documents/sg.pdf> for an online version.

American Cancer Society Resource Navigator

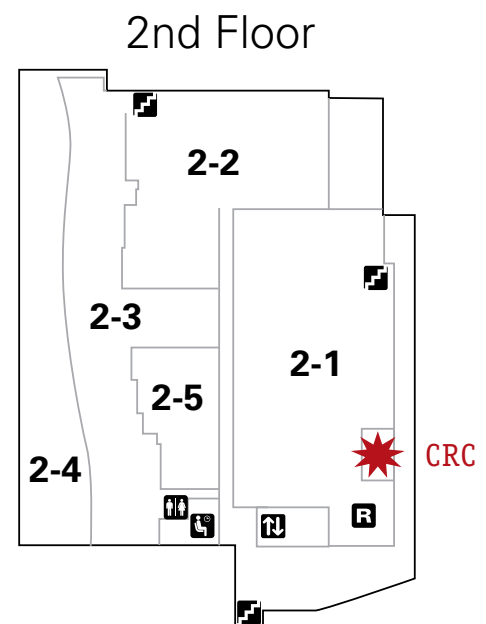
Monfort Family Foundation Cancer Resource Center

The Cancer Resource Center (CRC) is staffed by our resource navigator who can help you find the information you are seeking regarding transplants. This center is designed to help families get information about all aspects of their treatment.

At the CRC, you will find:

- » information related to specific cancer types
- » support groups and educational classes at our facility and in the area
- » lodging and transportation services information
- » audio/visual materials for use during your treatment at University of Colorado Hospital

* Topics include: stress release, guided imagery, stories,



spirituality, and relaxation.

- » tours of University of Colorado Hospital for new patients and caregivers
- » “Lemonade Tours” of the hospital for the children of cancer patients

PREPARING FINANCIALLY FOR TRANSPLANT

Social Workers

There are two social workers assigned to our team. One worker is located in the inpatient hospital setting for when patients are in the hospital. The second is available to patients/caregivers in the outpatient/clinic setting. Social workers may assist in a variety of ways and are experts at solving practical problems. Some of the many things done by our social workers include:

- » financial assistance
- » insurance planning and coordination
- » planning for services at home when you leave the hospital
- » help with housing and transportation
- » navigating complex paperwork

What do I do about income?

Treatment with a stem cell transplant is considered automatically medically disabling according to the guidelines established by the Social Security Administration (SSA). This means that if you have been working and paying into Social Security (usually a minimum of 10 years/40 quarters), you should be eligible for Social Security Disability Income (SSDI) assuming you are not able to work.

A person who is eligible for SSDI is able to work/earn a very small amount and still qualify for SSDI, however, usually collecting SSDI requires that the individual in question is not working at all. To find out if you are eligible for SSDI, how much your monthly payment will be and/or to start the application process, call 800.772.1212. It is recommended that you start the application process via phone and that you make either an in-person or phone appointment to apply versus applying on-line as completing/submitted an on-line application can be cumbersome, time-consuming and confusing.

However, the SSA’s web site – www.ssa.gov - is a great resource. Many people receive SSDI during the course of their treatment and recovery and then, once they are able to return to work, discontinue their SSDI benefits. Of note, if a person is still considered medically disabled/unable to work two years after the date of his/her first SSDI check, (s)he is eligible for Medicare, regardless of age. The individual may continue to benefit from Medicare coverage as long as (s)he is disabled per the SSDI. Also, a patient may have Medicare as his/her primary insurance coverage and private insurance as a secondary or supplement.

If a recipient of SSDI has minor children, each child will also receive a monthly stipend from the SSA as long as the recipient does.

Some employers also offer disability insurance – both short- and long-term disability. Sometimes these plans are automatically offered as part of an employee’s benefits, and sometimes the employee is required to purchase these plans as part of his/her benefit options/package. If you are not sure about whether or not you are eligible for, have, or qualify for disability benefits through your employer, you should contact your

employer's Human Resources/Employee Benefits Department.

Family Medical Leave Act (FMLA)

FMLA allows an employee to be absent from work for a medically-related issue for him/herself or to care for an immediate family member for up to 12 weeks – that do not need to be consecutive – in a 12 month period. An employer must offer employees FMLA if the employer employs 50 or more employees within a 75 mile radius. While FMLA protects an individual's job, it does not provide income to the individual. An individual may earn/receive income while on FMLA if (s)he has paid time off accrued. There is usually paperwork associated with FMLA that must be completed by health care providers. Your nurse coordinator or social worker may assist you with this paperwork.



Medicaid

Medicaid is a government-funded health insurance program for persons with little or no income and/or resources who qualify. Medicaid is administered by the states- i.e. each state has its own Medicaid guidelines meaning that the amount that a person is able to earn and/or the amount in assets that (s)he is allowed to have vary by state. Usually, to qualify for regular state Medicaid, a person must first be deemed medically disabled per the SSA. There are also different types of Medicaid. In Colorado, a person with minor children who meets the financial criteria could qualify for family Medicaid. Colorado also has long-term Medicaid available to those who are in long-term care facilities and/or who qualify for a type of Medicaid that is tied to the patient receiving help at home. **NOTE: Persons eligible for regular Medicaid usually receive Supplement Security Income (SSI) either indefinitely if they do not have the work credits for disability or until they receive their first SSDI checks. Also, it is possible for a person to be eligible for Medicaid and then lose his/her coverage when (s)he receives his/her first SSDI check as the SSDI puts the patient over-income for Medicaid.*

Medicare

Medicare is government-funded health insurance for the elderly, blind and/or disabled as well as for those who are on chronic dialysis. As was mentioned previously, if a person is considered disabled per the SSA- i.e. is receiving SSDI and has been disabled two years more years (two or more years following his/her first SSDI check), (s)he is eligible for Medicare.

Colorado Indigent Care Program (CICP)

If you are a Colorado resident and you meet the guidelines, you may be eligible for CICP. CICP is NOT insurance. It is for residents of Colorado who are uninsured or under-insured or who have insurance with high out-of-pocket medical costs and lower incomes. CICP can help patients pay out-of-pocket expenses like co-pays for physician visits, hospital stays, outpatient treatment, and prescriptions. CICP is only accepted by certain institutions and pharmacies. UCH is a CICP approved provider. To find out if you are eligible for CICP, call the UCH outpatient financial counseling office – located in 1020 AOP – at 720.848.1025 to talk with a financial counselor about your eligibility and to make an appointment.

If you have any questions regarding finances, insurance, disability, FMLA, or CICP, please contact your social worker.

Stem Cell Transplant

YOUR RESPONSIBILITIES

Throughout your transplant process, the most important member of the team is YOU. You play an important part in your care. You will have many things to do everyday to help yourself get better. Some of these things involve following the guidelines discussed in this book. Your cooperation with the health care team is important for your recovery. You know yourself best so the health care team depends on you to report any changes in your condition or concerns you may have.

IMPORTANT INFORMATION FOR YOU TO UNDERSTAND BEFORE YOUR ADMISSION

The following guidelines are in place to keep you safe and healthy.

- » The Blood and Marrow Transplant Unit has a special air filtration system called a hepafilter that helps to keep the air inside the unit as clean as possible and helps prevent infection from the environment.
- » Please do not leave the Blood and Marrow Transplant Unit if your transplant is performed in the hospital. This is to prevent you from being exposed to infection.
- » If you develop an infection that requires you to be in isolation (contact or respiratory), you will unfortunately not be able to leave your own room. In addition, family members and/or visitors may be asked to follow specific infection control precautions. If needed, ask the nurse to move the stationary bike or treadmill into your room for exercise.
- » When walking on the unit you must stay on the tiled, non-carpeted portion of the unit.

THE BLOOD AND MARROW TRANSPLANT UNIT

General Information

Patient Rooms

Rooms on the unit are private. Each room includes:

- » private bathroom with a shower chair and detachable shower head

- » blow dryer
- » sofa that folds down into a bed
- » telephone with a private number (phone number is on the phone)
- » TV/VCR/DVD player

Visitors

As a hospital that values patient and family-centered care, we encourage friends and family to visit during your hospital stay. Here are some things to keep in mind:

- » We do not have specific visiting hours.
- » Children over the age of 12 years are welcome to visit. If you have younger children whom you would like to visit, please consult with your doctor or nurse.
- » Please remind your family and friends NOT to visit if they are sick or have a cold/virus.
- » Before your visitors enter your room they must wash their hands or use the alcohol-based hand sanitizer outside your room.
- » One person can stay in your room overnight anytime during your stay.
- » Parking is free.

The Unit Routine

Change of Shift

The nursing staff change shifts from 7 am - 8 am and 7 pm – 8 pm. Please try to ask questions and make requests before or after these times, if possible.

Patient Rounds

The transplant physician sees each patient daily. We call these visits “rounds”. Your nurse practitioner will also see you several times each day. Your family is welcome to be in your room during the day to visit with the doctors and other team members. This is a great time to ask questions.

Vital Signs and Weight

You can expect your certified nursing assistant (CNA) to come to your room every four hours to take your

vital signs. These include your blood pressure, heart rate, respirations, temperature, oxygen saturation, and pain score. This means you will be awakened in the night. We will also weigh you twice a day. Changes in your vital signs and weight are important for your team to know while monitoring you throughout the transplant process.

Laboratory Tests

Your nurse will draw blood from your central venous catheter at least twice a day, usually around 4:00 pm and 4:00 am.

Medications

- » Throughout your transplant process you will receive intravenous fluids through your central venous catheter. These fluids prevent dehydration and flush medications from your body.
- » Electrolytes are minerals that your body requires, such as potassium, magnesium, and calcium. Chemotherapy and some other medications can affect your body's ability to maintain these minerals. Therefore you will need frequent infusions of electrolytes through your central venous catheter.
- » If you are having difficulty eating or are unable to eat enough, we may give you TPN (total parenteral nutrition). TPN is a special intravenous fluid that has protein, carbohydrates, electrolytes, and other nutrients that your body requires.
- » To prevent and treat infections, you will also receive antibiotics, antivirals, and antifungals through your central venous catheter.
- » You will likely need transfusions of red blood cells and platelets throughout your transplant process. The chemotherapy and TBI you receive will destroy red blood cells, white blood cells, and platelets. You need red blood cells to carry oxygen throughout your body. Platelets prevent bleeding. The exact number of red blood cell and platelet transfusions needed varies from patient to patient.
- » Several days after your transplant we may start daily subcutaneous injections of a growth factor (called Neupogen, also known as filgrastim or G-CSF) to help your new stem cells grow.
- » Throughout your hospital stay we will give you antiemetics (anti-nausea medications) to help control any nausea or vomiting. We may have to give you a combination of medications or change the medication to find the one that works best for you. Be sure to let your nurse know how the antiemetics are working for you.
- » Unfortunately, you may experience pain. For example, some patients have pain due to mouth sores and others may have bone pain due to the growth factor injections. As with the antiemetics, we may have to give you a combination of medications or change the medication to find the one that works best to control your pain.

THE DAY OF ADMISSION TO THE BLOOD AND MARROW UNIT, IF YOUR TRANSPLANT IS INPATIENT

On the day of your admission you may need to have a trifusion central venous catheter placed if you do not already have one. If a trifusion is needed, you will be notified several days before your admission of the time to arrive for this appointment. This procedure is done in the Interventional Radiology department on the 3rd floor of the Anschutz Inpatient Pavilion. You will then go to the 11th floor Blood and Marrow Transplant Unit once the trifusion line is placed. If you already have a trifusion (or other adequate central venous catheter) in place, the charge nurse of the Blood and Marrow Transplant Unit will call you on the morning of your admission day and let you know what time to arrive on the unit that day.

After getting settled in your hospital room, the nurse practitioner and floor nurse will ask you questions about your health history and your current medications. Your team will complete a physical assessment, health history, obtain your weight, and take vital signs. The nurse will draw blood from your central venous catheter for labs.

It is normal to feel overwhelmed on the day you are admitted to the hospital. To help you feel more comfortable your nurse will review information about the transplant and hospital stay with you and your family. He or she will begin to orient you to the Blood and Marrow Transplant Unit routines. Please feel free to discuss questions or concerns you may have with any of the team members.

The Transplant Timeline

- ▶ several days of chemotherapy, with or without TBI, depending on your treatment plan
- ▶ a day of rest (or no chemotherapy, depending on your treatment plan)
- ▶ stem cell transplant
- ▶ engraftment of your white blood cells/stem cells
- ▶ discharge once your condition stabilizes

CHEMOTHERAPY AND STEM CELL TRANSPLANT

As a review, here is guideline of what the typical transplant process looks like:

Nutrition During Transplant

Good nutrition during the transplant process is very important in order for your body to heal. Your calorie and protein intake needs to increase during this

process. You may have to eat more food than normal to maintain your weight. Sometimes you may have to choose foods that are higher in fat or sugar than you would normally choose. Even though these foods are not typically thought of as healthy, they are healthy for you at this time and should be eaten without any guilt. If you do not meet your calorie and protein needs you may have more fatigue, muscle loss, rapid weight loss, experience more side effects, or take longer to recover. Do your best to try and eat to maintain your current weight.

There are a number of side effects you may or may not experience. The type of treatment you receive plays a big role in what side effects you will encounter. Some common side effects include:

- » nausea/vomiting
- » loss of appetite (anorexia)
- » weight loss
- » taste changes
- » sore mouth and throat (mucositis/esophagitis)
- » thick saliva
- » dry mouth (xerostomia)
- » diarrhea
- » constipation
- » feeling full quickly (early satiety)

These issues may make it hard for you to get the needed amount of calories and protein for your body. Below is a list of the more common side effects and some tips to help control them.

Nausea/Vomiting

- » Take anti-nausea medications at the first sign of nausea. If your medication is not working, let your nurse practitioner or doctor know so a new medication can be prescribed.
- » Eat 5 to 6 smaller meals instead of three larger meals.

- » Please do not skip meals or snacks- having an empty stomach can make nausea worse.
- » Avoid strong odors by eating foods that are at room temperature or cold, drinking liquids through a cup with a lid and straw, and avoid being in the same room where foods are prepared.
- » Sometimes salty and sour foods can help with nausea. Examples of this would be lemonade and salty crackers or chips.
- » Overly sweet and greasy foods can make nausea worse for some people.
- » Keep a list of foods that have worked well the last time you were nauseated so you have ideas if the symptom should come back.
- » If you vomit often you are at an increased risk for dehydration. To prevent this you need to increase your fluid intake. Try fluids such as broth, sports drinks, water, juice, tea, gelatin, and popsicles.

Loss of appetite

- » Eat every 2-3 hours even if you do not feel hungry.
- » Set an eating schedule and stick to it. Eating or drinking something every time there is a commercial on television, or setting an alarm/ timer to go off can remind you to eat.
- » Eat your largest meal of the day when you are feeling the best.
- » Avoid drinking liquids with your meals as they may cause you to get fuller faster. Drink most of your liquids between meals.
- » Add more calories and protein to the food you are able to eat. Add peanut butter to fruit such as bananas or apples, add cheese to vegetables, put butter and jelly on your toast, mix granola into your yogurt, choose a cream based soup instead of a broth based one, etc. Ask your dietitian for a list of other ideas.
- » Use high calorie/protein drinks. It is often easier to drink calories than it is to eat them. Commercial products such as Ensure®, Boost® and Carnation® Instant Breakfast, fruit smoothies and milkshakes are all good things to try.
- » Make meal time relaxed, pleasant and enjoyable. When friends or family are over for a visit, have a meal or snack with them. Avoid bringing up other problems that are going on when you are eating.
- » Think of food the same way you do your medications. You have to take them in order to recover.
- » Be as physically active as you can to help improve your appetite.
- » If you think fear, depression, or other feelings are affecting you appetite you can contact the team psychologist for suggestions on how to help.

Diarrhea

- » Hydration is extremely important when you have diarrhea. Make sure to stay hydrated by drinking plenty of liquids. After each loose bowel movement drink one cup of fluid.
- » Diarrhea also causes you to lose electrolytes so it is important to replace these as well. Some foods that are good to eat includes broth, soup, pretzels, salty crackers, sports drinks, bananas, potatoes without skin, apricot or peach nectar, coconut water, or fruit juice.
- » Increase foods with soluble fiber. These include applesauce, bananas, canned peaches, pears, oatmeal, and white rice.
- » Decrease foods with insoluble fiber as they will increase the speed in which food moves through your GI tract. Insoluble fiber containing foods include raw vegetables and fruits, seeds, and whole grains.
- » Greasy, fried, spicy or very sweet foods may make your diarrhea worse. Avoid these foods if they increase your diarrhea.
- » Some people may have a hard time digesting milk products that contain lactose. If you notice cramping, gas, or an increase in diarrhea after consuming dairy products, take lactase enzymes

before eating these foods. You can purchase lactase enzymes at any drug or grocery store. Yogurt is usually tolerated.

- » Try to rest after your meals as this can decrease bowel activity.
- » Eat small, frequent meals during the day.
- » Avoid:
 - * Caffeine
 - * Carbonated beverages (may have if you leave them open from >10 minutes before drinking)
 - * Drinks with added sugar
 - * Sugar-free products that are sweetened with sugar alcohols such as sorbitol, mannitol or xylitol (these are usually in sugar-free products like gum, candy, and cookies)
 - * Very hot or very cold drinks
 - * Gas causing vegetables such as broccoli, brussel sprouts, cabbage, onions, garlic, and cauliflower

Sore mouth and throat (mucositis and esophagitis)

- » Keep your mouth clean by rinsing often with a baking soda and salt mouth wash. Swish and spit (do not swallow) the solution after meals and at bedtime. Avoid commercial mouthwashes containing alcohol as they might dry out and irritate the lining of your mouth.
- » Eat soft, bland, moist foods. Milkshakes, soups, scrambled eggs, canned fruits, casseroles, pudding, and non-acidic juices are all good examples. Try adding extra sauces and gravies to get more moisture.
- » Cut food into small bites or puree your food using a blender or food processor to help avoid painful chewing.
- » Drink with a straw to avoid the places in your mouth that are most painful.
- » Eat foods that are cold or room temperature. Hot foods may cause more discomfort.
- » Suck on ice chips or popsicles to help numb your mouth. Be careful not to accidentally bite the inside of your cheek or tongue.

COPING DURING THE TRANSPLANT

For some people, going through transplant is emotionally difficult, whereas others find it easier than they expected. Some people are relatively alert and active during the transplant, whereas others are extremely fatigued and lethargic. Giving up control and losing some of your independence and privacy can be difficult for many people. Experiencing physical discomfort and adapting to physical and emotional changes can also be exhausting. In some cases, the medications you will take may affect your mood. Dealing with a different status and new role in the family may also be difficult. You may find that other people are suddenly too protective or, in other cases, not as understanding as you would wish. Taking it one day at a time and remembering to be kind to yourself and others is helpful during the transplant hospital stay.

Common Emotions During Transplant

It can be difficult to be away from your family and loved ones. Being in the hospital for a long period of time can make patients feel isolated and alone, even if you have frequent visitors. You may begin to feel disconnected from

the outside world. Other common feelings include loss of control and uncertainty about the future. Adjusting to the routine of the hospital and giving up your own routine can be frustrating. It is common to feel that you are being forced to give up or change activities such as eating, sleeping, visiting with your family, and personal routines. For many people, this is their first experience with having to rely on others to take care of them.

Increase Your Sense of Control:

Our team would like you to retain as much control as possible during this time. We encourage you to be involved in making decisions for yourself, to be informed and ask questions, and maintain aspects of your daily care and routines that are important to you.

Here are some helpful tips:

- » take control of who can visit and when they can come
- » write a list of small things you want to accomplish each day
- » be assertive, ask for what you need (see section below)
- » plan a “work out” time each day (see exercise section)
- » keep a daily calendar and make goals for your stay

Make Your Needs Known – Be Assertive

Our team and your loved ones want you to feel as comfortable as possible and will try to accommodate your specific needs and preferences. Make sure to articulate your preferences and needs to those around you. Things that may seem obvious to you may not be obvious to others. Let your team know your preferences. This will help us provide the best care specific to your needs.

Reduce Feelings of Isolation

- » arrange visits from close friends or family members
- » bring a laptop or tablet with you to stay in touch with others
- » talk with a BMT psychologist or a chaplain
- » decorate your room with pictures of loved ones, cards and other familiar items

Dealing with the Transplant Side Effects

There are many things about the blood and marrow transplant process you may find stressful. Patients find that the treatment and side effects are physically draining. Physical symptoms, such as nausea or fatigue, will be worse on some days than others. During those days when you are not feeling well physically it may be more difficult for you emotionally. The doctors and nurses will monitor your level of discomfort and will give you medications, as needed, for pain management. Relaxation exercises can be helpful in managing pain and nausea. The psychology team is available to assist you in learning these techniques.

Sense of Humor

Laughter and a good attitude can be powerful sources of strength and healing. Clearly, if you are not feeling well, this can be challenging. To the extent possible, try to incorporate some fun into each of your days in the hospital. The transplant psychologists can also provide you with ideas for how to bring your mood up and maintain a positive attitude, and our team as a whole is often excellent at providing humor and a positive view if this is helpful to you.

Possible Complications After Transplant:

THINGS TO KEEP IN MIND

There are many side-effects and complications that can occur as a result of stem cell transplant. These may occur while you are in the hospital or after you return home. It is always important to contact someone if you are having side effects or complications. While you are on the Blood and Marrow Unit, speak with your nurses or doctor. After you leave the hospital, contact one of the Blood and Marrow Transplant Team members. Please do not hesitate to call with concerns or wait until your next scheduled appointment to let us know if you are experiencing any problems.

INCREASED RISK OF INFECTION

Neutropenia

You can expect to have a low white blood cell count and absolute neutrophil count (ANC) for several weeks after your transplant. During this time, you are what is called neutropenic (you have an absolute neutrophil count of less than $0.5 \times 10^9/L$). The neutropenic phase ends when your new stem cells begin to grow (engraft). We know when you begin to engraft by monitoring your blood counts at least twice a day while you are in the hospital.

Transplant and Infection

After transplant you are at high risk for developing infections. Even though your white blood cell count and absolute neutrophil count may be normal, please remember your immune system takes up to a year to recover fully. You are at an increased risk for infections during this time. Until your immune system recovers fully, you are considered "immunocompromised".

The impairment to your immune system from the chemotherapy alone or with TBI significantly impairs your body's ability to prevent or fight infections. You will receive medication to prevent or treat infections: antibiotics for bacterial infections, an antiviral medication for viral infections, and an antifungal medication for fungal infections.

Signs and Symptoms of Infection

We will monitor you closely for signs and symptoms of infections. We do this using routine blood tests, chest x-rays, and physical exams to check for infections throughout the transplant process. You must let us know if you experience certain signs and symptoms that may indicate infection:

Fever

Call your nurse coordinator during business hours Monday through Friday. On evenings and weekends, call the hospital

If you have a temperature of 100.4 degrees F for more than an hour OR a temperature of 101 degrees F for any period of time, call us right away!

operator at 720-848-0000 and ask them to page the BMT on-call nurse practitioner. If you do not hear back within 30 minutes, please call again. If there is no response within another 30 minutes, call the operator at 720-848-0000 and ask to have the BMT attending physician on-call paged.

A temperature can indicate an infection that needs to be treated as soon as possible. Do not take acetaminophen (Tylenol) unless your doctor, nurse, or nurse practitioner instructs you to do so.

Other signs and symptoms of infection include:

- » redness, warmth, tenderness, or drainage from your central venous catheter site
- » flu- like symptoms (chills, aches, fatigue)

- » sore throat or difficulty swallowing
- » cough with or without sputum
- » nasal drainage or congestion
- » feelings of frequency, urgency, itching or burning when urinating
- » diarrhea that is new or severe (several times a day, watery, cramping)

Lung Infections

Pulmonary or lung infections (like pneumonia) can occur after stem cell transplant. It is very important to let us know if you have a new cough, fever, shortness of breath, or chest congestion.

Shingles

Shingles is a complication that can occur after transplant. The same virus (varicella zoster) that causes chicken pox also causes shingles. Shingles can occur up to a year after your transplant. If you have any of the following symptoms of shingles, notify your doctor, nurse practitioner, or coordinator immediately:

- » pain or numbness (“pins and needles” feeling) on or under any part of the skin
- » red rash or blisters that appear only on one part or one side of your body
- » flu-like symptoms (usually without a fever) may develop just before or along with the start of the rash

It is also important to know that if you have shingles, it is possible to spread them to other parts of your body. Please wash your hands if you touch any open blisters.

Foodborne Illnesses

Food safety is extremely important during and after your transplant. Since your immune system will not be at full strength, it is important to make sure the food you eat is safe. Please refer to page 60 for a full discussion on food safety.

Bleeding

Platelets are the blood cells that help control bleeding by causing the blood to clot. During your transplant, you may have bleeding from your gums, nose, gastrointestinal tract, or under the skin (bruising) until your platelet count increases. Your platelets will begin to engraft (grow) several weeks after your white blood cells begin to engraft. You will receive platelet transfusions when your platelet count is low or if you are experiencing any bleeding.

Contact a team member if you experience any of the following:

- » a nosebleed that you cannot stop with pressure and ice to the bridge of your nose
- » bleeding gums when eating or when brushing with a soft toothbrush
- » blood in your urine, stool, or vomit
- » blood in your sputum
- » a menstrual period that is unusually heavy or lasts longer than usual

- » bruises that appear for no apparent reason
- » a cut or scratch that does not stop bleeding after applying pressure
- » the appearance of petechiae (small, pinpoint-sized red spots on skin from broken capillaries, or small blood vessels, under the skin)

Contact 911 immediately if you:

- » lose consciousness
- » become unusually drowsy, sleepy, or difficult to awaken
- » have a headache like none you have experienced before (“worst headache of my life”)
- » have changes or loss in coordination or speech

Mucositis

Mucositis is redness or sores that develop in the mouth, throat, or other parts of the gastrointestinal tract. Several things may cause mucositis such as some of the chemotherapy medications, total body irradiation, or infections such as herpes simplex virus (HSV) or fungus (Candida). Mouth sores can be painful and may require pain medications. Let your doctor or nurse practitioner know if you have redness, sores, or pain in your mouth, throat, or rectal area.

Mouth care is a must to prevent and control mucositis. If your transplant is done in the hospital, we will help prevent mucositis by encouraging thorough mouth care using a salt and baking soda solution and a toothette or very soft toothbrush four times each day. If you do develop mucositis, we may also give you a special prescription mouthwash. Please do not use dental floss, toothpicks, or a regular toothbrush until your platelet count is greater than $50 \times 10^9/L$. Do not use mouthwash containing alcohol.

If you wear dentures and notice any sores on your gums, remove your dentures and notify your doctor or nurse practitioner. Leave your dentures out if you have any irritation.

Skin Changes

You may notice that your skin is dry and more sensitive after transplant. However, if you develop any of the following, notify your doctor or nurse practitioner.

- » scaly patches
- » blister-like sores
- » petechiae (small, pinpoint-sized red spots)
- » open sores
- » a mole you have that gets larger or changes color or shape
- » a rash that starts on the palms of your hands and soles of your feet
- » changes in color or texture of your skin
- » any other change with your skin

Your skin will also become much more sensitive to the sun. If you are going to be in the sun for more than a short period of time:

- » use a sunscreen that is at least SPF 30
- » wear long sleeves shirts, long pants, and a hat

Fatigue

It is normal to feel tired or fatigued for some time after your stem cell transplant. Some days you may have more energy than other days. Many patients feel like they have the flu. Although you may hope to make this time go by faster by sleeping a lot or staying in bed most of the time, you must try to be out of bed most of the day. Staying in bed only causes you to be weaker, lose muscle mass, increase your risk of pneumonia and other infections, and causes skin problems. Be kind to yourself, but also consider putting yourself on a schedule to help you return to a “normal” level of energy after transplant. We encourage you to exercise some each day. Treadmills and stationary bikes are available for your use on the inpatient unit if your transplant is inpatient.

Pain

Some chemotherapy agents, total body irradiation, and other medications can cause pain or painful side effects, such as bone pain, achy muscles, or mouth sores. It is important for you to know that your pain can be relieved or controlled with pain medication, and you can ask for pain medication at any time if you need it.

Organ Complications

Some patients may develop complications involving the liver, kidneys, lungs, or heart. We monitor your organs very closely to identify complications that can be caused by chemotherapy, total body irradiation, or other medications so that we can begin treatment right away if they occur. Your risk of organ complications varies depending on the chemotherapy and radiation you receive to prepare for your transplant. Your doctor will talk to you about your specific risks.

Liver

Chemotherapy agents and total body irradiation may cause deposits of fibrous material to form in the small veins in the liver. The name for this condition is sinusoidal obstruction syndrome (SOS). It is also called veno-occlusive disease (VOD). SOS can be a serious complication and only happens in patients who have had a stem cell transplant. Symptoms of SOS are:

- » swelling of the liver
- » abdominal pain
- » weight gain
- » increased bilirubin (a liver enzyme measured through a blood test)
- » jaundice (yellow tint to the skin, whites of the eyes, or under the tongue)

Other potential complications include bacterial, viral, or fungal infections of the liver. Several medications used after your transplant can also cause injury to the liver. We will monitor your liver function frequently using blood tests.

Kidneys

Chemotherapy, total body irradiation, antibiotics, and other medications can hurt the kidneys. When this happens, your kidneys may decrease the amount of urine they make. This allows waste products to build up in the blood. Usually we can reverse this injury by changing some of the medications you are receiving and giving you increased amounts of IV fluids. Rarely, patients may require dialysis, a procedure that removes waste products from the blood using a filtering process. In most cases kidney function then recovers and there is no longer a need for dialysis.

We monitor your creatinine (a blood test) daily if your transplant is inpatient or at every clinic visit to ensure your kidneys are functioning properly. However, if you notice that you are urinating less or your urine has become darker in color, please let the doctor or nurse practitioner know.

Lungs

Complications may also develop in the lungs after transplant. Often, infections are the cause of lung complications. However, chemotherapy and total body irradiation can also cause conditions such as pneumonitis or pulmonary fibrosis. Pneumonitis is an inflammation of the lungs. Pulmonary fibrosis is a condition where the lung tissue develops areas of scarring. This often results in shortness of breath. We usually treat lung complications with antibiotics or steroids, such as prednisone. If you experience any of the following symptoms, contact a member of the team right away:

- » shortness of breath
- » difficulty breathing when sitting, lying, or walking
- » fever
- » a new cough

Heart

Certain chemotherapy agents can affect the heart and its ability to function. Although heart damage is very serious, this is a rare complication after transplant. If you notice heart palpitations (heart beating fast) or feel like your heart skips beats, please let your doctor or nurse practitioner know. If you have sudden chest pain, call 911.

Brain

It is not uncommon to feel like you can't concentrate or remember things as well for a period of time after transplant. Some patients call this "chemo brain". It is an effect our patients can feel for several weeks or months after transplant also because of the many medications they are on that can make them feel drowsy at times. However, please notify a Blood and Marrow Transplant team member if you have any of the following changes after your stem cell transplant:

- » tremors (shaking) in the hands, arms, legs, or feet
- » excessive sleepiness
- » confusion
- » changes in personality or mood

Graft Failure or Graft Loss

Engraftment occurs when the stem cells begin to grow. Graft failure occurs when the stem cells fail to grow or stop producing new blood cells after a period of time. Graft failure is a serious complication, but is also very rare. Factors that may contribute to the risk of graft failure include:

- » severe viral infection
- » damage to the stem cells during freezing and thawing
- » not transplanting enough cells

Although graft failure is unlikely, it is important that you know it is a possible risk during stem cell transplantation. If you experience this complication during your transplant, we will discuss a new plan of care with you and your family.

*Graft-versus-Host Disease (GVHD)- (*Allogeneic transplant patients ONLY)*

Graft-versus-host disease is a common side effect after **allogeneic** (but not autologous) stem cell transplant. There are two types of GVHD, acute and chronic. They differ based on symptoms. Chronic GVHD typically occurs after day 80 from transplant, but acute GVHD can happen at any time. GVHD ranges from mild to life-threatening. We will watch you very closely for signs of GVHD during your transplant course. You will receive a combination of drugs to prevent and treat GVHD.

What is Graft-versus-Host Disease?

In graft-versus-host disease, the immune cells from the donated stem cells (the graft) recognize your cells (the host) as foreign, or different. This most commonly occurs with the cells in the skin, gut (stomach and intestines), and/or liver. Although the graft was HLA (human leukocyte antigen) tested and matched, there are other markers on cells that can cause the graft to recognize the host as foreign.

Preventing and Treating Graft-versus-Host Disease

A combination of medications, known as immunosuppressants, help prevent and treat GVHD. Immunosuppressants will suppress or help decrease the ability of your new immune system to recognize your tissues as foreign. Some of the medications we use include:

cyclosporine (Neoral® or Gengraf®)	tacrolimus (Prograf®)
methotrexate	sirolimus (Rapamune®)
mycophenolate mofetil (MMF or CellCept®)	prednisone

You will begin taking these medications to prevent GVHD before you receive your donor's stem cells. You will continue to take these medications until approximately day +180 after your stem cell transplant or longer if you are experiencing GVHD.

Signs and Symptoms of Graft-versus-Host Disease

It is important to report any of these symptoms to a Blood and Marrow Transplant team member. The sooner we know of the problem, the sooner we can start the most effective treatment.

Acute Graft-versus-Host Disease

- » A rash, often over a large part of your body. It is usually a flat, red rash that does not itch. Your palms and/or bottom of your feet can also become reddened.
- » Stomach cramping, nausea, or diarrhea many times a day, if it affects your stomach and intestines.
- » Jaundice (yellow tint to the skin, whites of the eyes, or under the tongue) if it affects your liver.

Chronic Graft-versus-Host Disease

- » changes in color and texture of your skin
- » rash (as described in acute GVHD section)
- » dry, irritated, or burning feeling in your eyes.
- » pain, dryness, and sensitivity in your mouth
- » thinning hair
- » brittle fingernails or changes in the texture of your fingernails
- » nausea, vomiting, diarrhea, or an unexplained drop in weight
- » vaginal irritation and dryness
- » in advanced cases your joints may feel stiff

After Transplant

"I was driving in my car when it hit me that I felt good. Like really good. It was like a switch had flipped, and I had energy again."

– Louise Kirkland, Autologous Stem Cell Transplant Recipient

PREPARING YOUR HOME

After discharge from the hospital, you may be staying at your home or in other housing. Your location must be no more than a 30 minute drive from the hospital. You will need to prepare your home or temporary housing for your arrival.

Cleaning Your Home

We highly recommend that caregivers do a thorough house cleaning before you come home. They can either do it themselves or hire a house cleaner. A clean home is one way to protect yourself from infection. If you feel that your carpets need cleaning, please schedule this to be done soon after you are admitted to the hospital so that the carpets are not damp when you return home. Do not have home renovations done immediately before transplant and for at least one year after transplant. Carpet cleaning and renovations tend to “kick up” dust and dander.

Personal Care Items

Replace such items as jars of lotion (pump bottles need not be replaced), bars of soap, toothpaste, toothbrush, mouthwash, and make-up. Items opened and previously used may contain microorganisms that can cause infection.

Pets

Dogs and Cats

Although dogs and cats are great companions during your recovery, they often carry microorganisms that can cause infection. You can still enjoy the company of your dogs and cats if you follow these guidelines:

- » Keep their nails short to avoid being scratched by your pet.
- » Your caregiver needs to clean up your pet’s waste for at least three months (6 months for allogeneic transplant patients) after your transplant.
- » Be sure to wash you hands with soap and water after petting your dog or cat.

Birds and Reptiles

Pet birds and reptiles (lizards, turtles, and snakes) can transmit disease. For your safety, your caregiver will need to move your birds and reptiles out of your home before you arrive home. This is only temporary. Your birds and reptiles can move back home about three months (six months for allogeneic transplant patients) after transplant. Ask your doctor or nurse practitioner before moving your birds and reptiles back home. In addition, you should not visit a home that has birds or reptiles.

Other Pets

Fish can remain safely in your home. However, your caregiver must clean the aquarium for at least three months (six months for allogeneic transplant patients) after transplant. If you have other pets not mentioned here, please ask your nurse coordinator for instructions.

Plants and Flowers

You may have potted plants in your home but it is preferable that they not be right next to your bed. Please have your caregiver care for any plants in your house. You may also have cut flowers in your home as long as you do not handle them (arrange in vase, change water, throw them out).

OUTPATIENT CLINIC/BIC (BMT INFUSION CENTER) ROUTINE

We will evaluate you at least two times per week in the BMT Infusion Center (BIC) upon your discharge (if your transplant was inpatient). You will also see your doctor or a nurse practitioner in the outpatient clinic in the Cancer Center at least once a week. As you recover, your clinic appointments become less frequent. Your appointment will last at least one hour but will be longer if you need blood products, antibiotic infusions, electrolyte infusions, or IV fluids. Your visit will include the following:

- » evaluate your general well-being
- » take your vital signs and weight
- » draw blood for laboratory testing
- » completing tests to evaluate your disease status (such as bone marrow biopsies). These typically take place on day +100 and day +365 for autologous transplant patients and on day +28-30, day +80-100, and day +365 for allogeneic transplant patients.

On days you will see the doctor or nurse practitioner, please bring all of the medications you are taking so that he or she can review them with you.

COMMON MEDICATIONS AFTER YOUR HOSPITAL DISCHARGE

Listed below are common medications that you may take when you leave the hospital. The transplant pharmacist will talk to you about your medications and send prescriptions for them to the pharmacy before your discharge.

Anti-infective medications

Bactrim DS or Dapsone®

These medications prevent a specific type of pneumonia (Pneumocystis carinii or jiroveci pneumonia or PCP). You will take Bactrim DS twice a week or Dapsone daily for three months or longer after your transplant. If you are allergic to sulfa drugs, you will receive pentamidine nebulizer treatments instead.

Acyclovir or valganciclovir (Valcyte®)

These medications prevent and treat viral infections like cytomegalovirus (CMV).

Fluconazole (Diflucan®), voriconazole (Vfend®), or posaconazole (Noxafil®)

These medications prevent and treat fungal infections throughout your body.

Nystatin® liquid

This medication prevents yeast infections, like thrush, in the mouth.

Peridex® / chlorhexidine gluconate mouthwash

This medication prevents infections in your mouth.

Electrolytes

Magnesium is important for the functioning of your muscles and heart.

Calcium is important for regulating your heart and muscle function.

Potassium is important for the functioning of your heart.

Miscellaneous Medications

Neupogen (filgrastim or G-CSF)

This is a growth factor that stimulates your new stem cells to grow.

Antiemetics such as Zofran®, Kytril®, Compazine® and others

These medications help prevent or control nausea and vomiting.

Do not take products containing aspirin, non-steroidal anti-inflammatory drugs/NSAIDs (such as Advil, Motrin, ibuprofen), naproxen (Aleve), or Pepto-Bismol®. These can interfere with the functioning of your platelets. You may take Tylenol (acetaminophen), Mylanta®, Maalox®, or Tums®. Let your doctor or nurse practitioner know if you are taking these medications. When in doubt about whether or not you should take a certain medication, check with your doctor or nurse practitioner.

Do not take any other medications, including over-the-counter medicines, herbs, or vitamins, unless specifically ordered by your doctor or nurse practitioner. Some of these medications may interfere with the medications that you received or are currently taking.

Immunosuppressants (**For Allogeneic transplant patient ONLY*)

You will take immunosuppressants to prevent or treat graft-versus-host disease. As you recover, your doctor or nurse practitioner will start to taper, or decrease, the amount of drug you are taking. Eventually you will no longer take immunosuppressants. You will take these for at least 6 months.

Cyclosporine (Neoral or Gengraf)

- » On clinic days, do not take your cyclosporine until after you have had your blood drawn. We monitor your drug levels to be sure that you do not get too much or too little of this medication. Too much is not good for your kidneys.
- » Avoid drinking grapefruit juice or drinks with grapefruit in them (like Fresca, Squirt) since this can affect how much of the medication is

absorbed by your body. You may eat grapefruit and other citrus fruits.

- » Drink two to three liters (a liter is about a quart) of fluid a day to help flush your kidneys.
- » Cyclosporine increases magnesium loss from your kidneys. Magnesium is an electrolyte that is important for the functioning of muscles and the heart. It is very common to need either IV or oral magnesium supplements.
- » Side effects can include tremors, receding gums, high blood pressure, increased hair growth, infections, and high cholesterol.

Tacrolimus (Prograf)

- » On clinic days, do not take your tacrolimus until after you have had your blood drawn. We monitor your drug levels to be sure that you do not get too much or too little of this medication. Too much is not good for your kidneys.
- » Avoid drinking grapefruit juice or drinks with grapefruit in them (like Fresca, Squirt) since this can affect how much of the medication is absorbed by your body. You may eat grapefruit and other citrus fruits.
- » Drink two to three liters (a liter is about a quart) of fluid a day to help flush your kidneys.
- » Tacrolimus increases magnesium loss from your kidneys. Magnesium is an electrolyte that is important for the functioning of muscles and the heart. It is very common to need either IV or oral magnesium supplements.
- » Side effects can include tremors, high blood pressure, hair loss, infections, high cholesterol and high blood sugar.

Sirolimus (Rapamune)

- » Side effects can include high cholesterol, nausea, vomiting, and diarrhea.

Mycophenolate mofetil (CellCept)

- » Side effects can include nausea, vomiting, and diarrhea.

Methotrexate

- » Side effects can include loss of appetite, nausea, and mouth sores.

Prednisone

- » Take your prednisone with food to avoid an upset stomach.
- » Take prednisone in the morning to prevent problems with sleeping.
- » Side effects can include moon face, mood swings, high cholesterol, high blood sugar, high blood pressure, infection, and gastrointestinal (GI) bleeding. We will also put you on a medication (like Nexium® or Prilosec®) to protect your GI tract.
- » Special nutrition requirements while taking prednisone:

Protein

Prednisone can cause muscle wasting even though you may be gaining weight. Your body uses protein to build muscle and other tissue. Eating more protein helps counteract the effects of corticosteroids like prednisone on your muscles. After you stop taking prednisone, your protein needs will return to normal. Foods high in protein are eggs, meat, fish, poultry, nuts, and beans.

Calcium

Prednisone can cause bone loss. You can help reduce bone loss with vitamin D, calcium, and exercise. Foods high in calcium are dairy products, calcium fortified orange juice, and tofu.

Potassium

Prednisone can cause your kidneys to waste potassium. We will monitor your potassium levels closely and give you potassium supplements if necessary. Foods high in potassium are oranges, bananas, melons or melon juices, potatoes, tomatoes, and green or dried beans.

Glucose

In some patients, prednisone can increase blood sugar levels. This can be similar to diabetes and is a temporary effect while taking this medication. Your physician or a nurse practitioner will let you know if your blood sugar level is high and requires treatment or a change in your diet.

FOOD SAFETY

Food safety is extremely important during and after a transplant. Since your immune system will not be at full strength, it is important to make sure the food you eat is safe. Following is a list of foods that are allowed or not allowed after your transplant. If you have had an autologous transplant you need to follow these recommendations until you are day +90. If you have had an allogeneic or cord blood transplant please follow these recommendations until you are off of your immunosuppressive medications:

	ALLOWED	NOT ALLOWED
Meats, Beans, & Proteins	Well cooked meat, poultry, fish, game, seafood, or tofu	Undercooked or raw meat, fish, game, seafood, or tofu
	Well cooked eggs – both white and yolk are firm	Undercooked or raw eggs and nonpasteurized eggs
	Pasteurized eggs and egg substitute	Lunch meat from a delicatessen
	Lunch meats or hot dogs that have been heated until steaming	Raw nuts, or nuts in a shell
	Nuts that are roasted and out of the shell	Tempeh products
		Pickled fish
Fruits and Vegetables	Raw fruits vegetables and herbs that have been well washed prior to peeling, cutting, or eating	All sprouts (eg. alfalfa, mung bean)
	Canned, cooked, or frozen fruits and vegetables	Fresh salsa found in the grocery refrigerator case
	Dried herbs and spices	Nonpasteurized items containing fresh fruits or vegetables found in the grocery refrigerator case
	Shelf stable salsa	All miso products (miso soup, miso paste)
	Pasteurized juices	Salads from a delicatessen or salad bar
	Dried fruits	
Dairy	Pasteurized dairy products	Nonpasteurized dairy products
	Cheeses that have been commercially packaged or made with pasteurized milk (eg. mild and medium cheddar, swiss, parmesan, mozzarella)	Cheeses from a delicatessen
	Cooked soft cheeses (eg. Brie, feta, camembert)	Cheeses containing chili peppers or other uncooked vegetables
	Pasteurized yogurt	Cheeses with mold (eg. blue, gorgonzola, Roquefort)
	Commercially prepared eggnog	Mexican-style soft cheeses (eg. queso fresco, queso blanco)
Other items		Raw grain products
		Maté tea
		Sun tea
		Wine, nonpasteurized beer*
		Unrefrigerated cream-filled pastries
		Fresh salad dressings
		Raw honey or honey in the comb
	Items from a self serve bin	

*Before consuming any alcoholic beverage, clear it with your doctor due to possible interactions with medications.

Ensuring good food safety also includes safe meal preparation, transportation of foods, and cleanliness of your kitchen. There are four key steps to follow to help ensure good food safety. They are:

1. wash your hands and common surfaces often
2. keep raw meat separate from all other foods (do not cross contaminate)
3. cook foods to proper temperatures
4. promptly refrigerate foods to below 40° F

If you follow these four steps you are well on your way to having good food safety. Below you will find some other recommendations to defend yourself against food borne illness.

Keeping Your Kitchen Clean

- ▶ Common kitchen surfaces such as counter tops, refrigerator handles, and sink faucets should be cleaned daily with bleach wipes.
- ▶ Try to avoid using hand towels as they never seem to get a chance to completely dry out. If you use a sponge to clean your dishes, run it with your dishes in the dishwasher to help sanitize it. You may also get it damp and place in the microwave until it is steaming hot (approximately one minute).
- ▶ If your cutting boards have grooves in them from repetitive use replace them. Use a separate cutting board for raw meats and produce.

Keeping Your Refrigerator Clean

- ▶ The temperature of your fridge should be below 40° F. If your fridge doesn't have a built in thermometer you can purchase an appliance thermometer to help make sure the temperature is acceptable.
- ▶ Don't store any perishable foods in the shelves on the doors. The temperature here can fluctuate greatly. It is best to store items such as milk and eggs on a shelf in the fridge towards the back.
- ▶ Keep raw meats away from all other foods. They should be stored on the lowest shelf in the fridge in a container that will help prevent any juices from spilling onto other foods.
- ▶ Clean out your fridge once a week. If you aren't sure if a particular item should be kept or not, remember "when in doubt, throw it out!"
- ▶ Leftovers that are kept in the fridge should be consumed within three days of preparation.

Freezer Tips

- ▶ Having a freezer full of premade meals is handy on those days you don't have enough energy to make a meal.
- ▶ Make sure the temperature of your freezer is below 0° F by using an appliance thermometer.
- ▶ If you plan on batch cooking foods to freeze and save for later you should promptly get them cooled to below 40° F after cooking. It is best to place the food in long, shallow containers and put it in the refrigerator until the temperature comes down. You can then move it into the freezer after it has cooled for extended storage time. Foods should not be allowed to cool on the counter. This puts them at a dangerous temperature for too long.

Defrosting Foods the Right Way

There are a few different ways to appropriately defrost foods prior to using.

- ▶ Allow the product to thaw in the fridge by placing it on the lowest shelf in a container that will prevent juices from spilling. This method takes the longest amount of time so you do have to plan meals ahead of time, but it allows for slow safe defrosting.
- ▶ Placing the item under cold water is another option. Place the item in a plastic bag and submerge under cold water. Replace the water every 30 minutes and cook the foods immediately after they are thawed.
- ▶ Use a microwave. This method should only be used if you plan on immediately using the product.
- ▶ Do not allow foods to sit on the counter to thaw. This puts them at a dangerous temperature for too long.

Cooking Foods Properly

- ▶ Cooking foods to their appropriate temperatures is an essential step for protecting against food borne illnesses.
- ▶ Make sure you have a meat thermometer at home to help make sure foods get to their desired temperatures.
- ▶ Beef, pork, lamb and veal chops, steaks, and roasts need to be cooked to a minimal internal temperature of 145° F before you remove them from their heat source.
- ▶ Ground beef, pork, lamb or veal needs to be a minimum of 160° F.
- ▶ All poultry needs to be cooked to the minimum internal temperature of 165° F.
- ▶ When reheating leftovers they should also be cooked to 165° F.

Keeping Foods Safe at the Grocery Store

There are precautions you can take when shopping for foods as well.

- ▶ Make sure to keep raw proteins away from the rest of your foods. Use plastic bags to wrap meats so their juices do not spread and keep away from other foods in your shopping cart. After handling a package of raw meat make sure to wash your hands or use hand sanitizer.
- ▶ Shop for refrigerated and frozen products last so they don't have as long to sit at room temperature. Get them home and put away as soon as you can.
- ▶ When your groceries are being bagged, insist that raw meats go in a separate bag from the rest of your groceries.
- ▶ If you use "green" grocery bags, have a designated bag that will always hold raw meats. Wash your green bags after every few uses if they are able to go through your washing machine.

Eating Safe when Eating Out

Going out to eat is something you will be able to enjoy, but there are many precautions you should follow. You cannot really trust anyone's kitchen but your own, but with these precautions you will help minimize your risk of infection.

- ▶ Try to select a restaurant that appears to be well cleaned.

- ▶ While seated at the tables do not place your silverware directly on the table. Instead place it on a napkin or on the edge of your plate.
- ▶ Do not use any condiments that others have used. This includes items such as salt and pepper shakers, ketchup bottles, and steak sauce. You can ask for never opened bottles, individual packets or you can bring your own.
- ▶ If the restaurant you select uses ice that has to be scooped into your glass, you need to ask for your beverages to be served without ice. The scoop gets touched by multiple workers and has a higher chance of being dirty. If they use an automatic ice dispenser you may use that ice.
- ▶ Do not consume any fresh fruit or vegetables from a restaurant or allow them to touch your food. This includes lemons for your water and plate garnishes. You cannot be certain that the produce was well washed or if it came in contact with any other source of bacteria.
- ▶ When packaging up food to bring home ask to do this yourself at the table.
- ▶ You can also get food to-go and reheat it at home to a steaming temperature to help protect yourself.

For more food safety tips you can visit: <http://www.fsis.usda.gov>

TAKING CARE OF YOURSELF AFTER TRANSPLANT

The following information is very important. It will help you to maintain your health after transplant. If at any time you have a question about this information, ask your doctor or nurse practitioner. If you have questions about which activities or routines to continue or discontinue, ask your doctor or nurse practitioner. The doctor or nurse practitioner will monitor your blood work and overall health to determine if you are ready to return to your regular activities and routines.

Please remember that these recommendations are in place to keep you safe, healthy, and infection free.

Adult Caregivers

A caregiver may be a spouse, partner, adult child, parents, siblings, or a friend willing to care for you. Many patients have more than one caregiver.

Before your discharge from the hospital, caregivers will receive the necessary information and instructions to understand and perform the responsibilities expected of them. Your nurse coordinator will have a discharge teaching session with you and your caregiver(s) in your hospital room 1-2 days before your discharge or on your day of discharge.

Lodging after Transplant

Other hospitals may not be equipped to take care of stem cell transplant patients. Therefore, you must stay within a 30 minute drive of University of Colorado Hospital until day +30 (for autologous transplant patients) or day +80 (for allogeneic transplant patients). Your doctor or nurse practitioner will tell you when you may return to your home, if you are using temporary lodging after transplant.

Taking Your Temperature

Please take your temperature twice a day with the same thermometer at about the same time each day. Also take your temperature if you are not feeling well. A fever can indicate an infection. Call immediately if you have a temperature of 100.4 degrees F. for more than an hour OR a temperature of 101 degrees F. for any period of time!

Call your nurse coordinator during business hours Monday through Friday. On evenings and weekends, call the hospital operator at 720-848-0000 and ask them to page the BMT on-call nurse practitioner. If you do not hear back within 30 minutes please call again. If there is no response within another 30 minutes, call the operator at 720-848-0000 and ask to have the BMT attending physician paged.

Do not take any medications to lower your temperature unless your doctor, nurse coordinator, or nurse practitioner tells you to do so.

Wearing a Mask

Wearing a mask helps to prevent infections caused by microorganisms that travel through the air.

- » If a family member or friend you are with is feeling sick, they should wear a mask.
- » If you are feeling sick you should wear a mask if you are visiting the outpatient clinic.

A “simple mask” is adequate for protection- this is the mask that is soft and yellow and has elastic straps that go around your ears.

Hand Washing

Remember to wash your hands frequently with soap and water or use an alcohol-based hand gel. Always wash your hands after you use the restroom, handle your pets, or return home. In addition, please wash your hands before eating or preparing food. Good hand washing can dramatically cut the risk of infection. Your caregivers and family members should also wash their hands frequently. Visitors to your home should wash their hands when they enter your home. Avoid using bar soap to wash your hands as the bar may be contaminated with microorganisms that cause infection.

Sunscreen

After transplant most patients find that their skin is more sensitive. If you going to be out in the sun please use a sunscreen that is at least SPF 30 and wear a hat. For allogeneic transplant patients, this is especially important because a sunburn or longterm exposure to the sun increases the risk of graft-vs-host disease (GVHD) of the skin.

Wigs

You should not wear a wig until your absolute neutrophil (ANC) count is above $1 \times 10^9/L$. Wigs can irritate hair follicles. This in turn could lead to infection. You may feel more comfortable in a hat or scarf while recovering.

Glasses and Contact Lenses

If you wear prescription glasses we recommend you not change your prescription for at least 6 months after your transplant. It is common for your vision to take several months to adjust or stabilize after transplant. In addition, your eyes may feel tired, dry, or gritty after your stem cell transplant. Use natural tears eye drops if you experience discomfort.

You should not wear contact lenses for at least three months (for autologous transplant patients) or one year (for allogeneic transplant patients) after transplant. Wearing contacts sooner than this can cause you to get an infection and possibly have irritation or bleeding. When you do wear contact lenses again please wear daily, disposable contacts.

Windows, Air Conditioning, Swamp Coolers, Fans, Fireplaces, and Humidifiers

At home you may have open windows unless there are strong winds or you are in a construction area. Ceiling and stationary fans may be used as long as the blades are cleaned frequently. You may use attic fans and air conditioning with filtration. We recommend that you not use a swamp cooler for at least six months after transplant.

You may use gas fireplaces. Wood burning fireplaces cannot be used for at least 6 months after transplant. Please ask your doctor or nurse practitioner if it is safe to begin using them again.

Humidifiers or vaporizers may be used as long as the machine is new or has been thoroughly cleaned and the filter changed.

Gardening and Yard Work

You should avoid gardening and yard work for at least six months after transplant. It is also important that you stay out of the garden or yard while work is being done to prevent fungal infections, particularly in your

lungs. After this time, your doctor or nurse practitioner will evaluate your health status to determine if it is safe for you to resume these activities.

House Cleaning

Your caregiver should do all dusting, vacuuming, and cleaning for three months after autologous transplants or six months after allogeneic transplants. Please ask your doctor or nurse practitioner when it is safe for you to begin house cleaning again.

Driving

Your doctor or nurse practitioner will tell you when you are permitted to drive again after your transplant. There are several criteria that you should meet first:

- » your vision must be stabilized and no longer blurry
- » your platelets must have engrafted above $50 \times 10^9/L$
- » your energy level must be recovering
- » you should not be taking any narcotic pain medications, anti-nausea medications, or other medications that cause drowsiness

Catheter Care

You or your caregiver will flush your central venous catheter daily per the instructions given to you by the staff nurses or your nurse coordinator. Depending on your progress you may have a catheter for three months or longer after transplant. When you are stable your doctor or nurse practitioner will write an order to remove the catheter.

Dental Visits

You can begin going to the dentist six months after your transplant as long as your absolute neutrophil count (ANC) is greater than $2 \times 10^9/L$ and your platelet count is greater than $50 \times 10^9/L$. When you go to the dentist for a cleaning or other type of dental work you may need to take an antibiotic to prevent infection. Your doctor or nurse practitioner at the hospital or your dentist can prescribe the antibiotic. When you make an appointment with a dentist please be sure to tell them that you have had a stem cell transplant.

Immunizations (Vaccinations)

The antibodies you acquired from previous vaccinations are altered by your stem cell transplant and you may need to have your childhood immunizations (“baby shots”) repeated. In addition, you will need a yearly influenza vaccination (“flu shot”) and the pneumococcal vaccine every 5 years. However, you will not receive a varicella (shingles, or chicken pox) vaccine- this is a live vaccine that can be dangerous for a stem cell transplant patient to receive. The time to repeat your immunizations is different with each patient but they are typically started one year after transplant. It also depends on certain circumstances. (For example, if allogeneic transplant patients are experiencing graft-versus-host disease, immunizations may be delayed). The Blood and Marrow Transplant Team will determine when it is time for you to have your immunizations repeated. Please ask them before you consider getting any vaccination.

Caregivers and household contacts should also receive a yearly influenza vaccine.

Avoid anyone who has recently had a “live” vaccination for 7 days after they have been vaccinated. These include rotavirus and chickenpox/shingles vaccines. The person vaccinated can “shed” the virus used in the vaccine. This could cause an infection in you. If you have not had chicken pox and you come in contact with someone who currently has chicken pox be sure to notify your doctor or nurse practitioner immediately.

General Diet and Nutrition Guidelines After Transplant

If foods taste overly sweet, try adding a pinch of salt. If foods taste too salty or acidic, try adding a pinch of sugar.

After you have fully recovered from your transplant and no longer have any issues with side effects, it is important to try to focus on having good health. Eating a healthy diet, getting adequate exercise, and being at a healthy weight are important.

- » Eat a variety of foods everyday. There is not one food that provides all the vitamins and nutrients you need.
- » Increase the amount of fruits and vegetables you eat, aiming for at least five or more servings per day. Different colored fruits and vegetables offer different antioxidants and phytochemicals.
- » Increase fiber intake by switching to whole grains. Look for grain products that have whole grain listed as one of the first ingredients on their label.
- » Select foods that are lower in fat. Trim excess fat off of meats, select low-fat or fat free dairy products, and use products high in fat sparingly. Use cooking methods such as baking, broiling, or steaming to avoid using excess fat.

If you are overweight after transplant, trying to get to a healthy weight is beneficial. It is not recommended to lose weight if you are still having side effect complications. When trying to achieve a healthy weight, it is most effective and healthy to have a slow, steady weight loss of 1-2 pounds per week. If you have rapid weight loss, this is not healthy for your body and many people regain the weight.

Adequate regular exercise is also important. Talk to your physical therapist for help in developing an exercise program if you are having difficulty.

Complementary Therapy Treatments

You should ask your doctor or nurse practitioner if it is safe to resume massage, acupressure, acupuncture, or other complementary treatments.

Physical Activity

As you return to your life after your transplant there may be things that you, family members, co-workers, or friends expect of you. These expectations may be unrealistic for the pace of your recovery. To family members you may look like you are doing well. They may expect you to be able to do activities sooner than you are ready. If you have trouble motivating yourself, a small amount of “pushing” or encouragement from your family or friends can be helpful. However, it is important to tell your family and friends how you feel so they can be realistic in their expectations of you.

Physical activity remains an important part of your recovery. After transplant you will feel weak and tire easily. This is completely normal. Remember, it will take months to recover from your stem cell transplant. Your body will tell you when you have pushed yourself too hard and are too tired.

You will need to build your strength and endurance slowly. Learn to pace yourself. It may be necessary to take a midday nap for several weeks after your discharge from the hospital to increase your energy level. Your exercise routine should gradually increase over time.

You need a regular exercise routine at home. Avoid vigorous activities that might cause extreme fatigue or physical harm. Climbing up and down stairs, walking, and stationary cycling are good exercises in the beginning. If possible, do not walk near areas of construction, remodeling, or dusty places. Drink plenty of fluid before, during, and after exercising.

You may go to a gym if you have stable blood counts, adequate energy, and do not have any post-transplant complications. But please avoid locker rooms, pools, saunas, and hot tubs. Please ask your doctor or nurse practitioner when you may begin using these again. You must also have your central line removed before you can use pools or hot tubs. If you do need to enter the locker room, wear shower shoes. It is best to try to visit the gym at times when it is least busy and wipe down machines and equipment before use. Remember to wash your hands after visiting the gym.

Returning to Work

The right time to return to work is different for everyone. Many people are ready to return to work about 3-6 months after their stem cell transplant. If you had an allogeneic stem cell transplant, we recommend that you not return to work until at least six months after transplant. This is because you will be on immunosuppressant medications during this time which put you at an increased risk for infection. Being in close proximity to people at work who may be sick increases this risk even more. If you have a strenuous job, it may take longer for you to return to the energy level needed to begin working again. Your doctor or nurse practitioner will help you determine when it is safe to return to work. They will look at your absolute neutrophil count (ANC), red blood cell count, platelet count, energy level, and overall health status to determine if you are able to go back to work.

Travel and Vacations

For the first year after your stem cell transplant please discuss any travel or vacation plans with your doctor. Depending on where you will be traveling, your doctor may want to make tentative arrangements for you with another physician should you experience any problems while you are vacationing.

PSYCHOSOCIAL ISSUES AFTER TRANSPLANT – WHAT TO EXPECT

After Your Hospital Stay if Your Transplant is Inpatient

The change to the outpatient phase of your transplant process can be both exciting and scary. Patients often express excitement about being able to leave the hospital and resuming some normal activities in their daily life. You may notice that your interests in life outside the hospital increase as you prepare to leave.

Preparing for discharge can also bring up fears. Being isolated in your hospital room and on the Blood and Marrow Transplant Unit may have made you feel secure, therefore the ability to leave and go outside can be overwhelming. You may wonder if you will be “safe” from germs when you leave or if your caregiver will be able to handle your care needs. Separation from the staff, which you have come to depend on, may bring up additional anxieties. Discussing your fears and concerns will allow the team an opportunity to clarify any misconceptions or provide you and your caregiver with any additional information that may be helpful as you leave the hospital.

Managing Expectations

The recovery process varies tremendously from patient to patient following transplant. Although you will often expect to continue to improve daily after being discharged, problems can frequently arise after being released from the hospital. It can be very disappointing if you do not notice progress as quickly as you had hoped, especially if it means that you need to be readmitted to the hospital.

Sometimes patients get depressed when they have frequent physical problems or complications after being discharged. However, it is important for you to remember that the transplant process has “ups and downs.” It is not unusual for problems to arise in the weeks following discharge, which is partly why the Blood and Marrow Transplant Team will be following you outpatient for an extended period of time after the transplant. If you are getting discouraged or depressed, talk with the staff or with a psychologist. Many patients find it helpful to talk about their expectations and to make a plan for how to continue on the road to recovery.

Please remember, the outpatient phase is a time of transition and change. We expect there are going to be issues or problems that come up so please keep the staff informed if you have any problems, questions, or concerns, so we are able to help you and support you through this process.

Common Long-Term Psychosocial Effects

During the recovery process you will experience many physical, emotional, and social changes. You will begin to return to the roles you had prior to your transplant, such as family roles (mother, father, wife, partner, husband, etc.) and other important life roles (work, social activities, etc.). You will slowly increase your physical activity, your appetite will improve, and you will be able to resume intimate activities.

The pace of the recovery process varies from person to person. Some people are able to attain pre-transplant functioning levels within six months or so after the transplant. For most people it may take several months or longer before they feel normal or “back to their old self.” Some people feel they are never the same person physically or emotionally after transplant. They feel the transplant experience changed them and they look at life in a different way. The changes you experience may be seen as positive, negative, or both. Whatever form the recovery process takes for you it will require patience, stamina, and motivation to attain your post-transplant goals. The ultimate goal will be for you to return to a quality of life that is satisfying, meaningful, and enjoyable for you.

Depression and Anxiety

The time right after you are discharged from the hospital can be one of the first times people notice changes that have occurred in their body during the transplant process. For the first time they see the challenging road to recovery facing them. It can be hard to motivate yourself to do activities you are asked to do or to push yourself to eat. You may find yourself discouraged about the pace of your recovery or become more anxious.

When to Seek Help

Some amount of emotional distress is normal in this phase. In some cases the medications you may be required to take can contribute to depression or anxiety. Sometimes people experience more significant depression than just feeling “down” or “blue” for a day or two. If these feelings persist (if you feel depressed for several days, the level of depression interferes with your ability to function, or if you have recurrent anxiety attacks) you should

contact your BMT psychologist. A meeting or two with a BMT psychologist can help you develop a plan to manage these emotions and improve your mood. Sometimes medication can be helpful to treat the symptoms of anxiety or depression.

When to contact your BMT psychologist

- » feeling very “down” or “blue” for more than a few days
 - » low motivation that is preventing you from following the medical plan (medications, appointments)
 - » strong feelings of guilt, anger or hopelessness
 - » sudden changes in mood or behavior
 - » seeing or hearing things that others don’t see or hear (hallucinations)
 - » thoughts of suicide*
 - » nervousness, anxiety or feelings of panic
 - » conflict between you and your family or caregiver
 - » when you want support for emotional difficulties
- *Note: if you find yourself developing a plan to commit suicide or intend to commit suicide, this is a mental health emergency. Please call 911 or have your caregiver take you to the nearest emergency room immediately.

Living with Uncertainty

Living with the uncertainty or fear of cancer coming back is a common issue for people after transplant and for all cancer survivors. There are many ways to deal with these thoughts and fears:

- » focus on positive or hopeful thoughts
- » engage in distracting activities to keep your mind away from upsetting thoughts
- » prayer or meditation
- » direct your thoughts to the present moment and focus on the task at hand
- » contact others who have been through transplant (see LLS website on the next page)
- » join a cancer support group

Sometimes anxiety about recurrence of an illness can become such a focus that it can take up a lot of

time and energy. If it begins to interfere with your life, it may be helpful to talk with your transplant psychologist or another supportive person about these fears. Our psychosocial team can teach you practical ways of managing these feelings in addition to offering understanding and empathy.

Join a Cancer Survivors' Group or Network:
The Leukemia & Lymphoma Society

(Includes support for Myeloma, Myeloproliferative Diseases, Myelodysplastic Syndrome)

www.lls.org

**[www.lls.org/diseaseinformation/
getinformationsupport/supportgroups/
peersupport](http://www.lls.org/diseaseinformation/getinformationsupport/supportgroups/peersupport)**

(to contact others with your disease who have also been through transplant)

303.984.2110

The Bone Marrow Foundation

<http://www.bonemarrow.org/>

Cancer Information and Counseling Line

(CICL)/303.733.9971

www.mylifeline.org

www.carepages.org

Contact your team's psychologist, social worker, or your nurse coordinator for additional information about psychosocial resources and support.

Intimacy and Sexual Activity

Difficulty engaging in sexual activity affects many patients who have been through a transplant. Many of these difficulties are due to the direct physical effects of chemotherapy and radiation treatments. Common complaints include loss of sexual desire, difficulties with vaginal dryness, and difficulties getting and sustaining an erection. Many of these concerns are often temporary and may resolve within six months of transplant. However, intimacy and sexuality can be important parts of life. The psychosocial and medical team members are available to help solve these problems from both medical and

relational perspectives. There are many medical and psychological interventions available to help with the sexual health issues most often associated with bone marrow transplant.

For some people, discussions of sexuality and intimacy are difficult and even embarrassing. However, we encourage you to approach whichever members of the team you feel most comfortable with to discuss your concerns. The psychosocial team has specialized knowledge in this area and can also bring up medical questions with your physician if you find this uncomfortable.

It is always important to use contraception post-transplant even if you believe that you may be infertile. Chemotherapy and radiation may create the possibility of birth defects for a period of time post-transplant. You and your partner should not use diaphragms, cervical caps, or IUDs (intrauterine devices) because these methods could lead to infection.

Communication

Starting an open and honest dialogue with your partner is vitally important to navigating challenges to intimacy post-transplant. Approaching any set backs as challenges to be faced together helps couples continue to strengthen their relationship even when working through post-transplant physical changes. There are many other forms of intimacy aside from sexual intercourse and many couples find that exploring these are beneficial to their relationship.

The psychosocial team is also available to help you and your partner discuss relationship changes that occur due to the transplant process. These may be related to intimacy or to communication and changes in roles in the family post-transplant.

A relaxed, non-stressful environment will help you feel more comfortable when resuming sexual activity. Some individuals find that sexual desire may be improved after a nap or a good night's sleep. Please try to be patient it may take some time for your body to adjust after transplant.

Tips for Healthy Intimacy Post-Transplant

Issues Specific to Women.

- » If and when you begin your menstrual cycle again please do not use tampons for at least six months after transplant. Leaving a tampon in for more than a couple of hours can increase the risk of an infection.
- » If you experience vaginal discharge and/or bleeding other than or longer than a normal menstrual period, contact your doctor or nurse practitioner.
- » At times the vagina may be dry, even when you are sexually aroused. The vagina may not secrete enough fluid for comfortable and safe sex. If this occurs, you may use a water-based lubricant. Some water-based lubricants are K-Y® Jelly and Astroglide®. Do not use Vaseline® or other petroleum-based lubricants.
- » Do not use a douche.
- » Notify your doctor or nurse practitioner if you have any of the following:
 - * pain during intercourse (do not have sex again until the cause of the pain can be determined)
 - * bleeding or signs of a vaginal or bladder infection (burning with urination, itching, or odorous vaginal discharge)
 - * sores or lesions in your vaginal or genital area

Issues Specific to Men

- » Difficulty getting or maintaining an erection after stem cell transplant is a common and usually temporary side effect. If this occurs it is most often related to the chemotherapy and/or radiation that you received. Difficulty keeping an erection during sexual intercourse can also be related to anxiety or depression. Discussing these issues with a BMT psychologist or the medical team may be useful.
- » Notify your doctor or nurse practitioner if you have any sores or lesions on your genital area.

Family Members and Caregivers after the Transplant

Family members and caregivers may feel fear and stress around the time of your discharge from the hospital if it was performed inpatient. This is quite normal. Although you may be happy to see your family member getting better, you may also wonder whether or not you can provide the care they need. Your anxiety may decrease or increase when you go through the discharge education and learn about the care procedures for which you are responsible. It is important for you to let the team know of any questions and concerns you have so they can address them and help you feel more comfortable – even before your loved one is discharged. Most caregivers are overwhelmed at first, but then become comfortable with the routine of caring for their loved one outside of the hospital.

Preventing Burnout

Sometimes caregivers can begin to feel burned out by the long recovery process after transplant. The transplant process can feel like an emotional roller coaster as things change from week to week. It is important for you take care of yourself during this time and take breaks- whether you feel you need to or not.

If you are the sole caregiver, perhaps you can get away for a few hours while the patient is at their outpatient appointment. This is beneficial even if it is just a simple walk outside. It is important for you to remember to take care of yourself as well. You should not ignore your own needs during the time you are taking care of your loved one. Always remember that the team is available for the patient, family members, and caregivers.

Quick Reference Section

WHO TO CALL WITH QUESTIONS OR CONCERNS

Emergency: Call 911

Urgent

- » During business hours, call your Nurse Coordinator:
 - * Chris Koch: 720-848-0421
 - * Kelly Pacic 720-848-1637
 - * Lindsey McMenimen 720-848-2606
 - * Bone Marrow Infusion Center (BIC): 720-848-2207
- » After hours, call the hospital operator at 720-848-0000 and ask them to page the Bone Marrow Nurse Practitioner on call. If you do not hear back in 30 minutes, call back and ask them to page the Bone Marrow Transplant Physician on call.

General Questions

- » Call your Coordinator
- » For Appointments in the BIC, please call 720-848-2206
- » For the Scheduler, please call 720-848-0941 or 720-848-0695

Emergencies include difficulty breathing, uncontrolled bleeding, loss of consciousness, etc.

Urgent medical problems that are serious but not life threatening matters include new signs of infection, drug reactions, signs of a blood clot, and falls (that do not include head trauma).

General questions include inquiries about your schedule, why tests have been ordered, prescription refills, etc.

GENERAL GUIDELINES AFTER TRANSPLANT

for Autologous and Allogeneic Transplants

- » Take care of yourself - Your body has been through a lot. It is important to take the time to heal and let your body recover. The below guidelines were created to help our patients prevent infection and other complications after transplant. Please contact us if a situation occurs and you are unsure of an infection risk.

Types of Infections Seen After Transplant

- » The usual causes of infection after stem cell transplant include:
 - * Month 1 – bacteria, fungus, herpes simplex virus
 - * Month 2 - cytomegalovirus, other viruses, bacteria, and fungus
 - * Month 3 – shingles, bacteria, fungus
- » Even after you have recovered from the transplant, your immune system will be weakened.

Hand Washing

- » Likely the single most important thing that you and those near you can do to prevent the spread of infection.
- » We recommend washing your hands:
 - * Every time you and those you live with enter the house
 - * After using the bathroom or blowing your nose
 - * After touching a pet
 - * Before eating or preparing food
- » Alternate use of alcohol gel with soap and water hand washing throughout the day. Soap and water are recommended when hands are visibly soiled or after touching raw meat.

*Please use the following guidelines and your common sense to help us
keep you infection-free.*

Temperature

- » Take twice a day at same time each day with the same thermometer AND when you feel sick.
 - » If your temperature is greater than 100.4°F for over an hour, call your coordinator.
 - » If your temperature is greater than 101°F at any time, call your coordinator
 - » Do not take any medication (such as Tylenol) to lower your temperature unless the doctor, nurse coordinator, or nurse practitioner tells you to do so.
-

Daily Medications

- » We understand you may be taking more medications now than you have ever taken before. We cannot stress enough the importance of taking your medications as they are prescribed. If you have any questions about your medications, please contact our pharmacist or your coordinator.
 - » Do not take over the counter medications other than a daily multivitamin without iron. DO NOT take aspirin, ibuprofen (Advil, Motrin), NSAIDS, Naproxen (Aleve) or Pepto-Bismol, as they can interfere with platelet function. It is, however, all right to take Maalox, Mylanta, Tums, or Tylenol.
-

Breathing

- » Take a moment to think about your breathing. Do you have any chest tightness, shortness of breath, or a new cough? Some people find it helpful to have a daily exercise routine (i.e. walking up the stairs or around the block) as you can notice early signs of lung changes faster.
 - » If you develop a persistent cough, a cough with yellow or green sputum, or chest pain, please notify us.
-

Bowel and Bladder

- » If you develop diarrhea, frequent urination, painful urination, blood in your urine or stool, abdominal pain or any other gastrointestinal problems, notify us.

Line Care

- » One of the most common sources of post transplant infections is from your central line. Please notify us if you notice redness, swelling, tenderness or drainage at the site of your central line.
- » Please flush each lumen daily with heparin flush and make sure that the dressing is changed once a week in the clinic/BIC.
- » We typically remove the line when you no longer need it.
- » Please do not go into pools or hot tubs until your line has been removed.

Oral Care

- » The human mouth is full of bacteria which can be a source of infection.
- » Use a soft bristled tooth brush, and do not floss until your platelet count is $>50 \times 10^9/L$ and your ANC is $>1 \times 10^9/L$.
- » We recommend not going to the dentist until at least six months after transplant. When you do make your first post transplant dental appointment, please let your nurse coordinator know, as we will likely want you to take an antibiotic the day of the visit.
- » If you develop difficulty swallowing, oral pain, or sores please let us know.

Skin Care and Shingles

- » Examine your skin daily to look for any new rashes. Patients that have had an allogeneic transplant are recommended to stay out of the sun and wear sunscreen of at least 30 SPF as sunburn can trigger skin GVHD.
- » During this time you will be at an increased risk for shingles. Shingles can present as an area that is very sensitive and then breaks out in a painful rash with blisters. If you think that you may have shingles, cover the area with a bandage and contact us.

Eye Care

- » It is common for post-transplant patients to report changes in their vision after transplant. Mild changes are normal. In fact, we recommend not getting new glasses for at least 6 months after transplant as your vision may continue to change.
- » If you are having major vision changes such as tunnel vision, complete or partial loss of vision, or black spots in your vision, please let us know immediately.

Normal Post-Transplant Routine

- » Patients typically start out going to the BIC three times a week and seeing a provider once a week. As your health improves, the frequency of the visits will decrease. It is important to remember that visits to the BIC may vary greatly in time depending on what your body needs based on your lab results.
- » We do a full work up 60-100 days after transplant and one year post transplant. These workups will include a bone marrow biopsy, pulmonary function test (PFT), psychosocial evaluation, and possibly a PET scan (for certain diagnoses).

Immunizations

- » Childhood immunizations will need to be repeated starting one year after transplant.
- » Family members living with you should have their vaccines up to date and yearly flu shots.
- » Avoid direct contact with anyone who has just received the chicken pox vaccine for 72 hours.
- » If a baby in your household received a rotavirus vaccine, for one week everyone must wash their hands after changing the baby's diaper.

Going to the Gym

- » You may begin going to the gym when blood counts are stable and energy level is adequate. Ask your Provider prior to returning to the gym.
- » Avoid locker room, pools, saunas, hot tubs.
- » Do not go to the gym during crowded hours and wipe down machines and equipment before use.
- » Wear shower shoes at all times if you do enter the locker room.

Alcohol

- » DO NOT drink any alcohol until you receive permission from your NP/MD. You will be on an antifungal medication that can be hard on your liver. We monitor your liver closely by looking at your lab work, but the addition of alcohol could lead to serious strain on your liver.

Tobacco

- » Absolutely no smoking, chewing tobacco, or smoking marijuana. We frequently see fungal infections in the lungs of people who continue to smoke post transplant. In addition, smoking greatly increases your risk of developing additional cancers after transplant.
-

Sexual Activity

- » Remember to discuss birth control with your physician or nurse practitioner following transplant.
 - » It is important to use contraception following transplant until cleared by a doctor or nurse practitioner. However, do not use diaphragms, IUDs, or cervical caps.
-

Going Outside

- » Please enjoy walks outside when weather permits. Try to avoid construction and yard work.
 - » Wear sunscreen (at least SPF 30) on exposed skin at all times. Skin is usually very sensitive to the sun after transplant.
-

Vaporizers and Humidifiers

- » Acceptable to use if the machine is brand new or has been thoroughly cleaned and the filter changed.
-

Ceiling Fans and Stationary Fans

- » Fans should be kept clean and remain on low to decrease the amount of dust and dirt that you may breathe in.
-

Fatigue

- » Patients often report some level of fatigue for six months to a year after transplant.
- » Many people find it helpful to set up a regular daily schedule for nap and sleep times. You may find it helpful to rest between periods of activity or to be active for only a short time. It is important to be realistic about your plans for the day and do the most important activities first. Regular exercise has been shown to help reduce fatigue.

Possible complications from low platelets include the following:

Bleeding Risk

- » In addition to being at increased risk for infection, you are at an increased risk of having bleeding complications. While your platelet count is low, your body may have a hard time forming blood clots. We want you to watch for any blood in your stool, vomit, sputum, or the appearance of petechiae (small red dots on the skin). Notify us if any of these symptoms occur.
- » You are required to have a caregiver, in part, to get you help in the case of a bleeding complication.

Driving

- » You must have your doctor's or nurse practitioner's permission
- » Usually can drive when:
 - * Vision is no longer blurry
 - * Platelets are greater than $50 \times 10^9/L$
 - * Energy level is adequate
 - * You are not taking drugs that make you drowsy

Falls and Stroke Symptoms

- » It is important to be cautious and get assistance if you think you may fall. If you fall at home, please notify us immediately. If you were to fall and hit your head, you may have symptoms similar to a stroke, such as:
 - * Confusion
 - * Slurred speech
 - * Unable to be aroused
 - * Unbalanced when walking
- » If you or your caregiver notice any of the above symptoms, please call 911.

Nosebleed

- » If you have a nosebleed, apply pressure for 10 minutes and ice to the bridge of your nose. Notify us right away if this does not stop the bleeding.

ALLOGENEIC GUIDELINES

Adult Caregiver After Transplant First 80 Days after transplant

Patients benefit from different levels of caregiver support during the recovery process. The hope is that these recommendations will assist families in anticipating the need for caregiver support, which changes throughout the transplant process. During this first 80 days after transplant, many patients will need consistent support from a caregiver 24 hours a day and will need to be within a 30 minute drive of the hospital.

When in the hospital, patients do not require caregivers, though visitors are encouraged.

Outside of the hospital, caregivers are needed for up to 80-100 days after transplant.

Consistent support: Definition – Caregiver is present the majority of the time; breaks should be less than three hours. Patients left alone should have access to the phone, the ability to contact emergency services, the ability to get to the restroom, and access to food and fluid.

Examples of times that a patient would need a consistent caregiver include any of the following:

- » During conditioning, chemotherapy and radiation (**if being done outpatient**)
- » After initial discharge after transplant
- » Neutropenia (ANC < $0.5 \times 10^9/L$)
- » Thrombocytopenia: Platelets < $20 \times 10^9/L$
- » Altered Mental Status – drowsy, confused, impaired judgment, poor memory
- » Weakness/limited mobility, fall risk (cannot walk without assistance)

Intermittent Support: Definition – Does not need a caregiver for the majority of hours within a 24 hour period. A caregiver is available 2-3 times per day to provide assistance with medications, transportation, and processing information provided during conferences or clinic visits.

The BMT team will let you know which level of care you need as you recover from transplant. If you have any questions about caregiver support, please let us know.

Graft Versus Host Disease (GVHD)

- » Can occur anytime after transplant and can range from mild to life threatening. You will be on immunosuppressant drugs until at least day 180 after transplant to help prevent GVHD. If you do develop GVHD, you will be on the immunosuppressive drugs longer, though the dose will likely change. GVHD most commonly occurs in the skin and/or liver and/or the intestine.
- » Please notify the transplant team immediately if you have any of the following signs of GVHD:
 - * A new rash anywhere on your body and especially on your palms or the bottom of your feet
 - * New diarrhea (>4 times per day)
 - * Yellowing of your eyes or skin
- » Please refer to page 53 for a more in-depth description of GVHD.

We recommend following the below guidelines while you are on immunosuppressant drugs. If medically possible, we will start to taper your immunosuppressant drugs 80-100 days after transplant.

Wearing a Mask

- » If you or someone in your house is coughing, sneezing, or has a cold or the flu, a mask should be worn by the sick person.
- » If worn correctly, masks help decrease the spread of respiratory viruses and bacteria to others.
- » The yellow surgical masks should be secured over your ears with the bands, and the nosepiece should be fitted to the form of the bridge of your nose. These masks are most effective if worn for less than an hour, as they lose their protective properties when damp.
- » Masks help to prevent the spread of infections if worn by people who are sick, but handwashing and staying away from people who are sick are the best forms of infection prevention.

Food and Food Safety + Weight

ALLOWED	NOT ALLOWED
Pasteurized dairy products	Street Vendors
Well-cooked meats	Pot lucks
Reheated deli meats	Undercooked or raw meats
Thoroughly washed raw fruits and vegetables	Unpasteurized dairy products and juices
Tap Water	Cheese with molds
	Well water
	All sprouts

- » It is important that good food safety guidelines be followed while you are on immunosuppressant drugs. This is a very abbreviated list, please refer to the nutrition section on page 60 for more information.
- » Weigh yourself weekly. Let your dietitian or doctor know if you gain or lose more than three pounds a week.

Dusting and Vacuuming

- » Ideally, a thorough housecleaning should be done prior to discharge.
- » If you are getting your carpets cleaned, this should be done at least seven days prior to your discharge from the hospital.
- » Until off immunosuppressant drugs, you should not dust, vacuum, clean bathrooms, or do any other deep cleaning. Please allow a caregiver to do this for you.

We recommend following the below guidelines for six months or until you are off of immunosuppressant drugs, whichever is longer.

Hot Tubs, Saunas, and Pools

- » You will not be allowed to use these until at least six months after transplant and until your central line has been removed; ask your doctor or nurse practitioner prior to beginning use.

*Cats, Dogs, and
Other Hairy Creatures*

- » You may be around hairy pets as long as they are very clean, groomed, have clipped nails, and are current on vaccinations.
- » Do not clean up after pet or empty litter boxes for six months after transplant.
- » Strict hand washing is necessary after touching pets.
- » We recommend not getting a new pet for at least three months after transplant.

Fish

- » Do not clean tanks for six months.

*Birds and Reptiles
(Snakes, Lizards, Turtles)*

- » Must remain out of house for six months; ask MD when it is safe to bring them back in your home.
- » Cannot visit a home with birds or reptiles for at least six months.

Fireplaces

- » No wood burning fireplaces; we will reevaluate your health status at six months to determine if they are then safe to use.
- » Gas fireplaces are acceptable to use.

*Swamp Coolers and
Air Conditioners*

- » Swamp coolers are not recommended for at least six months after transplant.
- » Air conditioners are allowed, but someone else should replace the filter to help prevent your potential exposure to molds.

Plants and Yard Work

- » You may have potted plants in your house (but not next to your bed), but you may not be the one to care for them.
- » You should not do any gardening or yard work for at least six months to a year after transplant; we will then reevaluate your health status to determine if it is safe.
- » Stay indoors when gardening or yard work is being done for at least six months after transplant.

Oral Care

- » Continue with regular mouth care at home. Use a soft toothbrush and do not floss unless ANC > $1 \times 10^9/L$ and platelet count is greater than $50 \times 10^9/L$.
- » You may have cleaning and other work done after six months if absolute neutrophil count (ANC) is greater than $2 \times 10^9/L$ and platelet count is consistently at $50 \times 10^9/L$.
- » You must take antibiotics before going to the dentist; we or your dentist should prescribe them for you.

Contact Lenses

- » You cannot wear contacts for one year after transplant. When you do start wearing contacts again, they must be disposable and changed daily.

Traveling and Vacations

- » Let us know well in advance of any travel plans. You must be cleared by your physician prior to any travel outside of the Denver metro area. Usually after six months your blood counts are high enough that travel may be an option.

All of the above guidelines are just that - guidelines. Please know that if you are having frequent infections or other complications, the amount of time these apply may be extended. In addition, they do not cover every situation, only common issues. If you have any other questions about what we recommend, please ask.

AUTOLOGOUS GUIDELINES

Adult Caregiver First 30 Days After Transplant

The caregiver is present the majority of the time; breaks should be less than three hours. Patients left alone should have access to the phone, the ability to contact emergency services, the ability to get to the restroom, and access to food and fluid.

We recommend following the below guidelines for 3 months.

Wearing a Mask

- » If you or someone in your house is coughing, sneezing, or has a cold or the flu, a mask should be worn by the sick person.
- » If worn correctly, masks help decrease the spread of respiratory viruses and bacteria to others.
- » The yellow surgical masks should be secured over your ears with the bands, and the nosepiece should be fitted to the form of the bridge of your nose. These masks are most effective if worn for less than an hour, as they lose their protective properties when damp.
- » Masks help to prevent the spread of infections if worn by sick people, but the best forms of prevention are hand washing and staying away from people who are sick.

Food and Food Safety + Weight

ALLOWED	NOT ALLOWED
Pasteurized dairy products	Street Vendors
Well-cooked meats	Pot lucks
Reheated deli meats	Undercooked or raw meats
Thoroughly washed raw fruits and vegetables	Unpasteurized dairy products and juices
Tap water	Cheese with molds
	Well water
	All sprouts

- » It is important that good food safety guidelines be followed for at least the first three months after your transplant. This is a very abbreviated list; please refer to the nutrition section for much more information.
- » Weigh yourself weekly. Let your dietitian or doctor know if you gain or lose more than 3 pounds a week.

Contact Lenses

- » You cannot wear contacts for three months after transplant.
-

Hot Tubs, Saunas, and Pools

- » You will not be allowed to use these for at least three months after transplant and until your central line has been removed; ask doctor or nurse practitioner when it's all right to begin use.
-

Cats, Dogs, and Other Hairy Creatures

- » You may be around hairy pets as long as they are very clean, groomed, have clipped nails, and are current on vaccinations.
 - » Do not clean up after pet or empty litter boxes for six months after transplant.
 - » Strict hand washing is necessary after touching pets.
 - » We recommend not getting a new pet for at least three months after transplant.
-

Fish

- » Do not clean tanks for three months.
-

Birds and Reptiles (Snakes, Lizards, Turtles)

- » Must remain out of house for three months; ask MD when safe to bring them back into your home.
 - » You cannot visit a home with birds/reptiles for at least three months after transplant.
-

Dusting and Vacuuming

- » Ideally, a thorough housecleaning should be done prior to discharge.
- » If you are getting your carpets cleaned, it should be done at least seven days prior to your discharge from the hospital.
- » You should not dust, vacuum, clean bathrooms, or do any other deep cleaning for three months. Please allow a caregiver to do this for you.

We recommend abiding by the following guidelines for 6 months.

Fireplaces

- » No wood burning fireplaces; we will reevaluate your health status at six months to determine if they are then safe to use.
- » Gas fireplaces are acceptable to use.

Swamp Coolers and Air Conditioners

- » Swamp coolers are not recommended for at least six months after transplant.
- » Air conditioners are allowed, but someone else should replace the filter to help prevent your potential exposure to molds.

Plants and Yard Work

- » You may have potted plants in your house (as long as they're not next to your bed), but you may not be the one to care for them.
- » No gardening or yard work for at least six months after transplant, and then reevaluate health status to determine if safe.
- » Stay indoors when gardening or yard work is being done for at least three months after transplant.

Oral Care

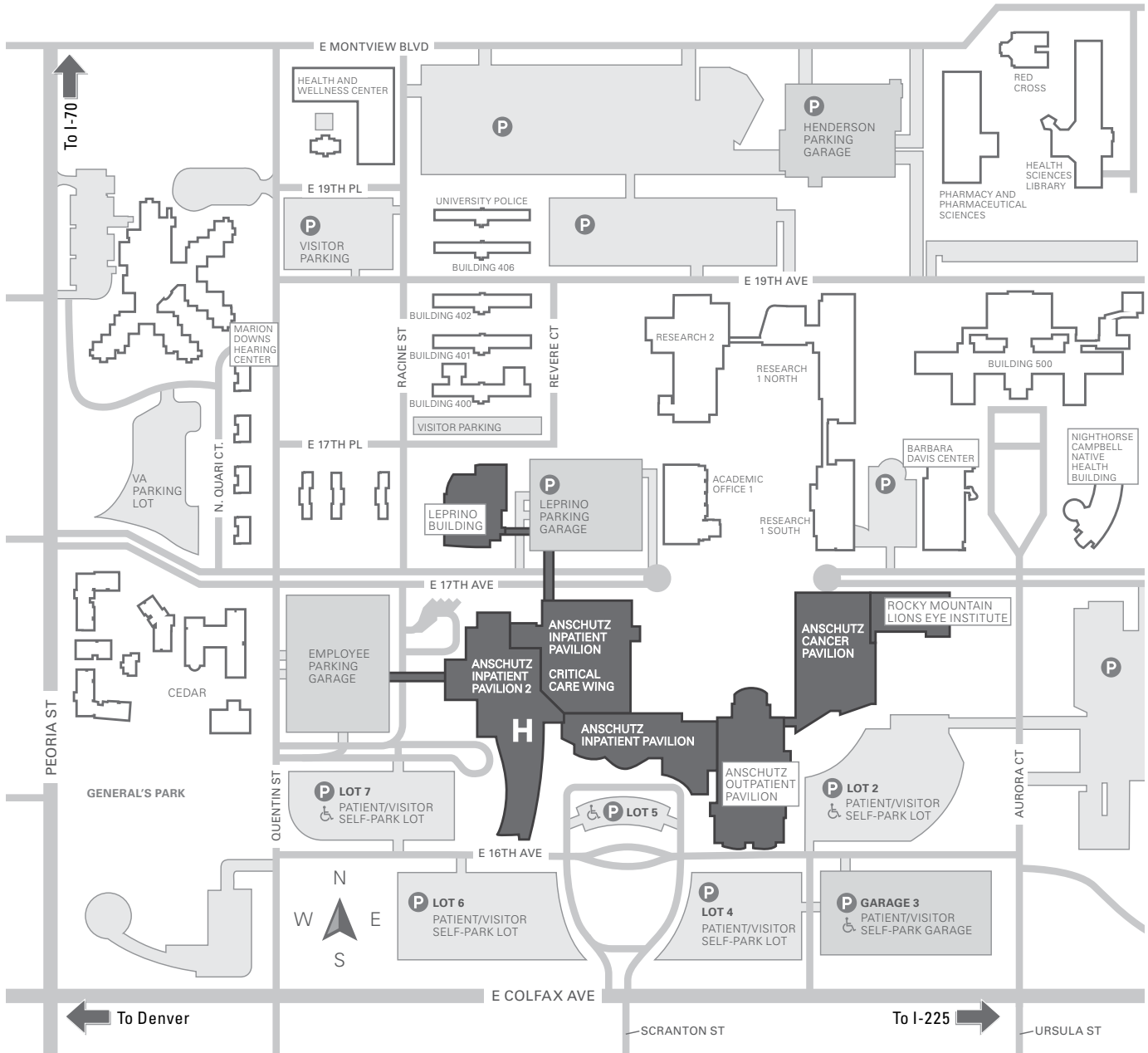
- » Continue to do mouth care at home, use a soft toothbrush, no flossing unless ANC > $1 \times 10^9/L$ and platelet count is greater than $50 \times 10^9/L$.
- » May have cleaning and other work done after six months if absolute neutrophil count (ANC) is greater than $2 \times 10^9/L$ and platelet count is $50 \times 10^9/L$ consistently.
- » Must take antibiotics before going to dentist; we or your dentist should prescribe them for you.

Traveling and Vacations

- » Let us know well in advance of any travel plans. You must be cleared by your physician prior to any travel outside of the Denver metro area. Usually after three months your blood counts are high enough that travel may be an option.

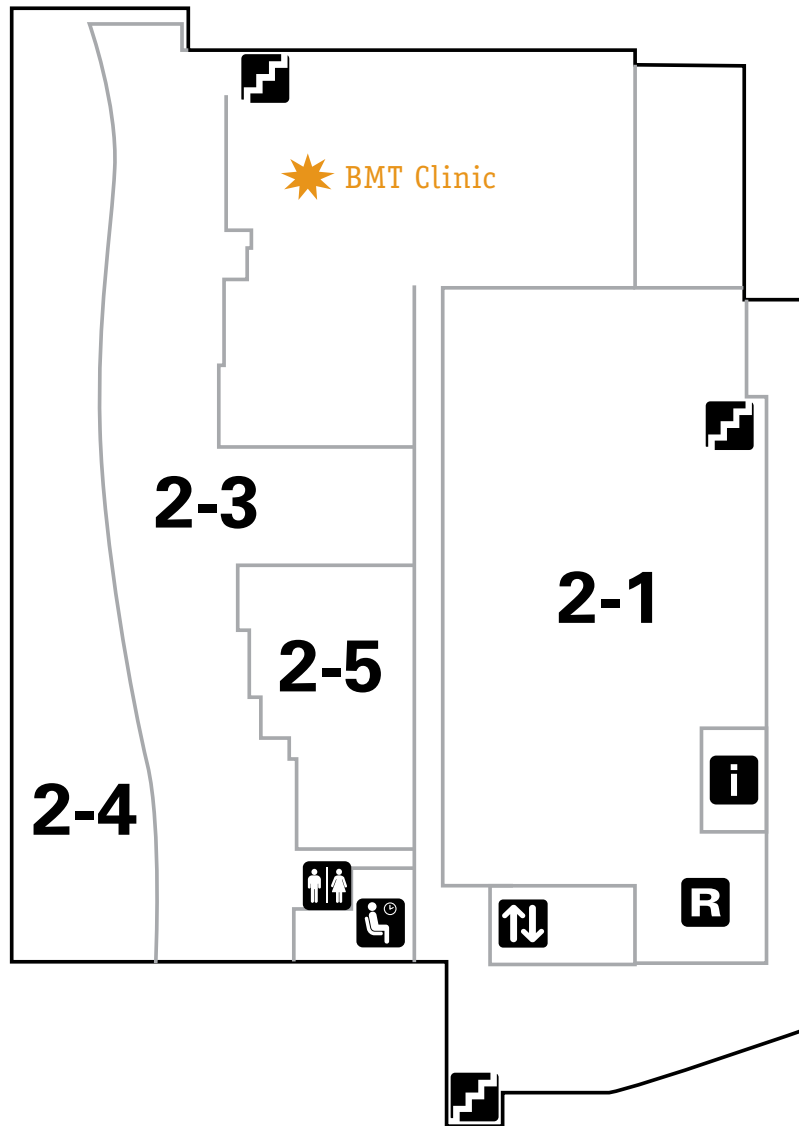
All of the above guidelines are just that – guidelines. Please know that if you are having frequent infections or other complications, the amount of time these guidelines apply may be extended. In addition, they do not cover every situation, only common issues. If you have any other questions about what we recommend, please ask.

CAMPUS MAP



CLINIC MAP

2nd Floor



LOCAL HOUSING LIST

- » The following lodging facilities, hotels and motels are provided as a convenience for your consideration. This is a list of lodging options close to University of Colorado Hospital's Anschutz Medical Campus.
- » Some hotels have hospital rates or discounts – please ask about such discounts. THESE RATES MAY VARY AND CANNOT BE GUARANTEED. You can alert them that you or your family member is a patient at our facility to see if they have this rate.
- » Please call hotel reservations for rate confirmation, transportation and other options.
- » University of Colorado Hospital does not inspect or approve these facilities and therefore cannot assume any responsibility for the accommodations or charges involved.

Legend

\$ = \$1-\$40

\$\$\$ = \$66-\$85

\$\$\$\$+ = \$106+

\$\$ = \$41-\$65

\$\$\$\$ = \$86-\$105

S & L term = short and long term availability

Mileage (Area)

Lodging Contact, Cost, and Information

0.0

RV Hook Up in the UCH Parking Lot

720-848-2385

Free

There are two spots and they are first come, first serve. There is electric hook up only. We need a copy of vehicle registration, proof of insurance and a driver's license and a cell phone number or hospital room number for contact. We also only allow two nights at a time, since we are not an official R.V. park.

0.5

**Fisher House 19th & Quentin (Anschutz Medical Campus)
for Veterans and their families**

Please speak with a hospital social worker to make a referral for you.

Free, per availability, S&L term

Patient or caregiver must be a veteran. Military ID/Paperwork required. Veterans who served post-1980 need to have had two full years of service in order to be eligible. Patients must have a 24/7 caregiver. Caregivers may stay there without patients. No transportation/shuttle, no pets and no wireless service. Parking is available. Private rooms (one & two beds) and shared community living space, including kitchen.

1.0

**Value Place
575 North Billing Street
Aurora, CO 80011**

303-344-4646

Weekly rate is \$250.21. \$100 deposit needed.

A furnished studio (bed/fold-out couch, bath and kitchenette with two-burner stove, full-sized ref. and microwave). Could be available for as low as \$209/week (one person). Cable TV included. Community coin-operated laundry. No transportation/shuttle, pets, or wireless service. Smoking and non-smoking rooms.

1.0

**Denver Meadows RV Park
2075 Potomac Street
Aurora, CO 80011**

303-364-9483 / 1-800-364-9487

Daily \$, Weekly \$\$\$\$+, Monthly \$\$\$\$+

No transportation. Pets are allowed (except for Rotweilers/Pit bulls). Coin-operated laundry area. Utilities included w/rate (water, electricity).

2.3

Motel 6
12020 E. 39th Avenue
Denver CO

303-371-1980 / 1-800-4-MOTEL-6

\$

No studios/kitchenettes; some rooms have ref/micro (\$3.00 extra/night). No breakfast. Coffee available at 6:00 am. No transportation. Located on a bus line. Pets allowed (there are no pet-free rooms) at no extra cost. One pet per room. Coin operated laundry. No free wireless service available.

2.7

Quality Inn
3975 Peoria Street
Denver, CO
www.qualityinn.com/hotel/col172

303-371-5640 / 1-800-4-CHOICE

\$\$

No transportation available. Pet allowed for an extra \$10/night. No pet-free rooms. Non-smoking and smoking rooms. Coin-operated laundry. Continental breakfast M-F 6:00 am – 9:00 am; weekends 7:00 am – 10:00 am Suites available with ref/micro, sink (no stove). King bed pullout couch. No free wireless service available.

3.1

Drury Inn
4380 Peoria Street
Denver, CO
www.druryinn.com

303-373-1983 / 1-800-DRURY-INN

\$\$\$, S&L term

No transportation. Pets allowed at no extra cost. No pet-free rooms. Coin-operated laundry. Hot breakfast seven days/week. Hot snacks at night. No studios. Smoking and non-smoking rooms. Free wireless service and fitness center.

3.16

The Timbers
4411 Peoria Street
Aurora, CO 80239

303-373-1444 / 1-800-844-9404

\$\$\$\$, S&L term

Free transportation. Shuttle to and from UCH available at no cost. Coin operated laundry. Studios with two Queen beds or one King bed with kitchenette (sink, burners, microwave, and small ref). Pets are allowed at \$25/pet/night (no cats). There are pet-free rooms. 90% non-smoking. Free wireless throughout.

3.8

Crowne Plaza - DIA
15500 East 40th Avenue
Denver, CO

303-371-9494

\$\$\$\$

Free transportation (shuttle) to Anschutz Medical Campus & Airport. Pets allowed for a \$25 fee. Most rooms are pet-free. Laundry service. Suites: Pull-out couch/living area. Fitness center. Non smoking rooms. Free wireless throughout.

3.9

Residence Inn - Marriott
16490 East 40th Circle
Aurora, CO 80011

303-459-8000

\$\$\$\$+

No transportation. Pets are allowed; there are not guaranteed pet-free rooms. Pets require a \$75.00 cleaning fee. Studios are mostly "fully-equipped" with King bed, pull-out sofa (there are some two bedroom, two bathrooms suites). There is guest laundry. A light meal is available Monday through Thursday from 5pm – 7pm. Non-smoking only. Free wireless throughout.

3.9

**La Quinta Inn
1011 South Abilene
Aurora, CO**

303-337-0206 / 1-800-NU-ROOMS

\$\$, S&L term

No free transportation, but RTD stops in front of the hotel. Two rooms have a kitchen. No pets. Smoking & non smoking rooms available. Free continental breakfast, laundry services, and free membership to Bally's fitness center. Free Wireless in rooms.

4.0

**Embassy Suites
4444 North Havana
Denver, CO
www.embassysuites.com**

303-375-0400 / 1-800-EMBASSY

\$\$\$\$+ (Hilton Points)

Free transportation to Anschutz Medical Campus and airport. Microwave and ref. in all rooms, non-smoking rooms only. Free full breakfast, free happy hour and light snacks every evening. No pets, work out facilities, or laundry facilities. Free wireless throughout.

4.2

**Sleep Inn
15900 East 40th Avenue
Aurora, CO
www.choicehotels.com**

303-373-1616 / 1-800-4-CHOICE

\$\$\$\$, S&L term (weekly)

Free transportation upon availability to Anschutz Medical Campus and Airport. Full kitchen in each room, pets allowed in five rooms. No complimentary food. Laundry facility available. Smoking and non smoking rooms. No work out facility. Free wireless in room.

4.04

CrossLand Economy Studios
3705 N. Chambers Rd.
Aurora, CO

303-307-1088 / 1-800-EXT-STAY

\$, S&L term

No free transportation, but RTD stops in front of hotel. Full kitchen in each room. No pets allowed. Coin-operated washers and dryers. No workout facilities. Smoking/non smoking rooms. Charge for wireless in room is \$4.99 per day.

4.3

Hyatt Place
16250 East 40th Avenue
Aurora, CO
www.amerisuites.com

303-371-0700 / 1-800-833-1516

\$\$\$\$+

Free transportation to Anschutz Medical Campus and Airport. Microwave and ref in all rooms. Smoking and non-smoking rooms. No complimentary food. Coin-operated washers and dryers. Workout facilities and free wireless service throughout.

4.4

Crystal Inn
3300 North Ouray Street
Aurora, CO
www.crystalinns.com

303-340-3800 / 1-888-890-3800

\$\$\$\$

Smoking and non-smoking rooms. No complimentary food. Coin operated washer and dryer. Pets allowed for \$25.00 fee, no special cleaning in pet rooms. Free wireless service throughout.

4.45

**Best Western Inn & Suites
800 South Abilene Street
Aurora, CO**

720-748-4800 / 1-800-WESTERN

\$\$\$, S&L term

No free transportation. RTD bus line stops in front of hotel. Microwave and ref in all rooms. Pets allowed in five rooms, \$15.00/night charge. Smoking and non-smoking rooms. Laundry facilities available. Free pass to go to Bally's workout facility a few doors down. Free wireless service throughout.

4.57

**Holiday Inn Express
1500 S. Abilene Street
Aurora, CO 80012**

303-369-8400

\$\$\$-\$\$\$\$ Standards and Suites

No free transportation. Bus line in front of hotel. Microwaves and ref in all rooms. No pets. Non-smoking rooms only. Free full breakfast daily, Wednesday evening social, happy hour and light snacks. Workout facilities, coin-operated washer & dryer. Free wireless service throughout.

4.6

**Hilton Garden Inn - DIA
16475 East 40th Avenue
Aurora, CO
www.denverairport.stayHGI.com**

303-371-9393 / 1-800-HILTON

\$\$\$\$+ Nightly, \$\$\$\$ Weekly, S&L term (Hilton Points)

Free transportation to Anschutz Medical Campus and Airport. Microwaves & ref in all rooms. No Pets. 96% non-smoking. Laundry service and workout facility available. Free wireless service throughout.

5.4

Radisson Hotel - Denver
3333 Quebec Street
Denver, CO

303-321-3500

\$\$\$ Weekly rate, \$\$\$ Nightly rate, S&L term

No free transportation. Bus line in front of hotel. Microwaves & ref in all rooms. Pets require \$25.00 refundable deposit. Smoking and non-smoking rooms available. Coin-operated washer and dryers. Free wireless service throughout.

5.51

Residence Inn
16490 East 40th Circle
Aurora, CO 80011
www.residenceinn.com/DENRI

303-459-8000

\$\$\$\$+, S&L term

No free transportation. Full kitchen amenities. Pets require \$75.00 non-refundable deposit. Non-smoking rooms only. Coin-operated laundry facilities. Workout facilities, heated pool, hot tub. Free full breakfast, happy hour seven days a week, light snacks. Free wireless service throughout.

5.59

Hotel 3737
3737 Quebec Street
Denver, CO 80207

303-388-6161

\$\$

Free shuttle to Anschutz Medical Campus. Pets require \$15 non-refundable fee (no special cleaning in pet room). Free continental breakfast. Gym on site. Smoking and non-smoking rooms available. Free wireless in room.

5.6 **Super 8 Denver**
7201 East 36th Avenue
Denver, CO

303-393-7666

\$\$, S&L term

No free transportation. Pets require a \$15.00 one time fee (no special cleaning in pet room). Free continental breakfast. Gym on site. Coin operated laundry on site. Smoking and nonsmoking rooms. Free wireless service throughout.

5.6 **Comfort Inn**
14071 East Iliff Avenue
Aurora, CO

303-755-8000 / 1-800-228-5050

\$\$

No free transportation. Shuttle costs \$22.00 per trip. Pets require a \$15.00 per night fee per pet (no special cleaning in pet room). Free continental breakfast. Coin-operated laundry service. Non-smoking rooms only. Gym on site. Free wireless service throughout.

5.8 **Denver Renaissance Marriot**
3801 Quebec Street
Denver, CO

303-399-7500

\$\$\$\$+

Free shuttle to and from airport. Refrigerator and microwaves in room. Pets allowed in some rooms with \$35.00 deposit. Pet rooms will be cleaned thoroughly. Workout facility. Free wireless service throughout.

5.8 **Fairfield Inn**
13851 East Harvard Avenue
Aurora, CO
www.marriot.com/denau

303-745-6700

\$\$\$\$ Weekly rate, \$\$\$\$ Nightly rate, S&L term

No transportation. No pets allowed. Ref/Microwave in each room. Free full breakfast. Non-smoking rooms only. Coin-op laundry. Gym/pool on site. Free wireless throughout.

5.8 **Red Lion Hotel**
4040 Quebec Street
Denver, CO
www.redlion.com
303-321-6666 / 1-800-RED-LION
\$\$ (Hilton Points)
Free Shuttle to and from airport. Pets require a \$25.00 not-refundable fee. Coin-operated laundry service. Complimentary breakfast. Smoking and non-smoking rooms. Outdoor pool and fitness center. 90% non-smoking. Free wireless throughout.

5.8 **Homestead Suites**
13941 East Harvard Avenue
Denver, CO
www.homesteadhotels.com
303-750-9116 / 1-888-STAY-HSD
\$\$ (\$35 nightly), \$ 7+ nights, \$ monthly, S&L term
No free transportation. Pets allowed, \$25/night fee. No free breakfast. Coin-operated laundry service. Non-smoking rooms only. Wireless is \$4.99/stay.

6.8 **Holiday Chalet Bed and Breakfast**
1820 East Colfax Avenue
Denver, CO
303-321-9975
\$\$\$\$
No free shuttle service. No pets allowed. Laundry service for \$5.00. Full kitchens in each room. Non-smoking rooms only. Each room has a private bath. Free full breakfast. Free wireless service throughout.

6.9 **Homestead Village Suites**
4444 Leetsdale Drive
Denver, CO
303-388-3880
\$\$\$ Nightly, \$\$ weekly, \$\$ monthly, S&L term
No free transportation. Pets require \$25/night non-refundable fee for 6 days. Coin-operated laundry. Smoking and non-smoking rooms available. Day passes to 24 Hour Fitness for guests. Wireless offered for \$5.18 per day.

7.0 **Best Inn & Suites - Northfield Stapleton**
4590 Quebec Street
Denver, CO 80216

303-320-0260

\$\$

No free transportation. Pets allowed only on 4th floor. Special cleaning for pet rooms. 90% of hotel is non-smoking. Coin-operated laundry service. All rooms have a full size refrigerator, two top stove burners, and microwave. Workout room available. Continental breakfast seven days a week for \$3.00/person. Free wireless throughout.

7.1 **Ramada Inn - Downtown**
1150 East Colfax Avenue
Denver, CO

303-831-7700

\$\$

No free transportation. No pets allowed. Free continental breakfast. Laundry service. Gym on site. Smoking and non-smoking rooms. Free wireless service throughout.

7.2 **Holiday Inn Select**
455 South Colorado Boulevard
Denver, CO

303-388-5561

\$\$\$\$

Shuttle service. No pets. Laundry service. Washer & dryer on premises. Workout facilities. Non-smoking rooms only. Free wireless service throughout.

7.2 **Staybridge Suites**
4220 East Virginia Avenue
Denver, CO

303-321-5757

\$\$\$\$ Nightly, \$\$\$ weekly, \$\$\$ monthly, S&L term

Shuttle service. No full kitchen. Complimentary hot breakfast buffet. Free laundry facilities. Located on Cherry Creek bike path. BMT patient-specific 2-bedroom/2-bath suites. Smoking and non-smoking rooms. Free Wireless throughout.

7.3

St. Christopher's House - Downtown
1780 Lafayette Street
Denver, CO

720-917-9900

\$, Contact social worker for info

Shuttle service 6:30am – 10pm. No pets. Up to four people in each room. Coin-operated laundry facilities available. Non-smoking rooms only. No wireless service.

7.5

Four Points Cherry Creek
600 South Colorado Boulevard
Denver, CO

303-757-3341 / 1-877-508-0190

\$\$\$

No free shuttle service. No complimentary meals. No pets allowed. Coin-operated laundry. Workout facilities. Non-smoking rooms. Free Wireless service.

7.9

Warwick Hotel Denver
1776 Grant Street
Denver, CO

303-861-2000

\$\$\$\$+, S&L term

No free shuttle service. No complimentary meals. No washer or dryer. Workout facility. Pet rooms are only specially cleaned if there is obvious soiling. Non-smoking rooms only. Free wireless service

8.3

Burnsley All Suite Hotel
1000 Grant Street
Denver, CO

303-830-1000

\$\$\$\$+

No free Shuttle. Every room has full kitchen. Pets on one floor, no specific cleaning. No workout facility. No Wireless Service.

8.45 **Equity Corporation Housing - Tech Center**
2945 South Havana
Aurora, CO

303-750-5181

\$\$\$\$

No special hospital rate. Furnished apartments with utilities. 30 day minimum. Daily rate dependent on season (higher during summer months). All over the Denver Metro Area. All housing includes internet. Optional cleaning service (cost is extra).

8.5 **Comfort Suites - DIA**
6210 Tower Road
Denver, CO

303-371-9330 / 1-800-4-CHOICE

\$\$\$\$

No free Shuttle. No pets. Complimentary continental breakfast. Coin-operated laundry service. Smoking and non-smoking rooms. Workout facility available. Free wireless service in room.

8.5 **Loews Denver Hotel**
4150 East Mississippi
Denver, CO

303-782-9300

\$\$\$

Free shuttle for 6-mile radius. Pets are allowed; they do not clean differently in pet rooms. No complimentary meals. Coin-operated laundry service and workout facilities available. Non-smoking rooms. Internet service fee is \$10.95 per day.

8.6 **Red Lion SE Hotel - I-225/Tech Center**
3200 South Parker Road
Aurora, CO

303-695-1700 / 1-800-962-7672

\$\$\$

Free Shuttle to Anschutz Medical Campus and to airport. Pets are allowed, deep cleaning after pet stay. Non-smoking rooms. Workout facilities available. Free wireless throughout.

8.6 **Hampton Inn**
6290 Tower Road
Denver, CO
303-371-0200 / 1-800-HAMPTON
\$\$\$\$+
Rates subject to change. Shuttle service to airport only. No pets. Laundry service paid. Breakfast included. Workout facilities available. Non-smoking rooms. Free wireless service throughout.

8.8 **Fairfield Inn/Marriott**
1680 South Colorado Boulevard
Denver, CO
303-691-2223
\$\$\$
No free shuttle. Pets require \$75.00 fee. Specific cleaning chemicals for rooms with pets. Complimentary breakfast. Workout facilities available. Dry cleaning available. Free wireless service throughout.

9.3 **Marriott Town Place Suites - Downtown**
685 Speer Boulevard
Denver, CO
303-722-2322
\$\$\$\$+ Nightly, \$\$\$ monthly, S&L term
No hospital rate available. Rates change daily. Pets require a \$100 fee. Pet sanitation in rooms. Complimentary breakfast. Coin-operated laundry service available. Workout facilities available. Bike path across street. Bally's free pass. No shuttle service. Free wireless throughout.

9.5 **Ramada Inn - DIA**
7020 Tower Road
Denver, CO
303-373-1600 / 1-800-2-RAMADA
\$\$\$\$+, S&L term
No free transportation. No pets allowed. Small refrigerator in each room. Laundry service. Free continental breakfast. Gym on site. Free wireless service throughout.

9.7

**Residence Inn Marriott
2777 Zuni Street
Denver, CO**

303-458-5318 / 1-800-331-3131

\$\$\$\$ - \$\$\$+\$

Free shuttle service within a 3-mile radius. Suites available with full kitchen, sleeps up to six people. Pets allowed with \$75.00 non-refundable deposit. Coin-operated washers and dryers. Free wireless throughout.

10.49

**La Quinta
6801 Tower Road
Denver, CO 80249**

303-371-0888

\$\$\$

No free shuttle. Pets are allowed, no special cleaning. Microwave/ref in all rooms. Free continental breakfast. Coin-operated laundry. Workout room. Free wireless.

**TRANSPORTATION
SERVICES**

If you have questions regarding transportation, please call the Cancer Resource Center at 720-848-0316 or ask to speak with your Social Worker.

<i>Cab Company</i>	<i>Phone Number</i>
Freedom Cab	303-444-4444
Metro Taxi	303-333-3333
Yellow Cab	303-777-7777

