

# CHAPTER 1. STEM CELL TRANSPLANT PROGRAM

*The Division of Immunotherapy at Northwestern University has an active program offering promising new therapies using autologous and allogeneic hematopoietic stem cell transplantation in treating autoimmune and non-malignant diseases.*

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Northwestern Memorial Hospital is a state-of-the-art facility located in the heart of downtown Chicago.

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## TYPES OF HEMATOPOIETIC STEM CELL TRANSPLANTATION

There are three types of hematopoietic stem cell transplants -- autologous, allogeneic and syngeneic.

An autologous hematopoietic stem cell transplant uses your own stem cells that are collected prior to chemotherapy, while an allogeneic hematopoietic stem cell transplant uses cells collected from a closely or completely matched individual. Syngeneic hematopoietic stem cell transplant uses cells from an identical

twin. In each of these three types of transplants, the stem cells can be collected from the bone marrow or from the peripheral blood.

You and the stem cell transplant team will decide which type of transplant type is your best treatment option.

## SUPPORT SERVICES

While under the care of the hematopoietic stem cell transplant team, we will make every effort to provide support services to you and your family. This will include financial counseling and clinical social workers.

*Financial counselors:* Hematopoietic stem cell transplantation is a very costly procedure. The Division of Immunotherapy has two dedicated financial counselors to assist you in the insurance process. You will be asked to fill out an intake form, which will request your insurance information. The financial counselors will supply your insurance company with any medical information required to get authorization for your transplant.

*Social Services:* A clinical social worker will be available to you as an inpatient. The social worker can provide counseling to each patient and his/her family in managing the stresses associated with the transplant.

### **Division of Immunotherapy and Autoimmune Diseases**

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## **THE TRANSPLANT PROCESS**

There is a common series of events that all patients undergoing a transplant will perform. These steps include:

- Initial Physician Visit
- Pre-transplant Testing
- Central Line Placement
- Stem Cell Mobilization
- Stem Cell Harvest
- Conditioning
- Stem Cell Reinfusion
- Follow-up Physician Visits

Once you are accepted into the transplant program, please do not take any new medicines, especially ones that affect bone marrow or platelet function (aspirin type drugs), unless you get permission from the transplant team. This is especially important before placement of the central line and until recovery of your blood counts following completion of the transplant.

### **Initial Physician Visit**

An initial physician visit is necessary to determine if you are a candidate for the transplant. Your past medical records, including radiologic studies (MRI, CT scans, x-rays) should accompany you or be sent in advance of your scheduled appointment. During this initial visit, you will undergo a history and physical examination and the transplant process, including potential complications, will be explained to you by the treatment team. You will be given an opportunity to ask

questions. In addition, if it is felt that you may be a candidate for the transplant, you will be given the protocol consent form to take home and read. If desired, you will be given an opportunity to talk to other individuals who have undergone a transplant for your disease. You will need to be in Chicago one to two days for this initial evaluation.

### **Pre-Transplant Testing**

You will need to undergo a series of tests to assess the status of your disease and to ensure that you are eligible for a hematopoietic stem cell transplant. Your physician will determine the tests that you will be required to undergo. Prior to starting any testing, you will need to sign the protocol consent form. You will be given another opportunity to ask questions of the treatment team before signing the consent form.

### **Central Line Placement**

During the course of transplant, you will need to have a plastic tube placed into a large vein in your upper arm or chest (a central line). For autologous or syngeneic hematopoietic stem cell transplants, the central line is usually placed in the upper arm and has two “lumens” or entry points exiting out of your upper arm ( this type of central line is commonly called a PICC line). For allogeneic hematopoietic stem cell transplants, the central line is usually placed in your upper chest and has three lumens exiting out of your upper

chest. The purpose of these central lines will be to help to avoid the pain and discomfort of the multiple blood draws that are required throughout the transplant process. In addition, chemotherapy, medications, blood products and the stem cells can be administered through the central line. For those individuals having an autologous hematopoietic stem cell transplant, the central line will generally be placed the morning you are scheduled to be admitted for your mobilization chemotherapy. For those individuals having a syngeneic or allogeneic hematopoietic stem cell transplant, the central line will generally be placed the morning you are admitted for the transplant. In both instances, you will go home for a period of time with the central catheter, and you will be taught how to care for the catheter. You will be required to flush the catheter daily and change the central catheter dressing at least three times per week. A home health care nurse will assist you with these procedures until you or a family member are able to perform them on your own.

If you are undergoing an autologous hematopoietic stem cell transplant, you will also need to have a second central catheter placed for the collection of your peripheral blood stem cells (this catheter is commonly called a VAS CATH). (Note: Donors for allogeneic or syngeneic hematopoietic stem cell transplants may also need to have a VASCATH placed prior to the harvest.) This line is placed the day before or the morning of the first day of your stem cell harvest, and will be removed when the harvest is completed. This

catheter has two large bore lumens, which will allow us to collect your stem cells, draw blood, and administer medications if needed. The catheter is placed into a large vein in your neck that leads to your heart. You will be given a local anesthetic before the procedure. You will not be required to care for this catheter. Flushing and dressing changes will be done in the blood center during your stem cell harvest. This catheter is uncomfortable, but will only be in place for a few days.

## **Stem Cell Mobilization**

After your pre-testing is completed and you are cleared for transplant, stem cells will need to be collected from you (autologous transplant) or your donor (allogeneic or syngeneic transplant).

***Allogeneic/Syngeneic Stem Cell Transplant.*** If you are having an allogeneic or syngeneic hematopoietic stem cell transplant, stem cells will be “mobilized” from their bone marrow to the peripheral blood where they can be collected using a growth factor called Neupogen® (GCSF). Approximately 3-4 days after starting the Neupogen® (which is given daily by subcutaneous injection), your donor's stem cells will be collected (harvested). The stem cell harvest for your donor will take 1-5 days depending on how successful the harvest is each day.

***Autologous Stem Cell Transplant.*** If you are having an autologous hematopoietic stem cell transplant,

you will be admitted to the hospital to receive your stem cell will be mobilized using chemotherapy and growth factor called Neupogen® (G-CSF). The purpose of the mobilization chemotherapy is to start mobilizing your stem cells from the bone marrow to the peripheral blood, so they can easily be collected from your peripheral blood. The stem cell harvest will begin approximately 10 days after the administration of the mobilization chemotherapy. The type of mobilization chemotherapy you receive is disease specific. The dose of chemotherapy may be two to four times higher than any chemotherapy you may have received in the past.

Acute side effects from this chemotherapy may include fatigue, anorexia, nausea, vomiting, and diarrhea. There will be anti-nausea and anti-diarrhea medications available during your hospitalization, as well as when you are discharged. Side effects from the chemotherapy can occur up to several weeks following its administration.

You will loose your hair approximately 14 days after your mobilization chemotherapy. You should not expect your hair to begin growing back until several months after the transplant.

Some patients do describe a generalized feeling of extreme fatigue from the time the mobilization chemotherapy is given.

The admission for mobilization chemotherapy is approximately 24-48 hours. You will then be discharged to your apartment or home. To prevent infection, you will start oral antibiotics

approximately 72 hours after receiving your chemotherapy. You will also start Neupogen® (G-CSF), which is an injection that either you or your caregiver will need to give to you every morning starting 72 hours after your chemotherapy. The injections will continue until your stem cell harvest is completed. The purpose of the Neupogen® is to stimulate your stem cells to grow and find their way from the bone marrow to your peripheral blood for a successful harvest. Side effects of the Neupogen® may include:

- Flu-like symptoms, including fever, muscle pain/aches, nausea and headache.
- Bone pain, which may be severe.
- Generalized rash.

You may take Tylenol for any of the above symptoms, unless otherwise directed by your physician.

You will have your blood counts monitored several times during the following week. You will need to come to the hospital to have your blood drawn, or you may be eligible for home health care nursing. We will be expecting your blood counts to be stable until approximately 7 days following your mobilization chemotherapy. At that time, your white blood cells will drop, and you will be neutropenic for approximately 3 days. **It is during this time that you will be susceptible to infection.** To prevent infection following mobilization chemotherapy, it is advised that you do not come in contact with individuals who are sick.

In addition, you should avoid large crowds.

You will feel fatigued and you may experience bleeding. In addition, you may run a temperature. If you develop a fever (100.5°F or greater), are unable to eat or drink enough fluids, experience bleeding, have chills, or just do not feel good, you should contact the transplant team immediately as you may need to be admitted to the hospital.

**IT IS VERY IMPORTANT THAT YOU NOTIFY YOUR NURSE OR PHYSICIAN IMMEDIATELY OF THE FOLLOWING:**

- **FEVER OR CHILLS**
- **ANY SIGN OF INFECTION**
- **BLEEDING**
- **AN INABILITY TO EAT, DRINK, OR TAKE YOUR MEDICATIONS**
- **ANY UNCONTROLLED SIDE EFFECT .**

## **Stem Cell Harvest**

***Allogeneic/Syngeneic Stem Cell Transplant.*** If you are undergoing an allogeneic or syngeneic hematopoietic stem cell transplant, the stem cells will be harvested from your donor on an outpatient basis. The stem cell harvest will begin approximately 3-4 days after your donor starts taking Neupogen® shots (the timing of the start of the harvest may vary between different research protocols). The stem cell harvest, which will take approximately 4-5 hours each day, will continue on a

daily basis until enough stem cells have been collected (approximately 1-5 days). In many instances, your donor will need to have a VASCATH placed on the morning of the first stem cell harvest. This catheter will be removed when enough stem cells have been collected. It will be important for your donor to continue taking the Neupogen® shots until the stem cell harvest is completed.

### ***Autologous Stem Cell Transplant.***

If you are undergoing an autologous hematopoietic stem cell transplant, your stem cell harvest will be performed as an outpatient, unless you had been hospitalized after your mobilization chemotherapy due to illness or complications. The stem cell harvest will start when your white blood cell count and platelets have recovered, which is approximately 10 days following administration of your mobilization chemotherapy. It is important to remember that your Neupogen® should be given prior to coming to your harvest each day, ideally two hours prior to your scheduled visit.

You will be advised where and what time you will need to have your blood drawn that morning.

Following the blood draw, you will need to report to Interventional Radiology to have the temporary VAS CATH placed, which will be used for the harvest.

You will report to the Rube Walker Blood Center immediately following your VASCATH placement. Your stem harvest will feel similar to a blood donation, only that your

collection will take longer. You will be hooked up to the machine for approximately 4-5 hours each day until we have collected the number of stem cells needed. It will be important for you to continue taking the Neupogen® shots until the stem cell harvest is completed. Once enough stem cells have been collected, the VASCATH will be removed.

***The Stem Cell Harvest Procedure.***

You or your donor will sit in a recliner during the harvest. Each recliner has a television that you may watch. You may bring headphones, books, puzzles, or a laptop computer if you wish. There is internet access available. You may also have a friend or family member with you during the harvest. You are allowed to eat and drink during the harvest.

The stem cell harvest is generally a well tolerated procedure. Patients do report feelings of increased fatigue, discomfort at the catheter insertion site, and often experience tingling in their extremities and around the mouth due to a drop in their calcium from the harvest. You will be given TUMS to take as directed if this should occur. You may also receive calcium intravenously during the stem cell harvest. If you do experience discomfort at the catheter insertion site at home, you may take Tylenol for the pain. If you do not feel that Tylenol is reducing the pain, please call your nurse or physician. Please do not take other pain medicine unless prescribed by the transplant team.

***Processing of Stem Cells.*** The stem cells collected from you or your donor

will be brought to the bone marrow processing lab immediately after the stem cell harvest each day. The types and numbers of different cells are calculated at the end of each harvest and this analysis will help determine how many days the harvest will continue. You or your donor will be updated on the success of the stem cell collection each day.

The collected stem cells will be stored by means of cryopreservation, a freezing storage technique, until the time of your re-infusion (transplantation).

## **CONDITIONING**

Conditioning is the phase during the hematopoietic stem cell transplant in which you receive a treatment regimen which has been specifically designed to treat your disease. It will consist of chemotherapy and, in some instances, drugs to suppress your immune system. Please refer to your consent form and the section entitled “The Inpatient Stay” for further details.

## **STEM CELL REINFUSION**

The reinfusion of the stem cells and/or bone marrow that were previously collected from you or your donor will occur following the conditioning regimen. Please refer to the section entitled “Stem Cell Reinfusion” for further information.

**POINTS TO REMEMBER:**

1. For situations that require immediate attention, call the answering service (312/915-8197) and ask for your transplant physician or nurse to be paged. Alternatively, you can call the Division office at 312/908-0059 during normal business hours.
2. For non-emergencies, call your outpatient nurse (Kate Quigley or Kim Yaung) at the Division office number (312/908-0059). They are in the office Monday – Friday until 4 PM and will return your call as soon as possible.
3. Please call for medication refills during normal business hours (Monday – Friday, 9 AM – 3 PM).
4. **If you are experiencing an emergency, please go to your nearest emergency room. Do not wait to call your physician or nurse here at Northwestern. Once at the emergency room, ask the emergency room personnel to contact your transplant team by calling the answering service (312/915-8197).**

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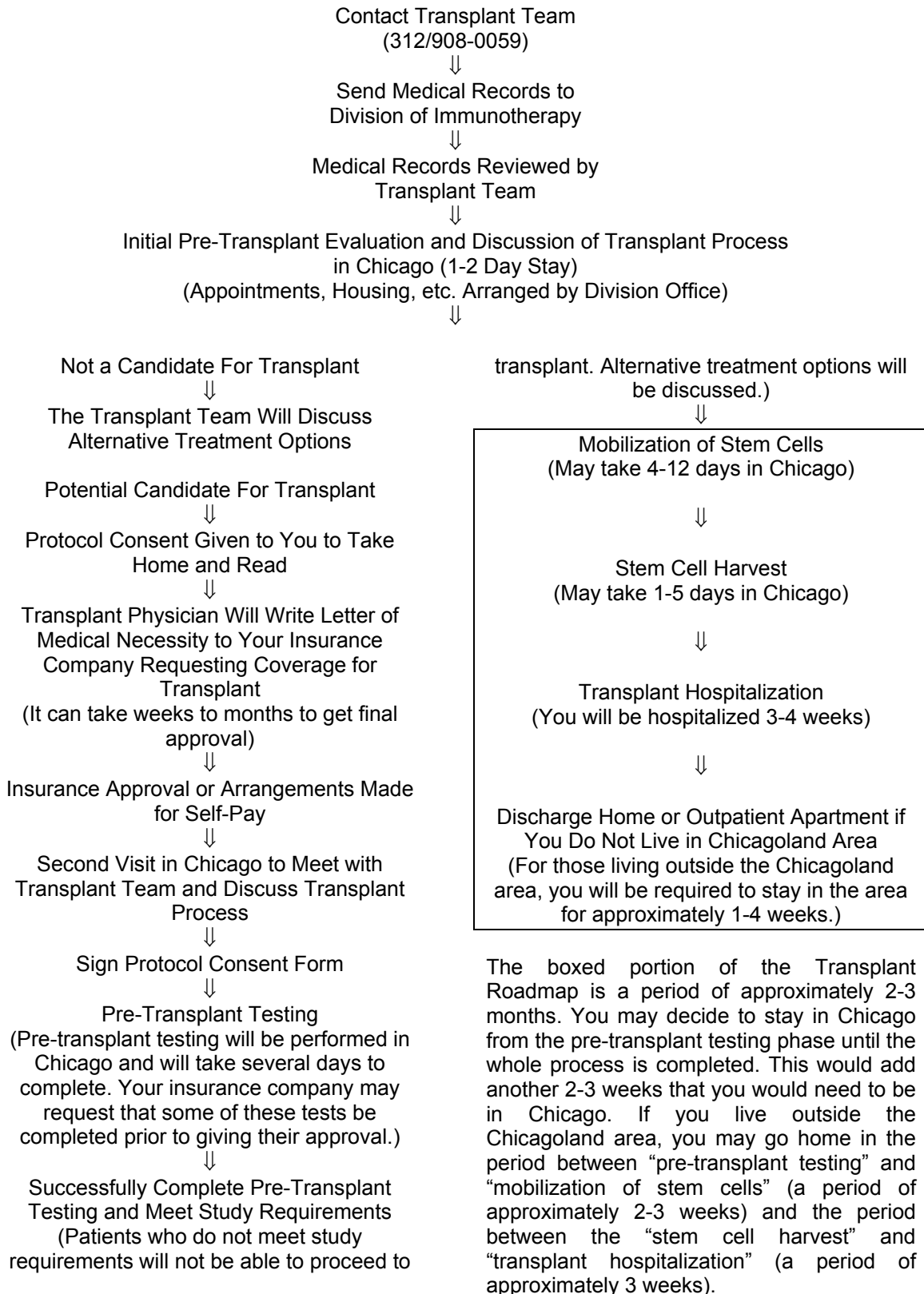
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# TRANSPLANT ROADMAP



## Division of Immunotherapy and Autoimmune Diseases

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## CHAPTER 2. THE INPATIENT STAY

*The following sections will give you an overview of what to expect while you are in the hospital. Be sure to share this information with your family.*

*The inpatient stem cell transplant unit is located on 15 East Feinberg or 10 East Feinberg. The staff on these units are specially trained to care for stem cell transplant patients and their families. The doctors and nursing staff work together to provide you with the best possible care. The team will include your stem cell transplant doctor and his/her associates, advanced practice nurses, consulting doctors, staff nurses, a dietician, and a pharmacist. Support services such as social services, psychiatry, pastoral care, and expressive arts therapists are also available to you and your family. Each room is fitted with an analog phone line, which may be used with computer modems. VCR's are not in each room; however, there are VCR's on carts which are available for your use.*

The staff nurse will explain the hospital routines to you and your family. You will be examined by several doctors and nurses who will participate in your care. You will be asked many questions by both the nursing and medical staff. The nurse will obtain samples (bacteria cultures) from your skin, throat, nose, urine, and stool. These cultures help identify any possible sources of infection.

You will be in a private room with a special filter in the ceiling. This helps clean the air. The staff will begin measures to help prevent infection. These measures are referred to as *neutropenic precautions*. Please let your family and friends know about the following precautions:

1. *Fresh flowers or plants* are not allowed in your room because of the bacteria and mold they contain. Silk flowers and silk plants are allowed as long as they do not have moss at the bottom.
2. *Balloons* are not allowed as they attract dust.
3. *Fresh fruits or vegetables* are not allowed in your diet because of the bacteria and mold they may contain. Pepper is also not allowed. Cooked food from home is allowed as long as it is stored properly.
4. *Staff and visitors must thoroughly wash their hands before touching you.* Handwashing is known to be the most effective means of preventing the spread of germs. *Staff must also put on gloves before touching you or anything used in your care (e.g. IV poles, blankets, etc.).*
5. *Visitors must wear masks if they have been exposed to colds. No one with a cold or temperature should visit.*
6. *You must wear a mask and gloves if you leave your room.*

The following is a list of items you may want to bring to make your hospital stay more comfortable:

1. Bathrobe, slippers, pajamas
2. Gym shorts, sweatpants
3. Wig, scarf, cap
4. Toiletry items
5. Reading materials
6. Stationary and scratch paper
7. Crafts/sewing
8. Cards/games
9. Telephone numbers of family and friends
10. Electric razor
11. Posters or pictures
12. Movie videotapes
13. Radio/cassettes/CD's
14. Laptop computer

Each patient room has a closet to store your personal belongings. We ask that you limit the amount of personal belongings that you bring from home because these items collect dust and place you at additional risk for infection once your blood counts decrease.

## **YOUR TREATMENT REGIMEN**

Your treatment regimen has been specifically designed to treat your disease. It will consist of chemotherapy and, in some instances, drugs to suppress your immune system. Some patients may also receive radiation therapy. The purpose for choosing a particular treatment regimen varies. In the case of cancer, chemotherapy and/or radiation therapy are used to kill cancer cells. In autoimmune diseases, chemotherapy and/or radiation therapy is used to kill the

immune cells that are causing your disease and may be damaging vital organs such as the lungs, brain, kidney, etc.. In both instances, these treatments will also kill normal cells that grow rapidly such as hair follicles, cells in the gastrointestinal tract (mouth and rectum), and bone marrow.

During chemotherapy and radiation, damage to your normal cells may result in side effects. The severity and type of side effects vary from person to person. Major side effects include nausea, vomiting, diarrhea, hair loss, and suppression of bone marrow function. Nausea, vomiting, and diarrhea can be controlled with medications. Hair loss cannot be prevented, but hair will re-grow in three to six months after treatment is completed. (You may want to bring wigs, turbans, or caps to the hospital with you.) Bone marrow suppression is usually the most serious side effect of the treatment plan.

The bone marrow is responsible for making red blood cells (RBCs), white blood cells (WBCs), and platelets. After treatment, your blood counts will be low while you are waiting for your new bone marrow to “engraft” or begin producing new blood cells. Until this occurs, you will receive blood transfusions. Some of the different blood products that are used are described below. They are all carefully screened for human immunodeficiency virus (HIV), and hepatitis. All of the blood or blood products you receive will be carefully tested to make sure that they are compatible with your blood.

## **Red Blood Cell (RBC) Transfusion**

RBCs carry oxygen to your vital organs and other tissues. When your red blood cell count is low you may feel weak and tired. We will monitor your RBC count and hemoglobin by drawing blood daily and more often if needed. Hemoglobin is the portion of the RBC that carries oxygen. RBCs will be replaced by a blood transfusion if your hemoglobin falls below a certain level.

## **Platelet Transfusion**

Platelets help your blood clot and prevent you from bleeding. Your nurse and doctor will examine you everyday for any signs or symptoms of bleeding. *It is very important that you notify your nurse or doctor immediately if you notice any bleeding from your mouth, nose, or rectum. You also should report any bruises or headaches.*

To reduce the chances of bleeding, you will need to use a soft toothbrush and an electric razor when your platelet count falls below 50,000. Use of dental floss when the platelet count falls below 50,000 is not recommended.

## **White Blood Cells (WBCs)**

WBCs fight bacteria that cause infections. It is important that while your white blood cell count is low, that measures are taken to help prevent infections. These preventive measures are necessary until your new bone marrow produces enough

WBCs to fight infection. These measures include thorough handwashing, wearing masks and gloves when you leave your room, no fresh flowers or plants, no balloons, and a special diet that does not contain pepper or fresh fruits and vegetables.

All hospital staff who touch you or anything in your room are required to wash their hands thoroughly and to put on gloves. (Visitors need only wash their hands thoroughly.) Hospital staff and visitors are not required to wear gowns or masks unless you are in special isolation (in which case a sign will be posted on your door indicating the precautions to be taken).

Most infections that occur during the transplant period are caused by an overgrowth of bacteria that we normally have in our own bodies. The first sign of infection is usually a fever. Most stem cell transplant patients develop a fever at some point during their stay. This is called "spiking a fever". It refers to any fever greater than 100.5°F. When you spike a fever, blood will be drawn from your catheter and vein in your arm. This test can determine if there is an infection in your bloodstream. You may also have a chest x-ray and give sputum samples to determine if there is an infection in your lungs. You will be asked to give a urine sample to test for a urinary tract infection. Finally, you may be asked to give stool samples to test for infection in the digestive tract. Antibiotics will be given to you through your catheter to fight the infection. Your nurses will keep you

informed of your blood counts on a daily basis.

In addition to thorough handwashing by patients, family members, visitors, and health care workers, an important part of our infection control program is an ongoing check for resistant microorganisms (germs). Since the early 1940's, when antibiotics first became available to fight infections, germs have been changing to develop resistance (immunity) to antibiotics. One of the most resistant microorganisms in hospitals today is Enterococcus. Enterococci are bacteria that are found in all normal people and live in the large intestine. Under certain conditions, these Enterococci may develop resistance to many antibiotics. Preventing the spread of resistant Enterococcus is a priority on the transplant unit. Each Tuesday, rectal swabs will be performed on all patients in order to identify the presence of resistant microorganisms. If you are found to harbor resistant microorganisms, you will be put on special gown and glove isolation so that the resistant organism will not be spread to other patients on the transplant unit.

## **YOUR RESPONSIBILITIES**

Just as your nurses and doctors have responsibility in your care, so do you. Some of your responsibilities include:

### **Hygiene**

It is very important that you take a bath or shower daily. It is also important to wash your hands before

and after going to the bathroom. You should clean thoroughly from front to back after each bowel and bladder movement. Since patients often develop diarrhea, you may notice tenderness and redness in your rectal area. It is important to notify your nurse and doctor if this occurs.

### **Mouth Care**

Good oral hygiene is important to help prevent mouth infections. *You will receive special mouthwashes—please use them as directed by your nurse or doctor.* Rinsing with the mouthwashes at least two or three times a day along with brushing your teeth carefully and gently, will further decrease the possibility of developing an infection. *Use a soft, nylon bristle toothbrush* and remember to brush your teeth without causing bleeding of the gums and increasing the risk of infection. *(The nylon bristles on the toothbrush can be made even softer by running the toothbrush under hot water for several minutes prior to applying the toothpaste.) The toothbrush should be new.* Old toothbrushes carry many germs that can cause an infection.

### **Exercise**

While you are in the hospital, it is important that you keep your strength up. Take walks in the corridor with your visitors. It is acceptable to leave your room as long as you have a mask on to protect yourself from infection. (We ask, however, that you not leave the unit.) Exercise also encourages full lung expansion and helps prevent lung infections. You

may also work with a physical therapist to develop a more extensive exercise program.

## **Diversion**

Activities that divert your attention will help you pass the time and focus on other things. Reading, television, hobbies, as well as visits from your friends and family are helpful. There is an expressive arts therapist on the unit who can also help you find ways to pass the time.

## **Nutrition**

During your inpatient stay, it is important that you maintain good nutrition. *Your family can bring cooked food for you, which can be stored in the refrigerator on the unit as long as the container is labeled with your name, date, and room number.*

There is a microwave available on the unit to heat food. The dietician will work closely with you to make sure that you are receiving enough protein and calories.

## **Emotions**

It is normal for you to experience a wide range of emotions during hospitalization. You may be worried about progress, or feel depressed, angry, or frustrated. Many patients feel scared about going home or concerned over the success of the transplant. We can help you sort through these many feelings. Please feel free to share your concerns and issues with us. We are also available

to help your family members with their concerns. Pastoral care and counseling through psychiatry and social work is available as well. There is also an expressive arts therapist who can help you with relaxation techniques.

## **WHAT TO EXPECT WHILE YOU ARE AN INPATIENT**

1. Because patients receiving stem cell transplants are easily dehydrated or overhydrated, we will weigh you twice daily around 6:00 AM and 6:00 PM. We will ask you to keep track of what you eat and drink, and we will measure your urine, stool, and vomit.
2. Your vital signs (temperature, blood pressure, respirations, and pulse) will be checked every four hours. If you are running a fever or have other changes in your vital signs, they may be checked more often.
3. Every morning, a group of doctors and nurses will visit you. There may be other visitors during the day, including social workers, physical therapists, expressive arts therapist, pharmacists, and other doctors who may be consulted on your care to ensure the highest quality care.
4. You will have a continuous intravenous drip for most of your hospitalization. This drip will be connected to a pump and pole, and it will take some time to adjust to always being connected to it.

5. Daily blood work will be drawn between 4 and 6 AM. Additional blood work may be drawn throughout the day if needed.
6. Meals will be delivered to your room at approximately 7:00 AM, 11:15 AM, and 5:45 PM. If you are consistently unable to eat because of mouth sores, nausea or vomiting, an intravenous nutrition called hyperalimentation may be started. We will stop the hyperalimentation when you are able to eat again.
7. The main goal of the nurses and doctors is to make the transplant process as comfortable for you as possible. While some of the rules may seem stringent, they are put into place to protect your health and safety. *Please note, because of the many procedures and treatments that are necessary in your care, there may be disruptions of sleep. While we will do everything possible to keep these disruptions at a minimum, please remember that they are being done in order to provide you with the best care possible.*
8. Your transplant doctor works with a team of doctors within the Division of Immunotherapy. These doctors rotate the care of inpatients. As a result, it is possible that while you are an inpatient, your care may be managed by an associate of your transplant doctor. Although you may not see your transplant doctor while an inpatient, the doctor managing your care will

discuss aspects of your care with your transplant doctor as necessary.

## VISITOR GUIDELINES

Visitors are allowed at the patient's discretion. Children 12 years and older are allowed to visit as long as they are with an adult, and are free of illness. Children under 12 years of age are not encouraged to visit due to the increased infection risk of many of our patients. However, special permission may be granted by the Clinical Nurse Manager or the resource coordinator. One adult is allowed to stay overnight in your room. Please remember it is important to rest, and do not overextend yourself while you are an inpatient.

1. Hospital visiting hours are from 11:00 AM to 8:30 PM seven days a week. Visitors must check in at the main lobby desk in Feinberg and with the 15<sup>th</sup> floor secretary.
2. Visitors must wash their hands when entering and leaving your room.
3. No visitors should use your bathroom. All visitors are required to use the guest bathrooms located on the unit because of infection control guidelines.
4. Discourage people who are not feeling well from visiting you. Because you will be more susceptible to infection, even a mild case of the flu in your visitor could make you very ill.



## CHAPTER 3. REINFUSION OF STEM CELLS

*The day of the reinfusion, better known as the transplant day or day 0, is looked forward to with excitement and sometimes, anxiety. The reinfusion process, however, is very simple and relatively short. Many patients compare the reinfusion of stem cells and/or bone marrow to receiving a blood or platelet transfusion. The day of the reinfusion is thought of as a type of birthday. In follow-up visits with the doctor or nurse, this date will be referred to frequently.*

The stem cells and/or bone marrow previously collected from you or your donor have been frozen in special blood bags since the collection. Depending on the number of bags you have to be reinfused, intravenous fluids may or may not be started prior to the procedure. The amount of bags to be reinfused is not directly proportional to the amount of cells which will be reinfused. Your doctor will determine the appropriate amount of cells to be reinfused.

The staff nurse will administer pre-medications (e.g., Tylenol®, Benadryl®) to you about thirty minutes prior to the actual reinfusion. These pre-medications are given to prevent complications during the reinfusion, such as an allergic reaction, and may make you feel sleepy.

At the time of the reinfusion, an advanced practice nurse (or a specially trained staff nurse) will connect you to a small machine that monitors your blood pressure, heart rate, and oxygen level every 15 minutes. In addition, your temperature and respirations will be checked every 15 minutes. A technologist will bring the collected stem cells and/or bone marrow to your room where they will be thawed.

Once thawed, the stem cells and/or bone marrow will be infused through your intravenous catheter. This is a painless procedure. The entire procedure generally lasts 15-30 minutes, although it could take up to 3 hours depending on the number of bags you have for reinfusion. Your vital signs (temperature, respirations, pulse, blood pressure) will be monitored every 15 minutes during the procedure and for one hour after the completion of the reinfusion.

Some possible side effects of the reinfusion include:

1. Pink- to red-tinged urine for up to 24 hours (this is unlikely if the stem cells and/or bone marrow have gone through a special selection process).
2. Fever
3. Chills
4. Allergic reactions (due to the DMSO used to preserve the stem cells and/or bone marrow after collection). Allergic reactions may include itching, hives, swelling, facial flushing, and shortness of breath. Emergency medications are kept at your bedside and are used immediately if an allergic





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## CHAPTER 4. ENGRAFTMENT AND COMPLICATIONS

*Engraftment is a term used to describe the process after the reinfusion of stem cells by which the new marrow starts working in your body to start producing red blood cells, white blood cells, and platelets start being produced. The initial sign of engraftment is a rising white blood cell count. Usually, the red blood cells and platelets engraft more slowly than the white blood cells. On day 0, (the day of the stem cell reinfusion), we begin to administer growth factor (G-CSF). This helps the bone marrow engraft the new stem cells and start producing blood cells and platelets. The growth factor is generally given until the white blood cell count is normal.*

Signs that the new stem cells are growing (engrafting) are expected approximately 1 to 3 weeks after the stem cell reinfusion. Often the first sign of engraftment is a rising white blood cell count. The red blood cells and platelets take 10 days to 4 weeks to engraft. This process may take longer in some patients, and this does not mean that anything is wrong. It is possible that some patients may even need red blood cell and platelet transfusions after being discharged.

During the time it takes the body to engraft the new marrow, several complications may occur. Some are temporary and relatively minor, but others may be life-threatening. The doctors and nurses on the transplant team will work to prevent as many complications as possible, and will monitor you for complications that can not be prevented.

Most patients experience the uncertainty of waiting for engraftment as stressful. Feeling defenseless and vulnerable are common experiences. Associated with daily monitoring, medical procedures, and treatments

is a feeling of loss of personal control. Coping at this time can be a challenge. Some patients find that working out the details of the day such as the timing of baths, walks, and treatments will help them maintain control and give structure to the period. Other patients say that it helps to talk with others and engage in activities that take your mind off things for a while. It is important for you to let us know how you are feeling so that we can establish a plan that will make this waiting period less stressful.

Most patients experience fatigue as they are recovering. They may find it hard to focus on reading a book, watching television, or having a conversation. Keep in mind that this is common and it is important to have reasonable expectations for yourself. Periods of rest, balanced with light exercise, help recovery and prevent the complications of bed rest. Sit up in the chair and take walks around the unit. Do not lie in bed all day. Inactivity can increase the chance for complications such as infection, appetite loss, and fatigue.

Some patients may experience temporary side effects from the chemotherapy, immune suppressant drugs, and/or radiation therapy administered prior to the reinfusion, or from medications used to prevent or treat the more serious complications of transplant. These side effects vary depending on the type of medications used. They include nausea, diarrhea, high blood pressure, high blood glucose (sugar) levels, and bone pain or flu-like symptoms (most common with growth factor). These side effects usually will end once the medication has been discontinued.

The following is an overview of the more serious complications that may occur:

## **NAUSEA**

Nausea may occur as a result of chemotherapy or radiation therapy. It also can be caused by medications that are used to protect you from more serious complications. The nursing staff, along with the transplant pharmacist, will work closely with you to prepare an anti-nausea regimen. It is important to try to control the nausea early, as it can be more difficult to control if left until the nausea is severe. Taste and appetite may also change. Foods may not taste the same, and this may decrease your desire to eat. Your appetite will return in time. Until then, the staff will work with you to try to find appealing meal choices. If you are unable to take adequate nutrition by mouth, your doctor may order

nutrition through your central venous catheter (hyperalimentation).

## **DIARRHEA**

Diarrhea may occur from chemotherapy, radiation therapy, medications, or infections. If you start having diarrhea, let your nurse or doctor know immediately. They will collect a stool specimen and send it to the laboratory to determine if an infection is causing the diarrhea. If an infection is present, antibiotics will be started. If no infection is present, medications such as Imodium may be given to stop the diarrhea. Diarrhea can be one of the most distressing side effects occurring during the transplant period as it is often frequent and urgent. Although every attempt will be made to lessen the frequency of diarrhea, it is often impossible to stop it completely until the white blood cells engraft.

## **SKIN AND HAIR CHANGES**

Skin changes may show up in several ways. First, your skin may be very dry or flaky. If this occurs, use a fragrance-free, mild lotion such as Eucerin® or Lubriderm® to moisturize your skin. Your skin may also be more sensitive. In some individuals, medications may cause a skin rash. If a rash develops, notify your doctor or nurse immediately.

After bowel movements, you may feel as though you are developing a diaper rash. If this soreness occurs, let your nurse know immediately.

Several special skin care products can be used to treat this.

Mouth changes also may occur as a result of chemotherapy and radiation therapy. You may develop mouth lesions or general mouth and throat soreness. If you develop mouth or throat pain, let your doctor or nurse know. Several medications can be used to help ease this discomfort.

Hair loss will occur with high doses of chemotherapy and radiation therapy. You may notice this hair loss anywhere from 10 days to four weeks after the chemotherapy or radiation therapy has been given. Generally, hair growth begins 3-6 months after transplant.

## **INFECTION**

Patients are at risk for developing infections while their blood counts are low and after the transplant when the counts are higher but their immune system is suppressed. It is very important to monitor for signs and symptoms of infection while you are in the hospital and after discharge from the hospital.

You are at risk for different infections, but the most common ones include:

- Bacterial infections
- Herpes infections, such as cold sores and shingles
- Cytomegalovirus
- Fungal infections
- Pneumocystis carinii, which is a lung infection

Because you are at increased risk for infection, you will be started on medications to help prevent infections while you are in the hospital. Some of these medications will also be continued after you are discharged. You will also have blood drawn daily while in the hospital to monitor your blood counts. Your vital signs will be closely monitored, and the doctors and nurses will perform daily physical assessments to check for any signs or symptoms of infection. It is important that you notify your doctor or nurse immediately if you detect any sign or symptom of any infection.

## **BLEEDING**

Bleeding may occur because platelet production has been greatly reduced by the chemotherapy or radiation therapy. Platelets may engraft within 10 days to 4 weeks, but this is highly variable. Daily blood draws in the hospital will let the stem cell transplant team monitor your platelet count. You will be transfused with platelets, as needed, to prevent or stop bleeding.

It is important to take an active role in monitoring for bleeding by checking for:

- Pink- or red-tinged urine
- Black stools
- Bleeding from your gums or nose
- Vaginal bleeding
- Pink dots on the skin called petechiae
- Bruising

The stem cell transplant team and the staff nurse will assess you daily for any signs of bleeding. To prevent bleeding, only use an electric razor once your platelet count falls below 50,000. Suppositories or medications injected into your muscle will not be given. Mouth care must be performed using a very soft toothbrush and no flossing is permitted once your platelet count falls below 50,000.

## **ORGAN COMPLICATIONS**

### **Liver**

Chemotherapy and radiation therapy can cause complications in the liver. One serious complication results from the deposit of materials into the veins of the liver. This obstructs blood flow out of the liver and is called veno-occlusive disease (VOD). The signs and symptoms of this complication are weight gain, abdominal pain and swelling, and changes in the liver function. This can be monitored by checking blood levels. Other potential liver complications include graft versus host disease (only seen in patients undergoing allogeneic stem cell transplant), hepatitis, inflammation of the liver, and infections. Antibiotics, diuretics to help rid the body of extra fluid, and steroids may be used to help treat these complications.

### **Kidneys**

Chemotherapy, radiation therapy, antibiotics, and drugs used to suppress the immune system can cause kidney problems. Signs and

symptoms of kidney problems include pink or red urine, weight gain, swelling, and decreased urine output. Blood levels can help monitor kidney complications. If symptoms of kidney problems do develop, the staff will carefully check your weight and urine output.

### **Lungs**

Infections, chemotherapy, and radiation therapy can cause changes in the lungs making them inflamed, congested, or fibrous. Signs and symptoms of lung complications include shortness of breath, cough, and fever. Antibiotics, diuretics, and steroids may help in the treatment of lung complications.

### **Heart**

Chemotherapy and infections can cause heart complications that reduce the ability of the heart to pump effectively. If this occurs, fluid may build up in the lungs, and you may notice shortness of breath and swelling in your legs. Depending on the cause, antibiotics, diuretics, and heart medications may be used to treat the heart complications.

## **GRAFT REJECTION/FAILURE**

*Graft rejection* is a term used to describe a complication in allogeneic stem cell transplants in which the body rejects the newly donated marrow. To reduce the risk for graft rejection, a Human Leukocyte Antigen test (HLA) is performed to insure you and your donor are a

compatible match. Despite HLA matching and other precautions, graft rejection may still occur.

*Graft failure* occurs when the new marrow does not begin or continue to produce new cells, including white blood cells, red blood cells, and platelets. This can occur in autologous and allogeneic stem cell transplants. To prevent this complication, a minimum number of stem cells must be collected prior to the transplant in order to proceed. This reduces the risk for graft failure.

Many of our transplant protocols have been designed so that if the transplanted stem cells fail to grow, your own stem cells will eventually grow. The process will just take longer. For those protocols where there is a reasonable concern that the transplanted stem cells may not grow, we have collected extra cells to be given later if the need arises. Finally, if you have undergone an allogeneic stem cell transplant, and the transplanted stem cells fail to grow, we may collect more cells from your donor to be given to you if necessary.

## **OTHER LONG TERM SIDE EFFECTS**

### **Infertility**

Infertility may be temporary or permanent. Sperm banking and egg harvesting are options to consider prior to admission to the hospital for transplant. Many women who undergo transplant develop menstrual irregularities and menopausal

symptoms. Hormone replacement may be an option, and should be discussed with your transplant doctor.

### **Fatigue**

Fatigue may be related to low red blood cell counts, or may be caused by recovering from the transplant experience. Make sure to exercise and give yourself rest periods each day. Studies have shown that mild to moderate exercise can actually decrease fatigue. Eating a balanced diet also decreases fatigue. If fatigue is related to a low red blood cell count, transfusions may be given. You also may be given an injection called Epogen® to help your bone marrow produce red blood cells.

## **SUMMARY**

*If you have any questions or concerns regarding any of the potential complications associated with stem cell transplantation, please do not hesitate to contact your transplant nurse or doctor.*

*If your transplant is a part of a research study, please be sure to read in detail the consent form your doctor and nurse has provided you. This consent form has been written to specifically detail the treatments and procedures you will undergo, as well as the potential risks of the transplant.*



## CHAPTER 5. GRAFT VERSUS HOST DISEASE (GVHD)

Graft versus host disease, or GVHD, is a common complication of an allogeneic hematopoietic stem cell transplant. GVHD is not seen following an autologous hematopoietic stem cell transplant. To understand GVHD, the function of the T-lymphocytes must be described.

T-lymphocytes, commonly called T-cells, are a type of white blood cell that recognize foreign matter in the body. T-cells normally protect the body from bacteria, viruses, and other foreign substances. They can also help distinguish what belongs in a person's body ("self") from what does not belong ("non-self").

On the surface of many human cells is an inherited set of genetic markers called human leukocyte antigens (HLA). Thousands of small proteins are presented on the HLA molecules to your T-cells. Like a fingerprint, no two people have exactly the same HLA and protein markers (except for identical twins). The T-cells use these HLA markers to distinguish "self" from "non-self". If a "non-self" human cell is encountered in the body, the T-cells quickly activate the immune system to destroy it.

Prior to allogeneic hematopoietic stem cell transplantation, extensive testing is done between you and your donor to try to make sure that you match immunologically (that is, that you have the same HLA type). Unless the donor is an identical twin, his or her tissue type (the HLA markers or

genetic fingerprints) will have differences that the transplant team cannot detect. These differences, however, can be detected by you or your donor's T-cells.

If your T-cells identify your donor's stem cells as foreign, or "non-self", they may attack the donated stem cells. This is called *graft rejection*. Your treatment (conditioning) regimen has been designed to disrupt the ability of your T-cells to recognize your donor's stem cells as "non-self" thereby preventing graft rejection.

During a stem cell harvest, T-cells are frequently collected along with the stem cells. These T-cells may be infused during the stem cell reinfusion. If the donor's T-cells identify the HLA markers on your cells as "non-self", they may unleash an attack on your tissues and organs. Because your own immune system is suppressed prior to the transplant, it cannot respond with a counterattack. This condition is called graft versus host disease. The "graft" is the donated cells and you are the "host". To prevent GVHD, you will receive medications before and after the stem cell reinfusion. These medications, which will suppress your immune system, will continue for at least one year following the stem cell transplant.

GVHD is often discussed as though it were one disease. In fact, it is two diseases (acute GVHD and chronic GVHD) and may involve different organs in different people. Acute and



chronic GVHD differ in their symptoms, clinical signs, and time of onset. You may develop one, both, or neither.

GVHD can be a temporary inconvenience or a serious, life-threatening disease. Older individuals undergoing allogeneic hematopoietic stem cell transplantation are more likely to develop GVHD than younger individuals. The incidence and severity of GVHD is also higher for transplant recipients whose stem cell donor is unrelated or is not perfectly matched. GVHD is not a complication of autologous or syngeneic hematopoietic stem cell transplants.

The symptoms of GVHD are numerous and varied. Most individuals who undergo allogeneic hematopoietic stem cell transplantation, with a related HLA-matched donor, only develop a mild to moderate case of GVHD. Although GVHD can be life-threatening or fatal, most individuals survive the disease without long-term, disabling side effects. In the case of leukemia, a mild case of GVHD may also be beneficial as it may indicate that your donor's stem cells are also fighting your leukemia cells. This is called graft vs. leukemia. It has also been proposed that this effect may also help fight autoimmune diseases and is called graft vs. autoimmunity.

## Acute GVHD

Acute GVHD generally occurs within the first 30 to 40 days following the stem cell reinfusion, but can occur up to 100 days or later. It may occur as

early as 7 days after the stem cell reinfusion. Acute GVHD often affects the skin, liver, and the gut. The earliest sign of acute GVHD is usually a skin rash, with or without itching, that first appears on your face, hands, and feet. The rash eventually may spread to other parts of the body and develop into a general redness similar to a sunburn. Blistering skin, similar to a third degree burn, is a symptom of severe GVHD. This is potentially life-threatening. Other early symptoms of acute GVHD are nasal stuffiness, congestion, and conjunctivitis (redness of the eyes). The liver is the second most common organ affected by acute GVHD. Early acute GVHD is first seen by abnormalities in liver function blood tests. As the GVHD worsens, jaundice (yellowing of the skin and eyes) becomes evident. Severe GVHD of the liver may be potentially life-threatening.

The gastrointestinal tract is the third most common organ affected by acute GVHD. Watery and bloody diarrhea, abdominal cramping, nausea/vomiting, heartburn, lack of appetite, and an inability to eat may develop. Watery and bloody diarrhea in large amounts is a symptom of severe GVHD of the gastrointestinal tract. This, too, is potentially life-threatening.

## Chronic GVHD

Chronic GVHD generally occurs after the first 100 days following stem cell reinfusion, although it can occur as early as 50 days after stem cell reinfusion. As many as 50-60% of

individuals who undergo an allogeneic hematopoietic stem cell transplant develop chronic GVHD. Like acute GVHD, older individuals are more likely to develop chronic GVHD than are younger individuals. Seventy to 80 percent of individuals who develop chronic GVHD have had acute GVHD. Chronic GVHD is more common if the donor is unrelated or if the stem cells are not perfectly matched. The risk of chronic GVHD is markedly decreased by depleting the T-cells in the graft.

Most individuals with chronic GVHD experience skin problems that include a dry, itchy rash, change in skin color, and tautness or tightening of the skin. Partial loss of hair or premature graying also may occur. If chronic GVHD of the skin continues to progress, the skin may become stiff, making it very difficult to move the arms and legs in a normal manner. The skin also may breakdown, causing ulcerations and possible infections that may be life threatening.

Chronic GVHD also can attack glands in the body that secrete mucous, saliva, or other lubricants. Individuals with chronic GVHD usually experience dryness or stinging in their eyes because the glands that secrete tears are impaired.

Glands that secrete saliva in the mouth are also frequently affected by chronic GVHD. It is common to experience a burning sensation in the mouth when using toothpaste or eating acidic foods. This dryness also may affect the esophagus, and make it difficult to swallow and eat.

Chronic GVHD may affect the liver. This is usually evidenced by jaundice (yellowing of the skin and eyes) and abnormal liver function blood tests.

Finally, chronic GVHD may affect the gastrointestinal tract. Although this may result in diarrhea, the most common symptoms of chronic GVHD of the gastrointestinal tract are nausea, inability to absorb food, weight loss, and inability to perform normal activities of daily living.

Although GVHD is not always preventable, steps can be taken to markedly reduce its intensity and severity. Your doctor will prescribe medications that will suppress your immune system in order to reduce the incidence and severity of GVHD. These drugs will weaken the ability of your donor's T-cells to launch an attack on your organs and tissues. It is extremely that you can these medications as prescribed by your doctor. If you are unable to take these medications as prescribed, due to an inability to swallow, nausea or vomiting, or inability to tolerate the side effects of the medications, it is extremely important that you let your doctor or nurse know immediately.

## **Treatment of GVHD**

The treatment of GVHD varies depending on the site of the disease, whether it is acute or chronic, and the drugs that you are currently taking to prevent GVHD. In general, most individuals will be treated with immunosuppressive drugs and/or steroids. Complications of GVHD,



<b>SIGNS/SYMPTOMS OF GRAFT VERSUS HOST DISEASE: QUICK REFERENCE GUIDELINES</b>	
<b>Early GVHD</b> Usually occurs before day 100 following stem cell reinfusion – termed “Acute Graft Versus Host Disease”	<b>Late GVHD</b> Usually occurs after day 100 following stem cell reinfusion – termed “Chronic Graft Versus Host Disease”
<b>Skin</b> - Blotchy, raised, reddened skin rash on the palms, soles, ears, and trunk (with or without itching)	<b>Skin</b> - Dry or scaly skin - Reddened rash - Changes in skin color - Skin tightening/hardening - Loss of sweating function - White patchy skin changes - Skin ulcerations - Difficulty moving joints - Nail loss - Thinning hair
<b>Gastrointestinal Tract</b> - Large amounts of green mucous, watery diarrhea - Stomach cramps, pain - Blood in stools - Nausea/vomiting - Lack of appetite - Weight loss	<b>Gastrointestinal Tract</b> - Lack of appetite - Difficulty swallowing liquids or solids - Painful swallowing - Mid chest burning or pain - Weight loss - Nausea/vomiting - Abdominal pain
<b>Liver</b> - Jaundice (yellow skin or eyes) - Dark, coke-colored urine - Light, tan-colored stool	<b>Liver</b> - Jaundice (yellow skin or eyes)
<b>Other Potential Causes of These Symptoms:</b> - Infection - Food intolerance - Medication sensitivity	<b>Eyes</b> - Dry, irritated eyes - Sensitivity to light - Burning sensation - Pain
	<b>Mouth</b> - Dry mouth - Sensitivity to acidic or spicy foods - Pain - Mouth sores
	<b>Lungs</b> - Shortness of breath at rest or during exertion
	<b>Other</b> - Vaginal dryness/painful intercourse - Low platelets - Increased risk of infection

**Any of the above changes may result from other causes. Talking with your doctor or nurse is important to identify the cause and get appropriate treatment.**

## CHAPTER 6. DISCHARGE GUIDELINES

Congratulations! You are preparing to be discharged from the hospital. The following information will help you during this very important and exciting transition. Please read the following material carefully. Before you are discharged, one of the advanced practice nurses will review the material with you and answer any questions you may have.

When your doctor determines that your blood counts have reached a safe level, and you are able to eat enough calories to sustain yourself, you will be discharged from the hospital to the outpatient apartment. (If you live in the Chicagoland area, you will be discharged directly to home.) You will need to have a caregiver as you transition from the hospital, to the outpatient apartment, to home. Once discharged from the hospital, you may need to have red blood cell and platelet transfusions. Your blood levels will be checked regularly at the clinic or at home. These arrangements will be made before you leave the hospital.

The central line catheter that was placed prior to transplant may be left in place upon discharge from the hospital so that you can have your blood drawn and receive blood transfusions or fluid hydration. Each lumen of the catheter will need to be flushed daily with a heparin solution to prevent clogging. This is done with a pre-measured syringe through the cap on the lumen. These caps and the clear plastic dressing must be changed once a week. You or your

caregiver will be taught how to care for the central line catheter prior to discharge from the hospital. The catheter will be removed on an outpatient basis after it is no longer needed for frequent blood draws, blood transfusions, or fluid hydration.

### CLINIC FOLLOW UP

Clinic visits will focus on how you are feeling and will be a time to assess your progress and any side effects from chemotherapy and/or radiation therapy. Bring your medications with you and a list of any questions you may have to each visit.

You will be scheduled to see your transplant doctor and outpatient nurse in clinic the first week after you are discharged from the hospital. Please call (312) 695-6120 to schedule a clinic appointment. The clinic is located in the Galter Pavilion on the 14<sup>th</sup> floor.

When your doctor feels that you have recovered sufficiently from the transplant, arrangements will be made for you to return to your referring doctor for care. You will be required to return to Chicago on a periodic basis for at least the first five years following transplant. Your doctor and outpatient nurse will inform you of when you should make an appointment here in Chicago for follow up visits.

Most patients who live outside the Chicagoland area will need to stay in

an outpatient apartment near the hospital for a minimum of 1-4 weeks after the transplant. If you are having several transplant related problems after discharge from the hospital, your stay in Chicago could last 4-8 weeks. You will need to have a caregiver stay with you during this initial post-transplant phase.

## **IMPORTANT PHONE NUMBERS**

### **Clinic:**

Call (312) 695-1855 anytime Monday – Friday 9:00 AM – 4:00 PM for an appointment.

### **Emergency:**

Call (312) 915-8197 and ask to speak to the doctor on call for the Division of Immunotherapy.

### **Non-Emergency:**

Division of Immunotherapy Office:  
(312) 908-0059 (Leave a message on the voice mail. If it is the weekend, someone will return your call on Monday.)

## **DIVISION OF IMMUNOTHERAPY STAFF**

### **Physicians:**

- Dr. Richard Burt, Chief
- Dr. Robert Craig
- Dr. Yu Oyama

### **Nurses:**

- Mary Brush, RN, MS, AOCN
- Kate Quigely, RN, MBA
- Kim Yaung, RN

### **Secretaries:**

- Kim Bracy
- Arlene Leitner

## **PROBLEMS THAT SHOULD BE REPORTED IMMEDIATELY**

- Temperature over 100.5 F
- Chills, sweating
- Change in the appearance of your central line catheter such as redness, swelling, pain or discharge
- Persistent cough, with or without sputum
- Shortness of breath or chest pain
- First sign of cold, flu, or sore throat
- Persistent nausea, vomiting, or diarrhea
- Frequent urination or burning or itching with urination
- Blood in the urine
- Frequent nose bleeds, blood in the stool, or bleeding that does not stop
- White coating on your tongue, or sores in your mouth or on your lips
- Exposure to chicken pox
- Abnormal discharge from your ears, nose, or vagina
- Sinus pain
- Skin rash
- Yellowing of the skin or the whites of your eyes
- Painful blisters on the skin
- Dizziness
- Inability to take keep fluids or medications down due to nausea or vomiting

**Be prepared to go to the emergency room if instructed to do so. Tell the emergency room staff that you are a stem cell transplant patient.**

## **INFECTION PRECAUTIONS**

Infection is one of the biggest risks that patients face during and after stem cell transplant. The high dose chemotherapy and/or radiation therapy given before the transplant temporarily disable the body's immune system making it more difficult to fight infection. Although your white blood cell count is at a safe level for you to leave the hospital, your immune system, overall, will not function normally for one year or longer.

Upon discharge from the hospital, you will be given medications to prevent infection while your immune system is temporarily disabled. However, certain germs are getting very hard to control and treat. Therefore, we will ask you to institute other measures in an attempt to prevent infection. The following guidelines are designed to help you stay healthy.

### **Antibiotics**

You will be asked to take an anti-viral medication (e.g., acyclovir, cytovene, or valacyclovir) for a period of one year. In addition, you will be asked to take an anti-fungal medication (e.g., fluconazole or voriconazole) for a period of six months. To prevent pneumocystis carinii pneumonia, you

will be asked to take Bactrim every Monday, Wednesday, and Friday for six months. If you are allergic to sulfa drugs, or if your disease is sensitive to sulfa drugs, you may be asked to have a breathing treatment with pentamidine once a month for six months. Your transplant doctor may change these medications or ask you to take them for a longer period of time based on your own particular circumstances.

## **Home Environment**

### ***Cleaning:***

Before you return home, your house must be thoroughly cleansed (dusted, vacuumed, mopped, etc.). Avoid any new construction on your home, or changing the carpeting, immediately prior to undergoing transplant or within the first year following transplant. You should avoid house cleaning activities for at least the first 3 months following transplant and should not be in a room that is being cleaned. Things to remember about keeping the home clean:

- Clean your home (e.g., dust, vacuum, mop) at least once a week. The bathroom and eating areas may need to be cleaned more often.
- Extreme cleaning measures are not necessary – just perform routine cleaning activities.
- Keep dust to a minimum. Use a damp cloth when dusting. Do not use a feather duster as it will stir up dust and disburse it into the air.

- Avoid intense and prolonged exposure to any chemical sprays and fumes.

**Pets:**

Animals can be carriers of bacteria that could potentially lead to infections. If you have had a pet for an extended period of time, this risk should be lessened. However, it is recommended that you do not introduce any new pets into your home for at least one year after stem cell transplant or for as long as you are on immunosuppressant drugs (e.g., prednisone or other drugs used to prevent graft versus host disease). Do not handle excretions of animals for up to one year post-transplant (e.g., litter boxes). Remember to always wash your hands after petting any animals.

**Plants:**

Plants can carry harmful bacteria and fungi. Established houseplants and flowers are allowed. You can water your plants, but you should not have direct contact with the soil. Avoid contact with outside plants (e.g., gardening, lawn mowing) for at least 3 months or for as long as you are on immunosuppression.

**Visitors:**

While you have been in the hospital, friends and family have been anxiously awaiting your arrival home. Although they may mean well, too many and too frequent visitors can be physically and psychologically exhausting. Have a close relative restrict the number of people who

visit you until you are feeling stronger. No more than 2 or 3 people outside of your immediate family should be visiting you each day for the first few weeks. It may be helpful to prepare for visitors by taking a nap before they arrive and resting after they leave. Remember, your visitors must be healthy in order to avoid passing an infection on to you. If your visitor has any signs or symptoms of infection, or if someone that they have been in recent close contact with has an infection, they should not visit you.

**Handwashing**

The best way to decrease exposure to possible sources of infection is HANDWASHING! You and everyone who comes in contact with you should wash hands carefully to avoid the transmission of bacteria and viruses from hand to mouth, hand to nose, or hand to eye. Handwashing should include plenty of soap and warm water and you should scrub for at least 15 seconds. Then rinse your hands well and dry thoroughly. Turn off the water using a towel. NOTE: It is not necessary to use antibacterial soap.

Who should wash their hands?

Yourself, your caregivers, family members, friends, nurses, doctors .... everyone!

When should hands be washed?

- Prior to any contact with you
- Prior to medication preparation
- Prior to food preparation
- Prior to central line care
- Before and after eating



- After petting the dog, cat, etc
- After using the bathroom
- After touching anything that may carry germs

## Activities With High Risk For Infection

There are some activities and exposures that carry a higher risk for a person who has just undergone a stem cell transplant and is immunocompromised. For instance, there is a higher risk of infection from contact with human or animal feces. *Aspergillus* fungi, a fungus that can cause pneumonia, is present in the soil and can cause a very serious and life-threatening infection in the immunocompromised person. Therefore, contact with soil, lawn waste, and compost is very risky and should be avoided. Even exposure to construction sites, including homes and buildings that are being destroyed or remodeled, is very risky as these sites can contain many germs that can cause infection.

To prevent infection, the following activities should be avoided:

- Touching human or animal feces such as:
  - Changing a baby's diaper
  - Touching bird droppings
  - Cleaning a fish tank
  - Emptying and cleaning litter boxes. Cleaning up after pets
  - Allowing pets to lick you
- Contact with soil, lawn waste, compost, grass, or logs such as:
  - Gardening
  - Turning or spreading compost
  - Sitting directly on grass or dirt

- Repotting plants or working with soil
- Pruning plants
- Mowing the lawn
- Raking leaves

- Exposure to large crowds within enclosed areas such as:
  - Restaurants
  - Church or Temple
  - Food, clothing, and other stores
  - Public transportation
- Exposure to potentially serious infections such as:
  - Respiratory syncytial virus
  - Influenza
  - Tuberculosis
  - Chicken pox
  - Shingles
  - Parvovirus
  - Meningitis

If you should come in contact with any of the above, wash your hands immediately. If it is absolutely necessary to change a baby's diaper, wear gloves and then wash your hands immediately after disposing of the gloves. If you are going to the park, take a blanket or mat to place on the grass for protection. If friends or family members send silk flower arrangements, ask them to omit the moss at the bottom. If it is necessary to go into enclosed areas such as a food store, wear a mask or shop when there will be fewer people in the store.

Finally, if you must use public transportation, such as an airplane or train, the use of a respirator mask is recommended until your immune system has returned to normal.

## Temperature

In the first 2-3 weeks following transplant, take your temperature twice a day, once in the morning and once in the evening. In addition, take your temperature whenever you are feeling ill or suspect a fever. ***If your temperature is greater than 38.3 C or 100.5 F, call the transplant team immediately.***

## Swimming

Swimming may expose you to microorganisms capable of causing infections. Therefore, you should avoid swimming in lakes, rivers, swimming pools, or hot tubs, public or private, for the first six months following transplant or for as long as you are on immunosuppressive medications. You should never swim while you have a central line catheter in place.

## Personal Hygiene

Your skin is your first line of defense against infections, therefore, it is very important that you take good care of it. Guidelines to follow include:

- Shower or bathe daily to reduce the amount of bacteria on your skin. Use soap and warm water and rinse thoroughly. Use a mild soap so that your skin does not become dry.
- Use your own towel for drying and dry yourself thoroughly. Change the towel daily.
- Pay special attention to skin folds and genital and rectal areas.

- Apply a moisturizing lotion to your skin after the shower or bath and as needed throughout the day for dry skin. Use perfume-free, mild lotions such as Eucerin® or Lubriderm®.
- Shampoo your head/hair once a day. Use a cream rinse or conditioner after shampooing to moisturize your hair and scalp.
- Change clothing once a day. Wear nonrestrictive, comfortable clothing and wear good-fitting shoes.
- DO NOT self-treat for vaginal infections or discharge. DO NOT douche unless it is prescribed by your doctor.

## Illness In The Family

Avoid exposure to persons who are sick, or who have been around others who have been sick. Be especially careful around school-aged children since they are often exposed to other children who are ill. If someone in your immediate family is sick, avoid close contact. Stay in another room or, if possible, go to stay at another family member's or friends home until your family member is no longer sick.

Avoid contact with babies and children who have been recently vaccinated with the live-virus oral polio vaccine for at least 8 weeks. They can shed the virus in body excretions (saliva, stool) and infect you. If a child living with you needs a polio vaccination, they should be given the inactivated polio vaccine by injection.

## BLEEDING PRECAUTIONS

Although your platelet count is high enough for you to be discharged from the hospital, you may still require platelet transfusions or continue to be at risk for bleeding problems.

The following precautions are suggested to help prevent bleeding. As your platelet count gradually reaches normal levels (150,000 – 300,000), your doctor or nurse will discuss which precautions are still important.

- Do not take over the counter medications without consulting your doctor or nurse. Certain medications may increase your risk of bleeding. Do not take aspirin, ibuprofen, amproxin (Aleve®), Alka-Seltzer®, or cold remedies containing these drugs.
- Take blood pressure medications as ordered. High blood pressure can trigger bleeding.
- Do not engage in sexual intercourse or until your platelet count is above 50,000. If women have any breakthrough vaginal bleeding within the previous two weeks, they should not engage in sexual intercourse.
- No anal sex until platelets are stable.
- Use an electric razor rather than a straight edge razor for shaving.
- Do not blow your nose hard or scratch the inside of your nose.
- Use a soft bristle toothbrush.
- **Use caution to avoid falls.**

Avoid contact sports or strenuous exercises that might result in injury.

- Do not use rectal thermometers, suppositories, enemas, or tampons.
- Do not use motor vehicles that have a high risk for injury such as snowmobiles, waterjets, or motorcycles.

### If bleeding starts:

- Apply pressure to the bleeding site. For example, if you have a nosebleed, pinch or put pressure over the bridge of the nose for 10 minutes. Or wrap ice in a soft cloth and press it firmly against the nostrils.
- If you cut yourself, wash the area with cold water and put pressure over the site for 10 minutes before checking to see if the bleeding has stopped.
- Stay calm!

### Call the transplant team within 24 hours if any of the following develop:

- You bruise easily or have blood blisters
- You notice small, red spots under the skin (called petechiae)
- You bleed from your gums or nose

### Call the transplant team immediately if any of the following develop:

- You see blood in your stool, urine, vomit, or eyes
- You fall or hit yourself and begin to develop swelling in the injured area

- You fall and hit your head
- You have a nosebleed or other site of bleeding that does not stop after 30 minutes of pressure

## PHYSICAL ACTIVITY

Throughout your stay in the hospital, you have been encouraged to exercise and stay active. Although you may feel strong when you are discharged, you may notice that you tire easily at home. You will need to build your strength and endurance slowly. The following suggestions will guide you in returning to your normal, active life.

### Fatigue

Fatigue is a common complaint of individuals with chronic illnesses. While in the hospital, the fatigue may seem to lessen. However, once you return home, it is not uncommon to feel increasingly tired, perhaps even more so than prior to your transplant. Some patients may even begin to feel that the transplant was unsuccessful because of the amount of fatigue that they are experiencing. It is important for you to know that fatigue following stem cell transplant is very common and can last 3-6 months following the transplant. There are a number of possible causes for the fatigue: the intensive treatments, medications, a lower than normal number of circulating red blood cells, disruption of normal resting and sleep habits, or feeling depressed. As your body adjusts to increasing activity levels, you will find that you gradually have

more energy. Steps you can take include:

- Set up a regular daily schedule for nap and sleep times.
- Keep active during the day so that you will sleep better at night.
- Play soft music, put on the TV as background sound, engage in meditation or prayer, or ask a family member for a back rub to help you sleep or rest.
- Rest between bathing, treatments, exercise, and other activities.
- Space your activities – do not try to do everything at once.
- Do not overdo it. Be realistic. Decide on the most important activities for the day.
- Get regular exercise.
- Eat snacks between meals to keep up energy.

Call the transplant team if you feel your fatigue is getting worse or if you find yourself staying in bed all day.

### Exercise

Exercise is an important part of your recovery following stem cell transplant. Regular exercise is important to improve your strength. Walking and cycling are excellent ways to slowly improve your strength and energy level. Choose slow-paced, easily controllable exercises that will not exert unnecessary stress on your body. Avoid contact sports, or strenuous exercises, until your platelet count is greater than 100,000 without transfusions. Remember, do not overdo it. Too much exercise on one day may leave you too fatigued to do much of anything for days to

come. Slowly build up the amount of exercise you do each day.

## **Driving A Motor Vehicle**

Since some medications may cause drowsiness or affect concentration and reflexes, check with your doctor before driving any motor vehicle.

## **Work/School**

If you are interested in returning to work or school, first check with your doctor. Many people who return to work do so on a part-time basis initially.

It is not unusual to be unable to return to work/school for a period of 3 months or longer following stem cell transplant. Your doctor will make recommendations based on the type of transplant you received, your profession, and your medical needs. Please contact the transplant team if you need a letter or telephone call to your employer or teacher.

## **SUN EXPOSURE**

Following chemotherapy and/or radiation therapy, your skin will be very sensitive to the sun. Certain medications can increase this sensitivity. If you have had an allogeneic hematopoietic stem cell transplant, sun exposure can trigger graft versus host disease. When outside, please follow these instructions:

- Limit your exposure to sunlight.
- Always wear protective clothing.

- Use a sunscreen with a skin protective factor (SPF) of 30 or higher.
- Notify your doctor if you have a severe reaction from the sun.

## **NAILS AND HAIR**

Chemotherapy and radiation therapy can cause changes in the appearance and texture of your nails and hair. If this happens, healthy nails will regrow as your body recovers. The regrowth of hair may occur three to six months after transplant. The new hair may be a different texture and color from your previous hair. Although it is most common to lose hair on your head, you may lose hair anywhere on your body (e.g., face, arms, legs, pubic area).

## **NUTRITION**

Good nutrition plays an important role in helping you recover from the intensive chemotherapy and/or radiation therapy you have received. A sound diet also will help you to feel better, quicker! Unfortunately, your appetite may not have returned by the time you leave the hospital, so you may have to try harder to get the calories you need. If you are having difficulty eating a normal amount of food, or if you have lost a significant amount of weight while in the hospital, here are some guidelines to help improve your nutritional status:

- Eat small snacks and five or six small meals daily instead of three large meals.
- Eat high-calorie, high-protein snacks such as milk shakes, cheese and crackers, nuts, high-calorie supplements, etc.. Melt cheese on sandwiches, meats, fish, vegetables and desserts or add it to casseroles, vegetables, potatoes, breads, or sauces.
- Blend whole milk and skim milk powder together. Use this high protein milk as a beverage and as a cooking substitute for water.
- Add powdered milk to casseroles, meat loaf, breads, soups, puddings, cakes, cookies, and milkshakes.
- Spread cream cheese on fruits, crackers, or sandwiches; roll cream cheese into balls and coat them with nuts, granola, or wheat germ.
- Add small pieces of meat to soups, salads, biscuits, souffles, omelets, quiches, or stuffed baked potatoes.
- Spread peanut butter on toast, sandwiches, crackers, fruit slices; use it as a dip for raw vegetables or blend it with milk drinks.
- Drink high protein, high calorie supplements (2 to 3 eight ounce servings per day).
- Use margarine, mayonnaise, oil, sour cream, salad dressings, and gravies whenever possible.
- Add ice cream to desserts (cakes, pies) or try custards and puddings.
- Drink eight large glasses of fluid daily. Try to include fluids with calories (instant breakfast, sports drinks, etc.) and avoid excessive

amounts of caffeine (e.g., colas, coffee, tea).

- Avoid alcoholic beverages. They can have some unpleasant interactions with your medications.

Inform your transplant team if you find you are unable to eat and drink adequately. Weigh yourself once a week and let the transplant team know if you have a weight loss of five pounds or more.

## Food Safety Guidelines

- Always wash your hands before, during, and after preparing food.
- Wash your hand before eating.
- Keep foods at safe temperatures: hot food above 140° F and cold food below 40° F.
- Cook meat until well done. Red meat should reach an internal temperature of 165° F and poultry to 180° F. There should be no pink coloration. The juices should run clear.
- Do not eat raw meats, fish, or sushi.
- Thaw meat, fish, or poultry in the refrigerator or microwave. Place on a dish to catch drips. Cook defrosted meat right away; do not refreeze.
- Never leave perishable food out of the refrigerator longer than two hours. Egg dishes, meat, fish, poultry, cream- and mayonnaise-based foods should not be left unrefrigerated for more than one hour.
- Never use raw eggs, non-pasteurized, homemade Caesar salad dressing or mayonnaise.

- Wash fruits and vegetables thoroughly under running water before peeling and cutting.
- Do not eat food from salad bars.
- Wash tops of canned foods before opening. Clean the can opener before and after use.
- During food preparation, do not taste the food with the same utensil used for stirring.
- Cook egg until whites are completely hard and the yolks begin to thicken. The yolk should no longer be runny but need not be hard.
- Do not buy meats or cheeses at the delicatessen. Packaged deli meats and cheeses are OK.
- Avoid unpasteurized dairy products and dairy products that contain molds (e.g., blue cheese).
- NEVER TASTE FOOD THAT LOOKS OR SMELLS STRANGE!

### **Microwave Cooking**

- Microwave cooking can leave cold spots in food where bacteria can survive. Rotate the dish a quarter turn once or twice during cooking if there is no turntable in the appliance.
- When heating leftovers in the microwave, use a lid or vented plastic wrap to cover them. Stir several times during reheating.

### **Grocery Shopping**

- Look at the "sell by" and "use by" dates on the product. Select only the freshest products.
- Do not buy damaged, swollen, rusted, or deeply dented cans.

Check that packaged and boxed foods are properly sealed.

- Buy fruits and vegetables that look fresh. Do not select blemished fruits or vegetables.
- Do not buy or use any foods with mold present.
- Do not eat foods from delicatessens, including prepared salads and sliced meats and cheeses.
- Avoid unrefrigerated cream- and custard-containing desserts and pastries.
- Do not eat foods from self-serve bulk containers or bins.
- Do not eat yogurt and ice cream products dispensed from soft-serve machines.
- Do not taste free food samples.
- Do not buy or use cracked, unrefrigerated eggs.
- Select frozen and refrigerated foods last.
- Never leave perishable food in the car. Refrigerate or freeze them promptly.
- Shop early in the morning or late in the evening to avoid crowds.

### **Dining Out**

- Avoid eating out in the first 2-3 months following transplant.
- Check the general condition of the restaurant. Are the plates, glasses, and utensils clean? Are the restrooms clean and stocked with soap and paper towels? How clean the restaurant looks may tell you the amount of care that is taken while preparing the food. If the restaurant appears dirty in any way, do not eat there.
- Eat early to avoid crowds.

- Ask that food be prepared fresh in fast food restaurants. Ask if fruit juices are pasteurized.
- Do not eat raw fruits and vegetables when dining out.
- Ask for single serving condiment packages. Do not use public self-serve condiment containers.
- Do not eat at high-risk food sources: buffets, potlucks, salad bars, delicatessens, sidewalk vendors, or smorgasbords.

**See pages 47-49 for examples of foods and beverages you may eat and those you should avoid.**

## **EMOTIONAL CONCERNS**

Congratulations! You have met and conquered the challenges of the first phase of the stem cell transplant. As you prepare to resume your daily activities, or begin new activities, we have a few recommendations that might be helpful.

### **Feeling Blue**

While you may experience feelings of having accomplished something great (and you have), it is not unusual or uncommon to also experience a "let down". Your stay in the hospital may have been characterized by a great deal of structure with schedules, tests, and the involvement of numerous health care providers. Now that you're home, you won't be surrounded with the same amount of structure. In addition, you may not feel quite up to par or your "normal self" immediately after transplant. If you were transplanted for an

autoimmune disease, you may even need to continue taking some of the medications that you took prior to the transplant (e.g., steroids, high blood pressure medications, etc.) until the disease completely goes into remission, which could take a few months following transplant. Not feeling well immediately after transplant, or having to continue medications for your disease that you had hoped would be discontinued, may lead to feelings of depression. It will become important for you to remember that recovery following transplant takes time. Be patient as you resume your lifestyle and activities.

Symptoms of depression can include feelings of helplessness, despair, and sadness. In addition, depression may result in loss of appetite, changes in sleep patterns, lack of energy, and inability to focus. If you experience any of these symptoms, you may find it helpful to talk to a close relative or friend, or even a former patient. If your feelings persist, contact your transplant doctor or nurse. Contact your doctor or nurse as soon as possible if you experience any of the following:

- Feeling sad most of the time for several days.
- Feelings interfere with your ability to care for yourself.
- You have thoughts about hurting yourself.
- You have mood swings that you cannot control.

Allow yourself time and patience in resuming old roles and relationships. Because of the intensity of this



experience, your expectations and perspective may be altered. Relationships may be affected with your family as well as your community at large. Again, allow time and patience to prevail. Guidance from or discussion with your clergy, support group, or members of the medical team might be appropriate at this time.

## Memory and Concentration

Changes in memory and concentration are common during the early phases of transplant and after transplant. These changes are almost always medically related. In most cases, they will be temporary and will decrease as you continue to get better.

Memory and concentration problems may vary day by day due to stress, pain, medications, and fatigue. Some suggestions on how to cope with temporary changes in memory and concentration include:

- Write down important information. Keep these notes on a notepad that is small enough to keep with you at all times.
- Ask people to repeat things.
- Keep a list of questions for your doctor. Write the answers down.
- Tape record important conversations or conferences.
- Get important information in writing. Ask people to write it down for you.
- Place notes around the house to remind you of things.
- Keep an appointment calendar.

- Use a device to remind you to take your medications such as a watch that can be programmed to go off at times when medications need to be taken.
- Keep things in a designated place, for example: always keep your keys in the same place.
- Be understanding with yourself and know that these temporary changes are to be expected.

## Sleep Patterns

Sleep patterns may be affected. You may experience a persistent fatigue or conversely, may find that your normal sleep pattern is disrupted. Don't be alarmed if this happens. Continue to take care of your needs and take a nap during the day if you feel tired. If your normal sleep pattern does not return, talk with your doctor or nurse.

## Survivor Syndrome

Some patients have guilt feelings because they are alive when others did not survive. Frequently, discussion with a minister, priest, or rabbi can help put this in perspective.

## Looking Ahead

Some patients, especially those who have a stormy transplant course, find it hard to plan for the future. Alternatively, some patients who have been chronically ill for a long time do not know what it means to live a "normal" life. Give yourself time, but try not to be afraid to re-evaluate what you want to do for the rest of your life.

**Delay routine checkups for 9-12 months post-transplant.**

## **Helpful Hints To Remember:**

- You are your own best friend. Take care of yourself. Get enough rest, exercise, and good nutrition. Be patient with yourself and with others.
- Try to take one day at a time, particularly after you first return home.
- Don't be afraid to ask for professional guidance. You deserve it! Almost everyone receives some kind of help.

## **DENTAL HYGIENE**

It is important to maintain good dental hygiene following transplant in order to avoid infection. Recommendations include:

- Brush your teeth twice a day with a soft bristle toothbrush.
- Floss once a day as long as it is comfortable and bleeding does not occur.
- Avoid using mouthwashes that contain alcohol as these can dry and irritate your gums and the tissue in your mouth.
- Continued use of saline rinses can help if your mouth is dry, if you have excessive mucous, or if you are being treated for oral fungus. Use  $\frac{3}{4}$  teaspoon table salt with 1 quart of warm water.
- See your dentist at least twice a year for routine cleanings. Be sure to tell your dentist that you had a stem cell transplant and what medications you are taking. **Note:**

Notify your transplant doctor or nurse for any change such as ulcers, stinging, burning, dryness, pain, white coating on the tongue, difficulty eating, or loose teeth.

## **VISION**

It is not uncommon for patients to have vision changes during and after transplant. You may have difficulty reading or seeing the television clearly. These changes are most commonly due to the medications that you receive during and after the transplant. It is expected that your vision will return to normal in the months following transplant. If you continue to have vision problems, notify your transplant doctor or nurse. Notify your transplant doctor or nurse within 24 hours if you experience the following:

- "Gritty" feeling
- Discharge
- New changes in vision
- Continual redness

20% of patients who receive irradiation during transplant will develop cataracts. They form 1 to 5 years after transplantation. Cataracts can be removed surgically and lenses replaced.

## **SEXUALITY**

After a stem cell transplant, you may need some time to recover physically and emotionally. Regaining a sense

of closeness is an important part of any intimate relationship, and this is especially true after a lengthy hospitalization.

As your strength returns, resuming sexual activity is healthy and normal. Plan quiet evenings with your partner to relax and ease the transition back to your normal life. Sexual desire is affected by physical strength and energy level and may improve after a nap or a good night's sleep. Use common sense, be gentle with yourself, and make sure your partner is gentle with you. The best way to re-establish intimacy with your partner is to maintain open communication and give yourselves time.

Platelet counts must be above 50,000 to resume intercourse. Your doctor and nurse are available to answer any questions or concerns you may have.

The following health practice guidelines are for everyone, including the transplant patient:

- Keep self and partner clean.
- Use a water-soluble lubricant to decrease friction irritation during sexual activity.
- Married or committed couples who are mutually monogamous do not need to use condoms. Condoms are recommended in situations where couples are not mutually monogamous. If the partner has or is suspected to have a sexually transmitted disease, a condom is not a sufficient barrier. That means no sexual activity is best at this time. Examples of sexually transmitted diseases are:

- Chlamydia
- Human Immunodeficiency Virus (HIV)
- Human Papilloma Virus (HPV)
- Trichomonas
- Syphilis
- Gonorrhea
- Hepatitis B Herpes Simplex Virus (HSV)
- Yeast (vaginal)

- Oral genital sex is okay if oral hygiene is good and there are no oral lesions or genital lesions (sores).
- No anal sex until your platelets are above 100,000 and/or until you are off all immune suppressant drugs.
- No anal sex if you have anal fissures, hemorrhoids, bleeding, diarrhea, or lesions.
- Urinate after intercourse to avoid urinary tract infections.
- Drugs for impotence should not be used without a cardiac evaluation and should be avoided while on immunosuppression.

Notify your doctor if any of the following occur:

- New development of pain during intercourse.
- Vaginal discharge and/or persistent bleeding.

## **Fertility/Contraception**

The effects of chemotherapy and radiation therapy will cause temporary or permanent sterility in men and women. It still may be possible, however, to become

pregnant. Therefore, it is important to use birth control since some anticancer drugs may cause birth defects.

Following a transplant, women should not use an IUD, diaphragm, or a sponge for birth control. Depending on your WBC and platelet count, these methods may cause infection and/or bleeding. Discuss alternative methods, such as birth control pills or condoms with spermicidal foam, with your doctor. Women treated for breast cancer should consult their doctor before taking birth control pills. Pregnancy is not recommended for at least 3 to 5 years after a stem cell transplant. If a man has stored his sperm before treatment, artificial insemination may be possible. Please discuss any plans for pregnancy with your doctor.

## **Early Menopause**

Chemotherapy also can cause hormone changes and some women may experience symptoms of early menopause. "Hot flashes", vaginal dryness, interrupted menstrual periods all may occur. Discuss these symptoms with your doctor since hormone replacement therapy may be a treatment. A water-soluble lubricant such as K-Y jelly may be helpful in decreasing vaginal dryness.

## **SECONDARY MALIGNANCIES**

There is an increased risk of cancer (secondary malignancy) following stem cell transplantation due to the chemotherapy, immune suppression,

and/or radiation therapy. This increased risk has been seen in patients who were transplanted for a malignancy (individuals who may already have a genetic susceptibility to malignancy). The hematopoietic stem cell transplants for autoimmune diseases have been designed to minimize this risk, although the possibility of a future malignancy still exists. Therefore, it is recommended that a yearly cancer screening evaluation be performed and should include:

- Complete physical examination, including a thorough skin and oral examination
- Prostate/gynecological exam
- Breast examination
- Mammography
- Colon cancer screening
- Prostate cancer screening

Avoid activities that may increase the risk of cancer such as smoking, significant alcohol intake (no alcohol if you are still on immune suppressant drugs), or prolonged sun exposure.

## **IMMUNIZATIONS**

Your response to immunizations varies depending on the ability of your immune system. During the first year after transplant, you should avoid immunizations. Please check with your doctor before you or anyone in your family receives immunizations. General precautions to be aware of include:

- ***Live virus vaccines should be avoided unless recommended by your transplant physician.***

After the first year post-transplant, you may receive killed-virus immunizations (e.g., tetanus). Antibody titers can be done on your blood to determine whether or not a booster is needed. ***Consult your transplant doctor before receiving any vaccine, including flu shots.***

- If polio vaccine needs to be given to household members within the first year after transplant (or longer if you are on immune suppressants), the inactivated vaccine should be administered. Close contact between those receiving oral live vaccine and the transplanted patient should be avoided for 8 weeks after vaccination, since live virus shedding can occur in the feces.
- If a household member receives Varicella (chickenpox) vaccine, and then develops lesions (or pox), the person with the lesions will need to be isolated while the lesions are present. Isolation does not need to be used for family members given MMR (measles, mumps, and rubella) vaccination.

One year following your hematopoietic stem cell transplant, your transplant doctor will draw blood to determine your immunity to the common childhood illnesses (e.g., mumps, rubella, measles, tetanus). If it is determined that your immunity to these diseases is low, then you may be re-immunized. In addition, your transplant doctor may recommend

that you be immunized against adult diseases such as hepatitis and influenza.

## **MEDICATIONS**

All medications have potential side effects and drug interactions with other medications. Consult your doctor before starting any new medication (including over-the-counter medications or herbal/nutritional supplements).

## **HOW WILL I KNOW IF THE TRANSPLANT WORKED?**

In the months and years following your transplant, we will continue to monitor you and repeat tests to check the status of your disease. It is not uncommon for it to take a few months after transplant for your tests to return to normal. This is to be expected. For some patient's (e.g., patient's with lupus), it may even be necessary to continue on some of the same drugs (e.g., prednisone) that you were taking prior to the transplant. Again, this is normal and does not indicate the transplant did not work. We will always inform you of your test results and examinations in a timely fashion. If you ever have questions or concerns as to whether the transplant worked, or whether your disease has returned, please call your doctor or nurse.

## NUTRITION GUIDELINES

FOOD GROUP	MAY EAT	DO NOT EAT
<b>Dairy</b>	<ul style="list-style-type: none"> <li>• All <u>pasteurized</u> grade "A" milk and milk products</li> <li>• Commercially-packaged cheese and cheese products made with pasteurized milk (e.g., mild and medium cheddar, mazzarella, parmesan, Swiss, etc)</li> <li>• <u>Pasteurized</u> yogurt</li> <li>• Dry, refrigerated, and frozen <u>pasteurized</u> whipped topping</li> <li>• Ice cream, frozen yogurt, sherbet, ice cream bars, homemade milkshakes</li> <li>• Commercial nutritional supplements and baby formulas, liquid and powdered</li> <li>• Commercial eggnog</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Unpasteurized</u> milk, cheese, yogurt, and other milk products</li> <li>• Cheeses from delicatessens</li> <li>• Cheeses containing chili peppers or other uncooked vegetables</li> <li>• Cheeses with molds (e.g., blue, Stilton, Roquefort, gorgonzola)</li> <li>• Sharp cheddar, brie, feta cheese, camembert, farmer's cheese</li> </ul>
<b>Meat and Meat Substitutes</b>	<ul style="list-style-type: none"> <li>• All <u>well cooked or canned meats</u> (beef, pork, lamb, fish, poultry, shellfish, game, ham, bacon, sausage, hot dogs)</li> <li>• <u>Well cooked</u> eggs (white cooked firm with thickened yolk is acceptable)</li> <li>• <u>Well cooked, pasteurized</u> egg substitutes (e.g., Egg Beaters®)</li> <li>• <u>Commercially packaged</u> salami, bologna, and other luncheon meats</li> <li>• Canned and commercially packaged <u>hard smoked</u> fish; refrigerated after opening</li> <li>• Cooked tofu</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Raw or undercooked</u> meat, poultry, fish, game, or tofu</li> <li>• <u>Raw or undercooked</u> egg and egg substitutes</li> <li>• Meat and cold cuts from delicatessans</li> <li>• Hard cured salami in natural wrap</li> <li>• Cold smoked salmon (fish) or lox</li> <li>• Pickled fish</li> <li>• Tempe (tempeh) products</li> </ul>
<b>Entrees, Soups</b>	<ul style="list-style-type: none"> <li>• All cooked entrees and soups</li> </ul>	<ul style="list-style-type: none"> <li>• All miso products (e.g., miso soup)</li> </ul>

FOOD GROUP	MAY EAT	DO NOT EAT
<b>Fruits and Nuts</b>	<ul style="list-style-type: none"> <li>• Canned and frozen fruit and fruit and <u>pasteurized</u> juices</li> <li>• <u>Well washed</u> raw fruit or foods containing well washed raw fruits</li> <li>• Dried fruits</li> <li>• Canned or bottled roasted nuts</li> <li>• Nuts in baked products or shelled roasted nuts</li> <li>• <u>Commercially packaged</u> peanut butter</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Unwashed</u> raw fruits</li> <li>• Unroasted raw nuts</li> <li>• Roasted nuts in the shell</li> <li>• <u>Unpasteurized</u> fruit and vegetable juices</li> </ul>
<b>Vegetables</b>	<ul style="list-style-type: none"> <li>• All cooked frozen, canned, or fresh vegetables and potatoes</li> <li>• <u>Well washed</u> raw vegetables</li> <li>• Fresh, <u>well washed</u> herbs and dried herbs and spices (added to raw or cooked foods)</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Unwashed</u> raw vegetables or herbs</li> <li>• All raw vegetable sprouts (alfalfa, radish, broccoli, mung bean, etc.)</li> <li>• Salads from delicatessans</li> <li>• Commercial salsas stored in refrigerated case</li> </ul>
<b>Bread, Grain, and Cereal Products</b>	<ul style="list-style-type: none"> <li>• All breads, bagels, rolls, muffins, pancakes, sweet rolls, waffles, French toast</li> <li>• Potato chips, corn chips, tortilla chips, pretzels, popcorn</li> <li>• Cooked pasta, rice, and other grains</li> <li>• All cereals, cooked and ready-to-eat</li> </ul> <p>*Patients themselves should not make (mix or knead) any bread product containing yeast.</p>	<ul style="list-style-type: none"> <li>• Raw grain products</li> </ul>

<b>Beverages</b>	<ul style="list-style-type: none"> <li>• Tap water and ice made from tap water</li> <li>• <u>Commercially bottled</u> distilled, spring, and natural waters</li> <li>• All canned, bottled, powdered beverages</li> <li>• Instant and brewed coffee or tea; cold brewed tea made with boiling water</li> <li>• Brewed herbal teas using commercially packaged tea bags</li> </ul>	<ul style="list-style-type: none"> <li>• Well water (unless tested yearly and found to be free of coliforms)</li> <li>• Cold-brewed tea made with warm or cold water</li> <li>• <u>Unpasteurized</u> fruit and vegetable juices</li> <li>• Maté tea</li> </ul>
<b>Beverages Continued</b>	<ul style="list-style-type: none"> <li>• Commercial nutritional supplements, liquid and powdered</li> </ul>	
<b>Desserts</b>	<ul style="list-style-type: none"> <li>• Refrigerated commercial and homemade cakes, pies, pastries, and pudding</li> <li>• Refrigerated, cream-filled pastries</li> <li>• Homemade and commercial cookies</li> <li>• Shelf-stable cream-filled cupcakes (e.g., Twinkies®, Ding Dongs®), fruit pies (e.g., Poptarts®, Hostess® fruit pies), and canned pudding</li> <li>• Ices and popsicle-like products</li> </ul>	<ul style="list-style-type: none"> <li>• <u>Unrefrigerated, cream-filled</u> pastry products (not shelf-stable)</li> </ul> <p>*Shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature; container may require refrigeration after opening.</p>
<b>Fats</b>	<ul style="list-style-type: none"> <li>• Oil or shortening</li> <li>• Refrigerated lard, margarine, or butter</li> <li>• Commercial, shelf-stable mayonnaise and salad dressings (including cheese-based salad dressings; refrigerated after opening)</li> <li>• Cooked gravy and sauces</li> </ul>	<ul style="list-style-type: none"> <li>• Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw eggs, stored in refrigerated case</li> </ul>





## GLOSSARY

**Allogeneic Transplant** – A type of peripheral blood stem cell or bone marrow transplant that uses a donor's cells.

**Alopecia** – Partial or complete hair loss, usually a temporary side effect of the chemotherapy.

**Anemia** – A condition that occurs when the body's red blood cell count is low.

**Antibody** – A protein produced by white blood cells to battle foreign substances that enter the body.

**Apheresis** – The peripheral blood stem cell collection process in which blood is taken from the patient and circulated through a machine that separates out the stem cells. The remaining cells are returned to the patient.

**Autologous Transplant** – The patient donates his/her own bone marrow or peripheral blood stem cells for transplant.

**Bone Marrow** - The spongy tissue found in the cavities of the body's bones where all the blood cells are produced.

**Central Line** - A small, plastic tube inserted into a large vein to inject or remove fluids. The central line used in a stem cell transplant allows blood samples to be drawn, drugs to be given and the actual transplant to occur with little discomfort.

**Chemotherapy** – Medicine or a combination of medicines designed to stop the growth of cells.

**Conditioning** – A phase in the stem cell transplant process involving high doses of chemotherapy and/or radiation therapy.

**Electrolyte** – Minerals found in the blood such as magnesium and potassium that must be maintained to prevent organ dysfunction.

**Engraftment** – Process in which transplanted stem cells begin to grow in the recipients bone marrow and produce new white blood cells, red blood cells and platelets.

**GCSF or growth colony stimulating factor** – A subcutaneous injection of proteins given to transplant recipient patients before and during the harvest to increase the number of stem cells in the blood. GCSF is also given daily by subcutaneous injection following the stem cell reinfusion.

**Graft Versus Host Disease** – A condition that can occur follow an allogeneic stem cell transplant in which the donor’s cells attack the patient’s tissues and organs.

**Immunocompromised** – A condition in which the patient has a much higher risk of infection due to a weak immune system.

**Immune system** – The group of organs and cells in the body that fight infection and other diseases.

**Mobilization** – Moving more stem cells from the bone marrow into the bloodstream through chemotherapy and/or a growth factor.

**Mucositis** – Mouth sores caused by chemotherapy and/or radiation therapy.

**Neutropenia** – A shortage of neutrophils (the good white blood cells) in the blood, which increases the risk of infection.

**Platelets** – Blood cells that act as a clotting agent to prevent bleeding.

**Protocol** – A specifically designed treatment plan.

**Reinfusion** – The return of healthy stem cells into the transplant recipient’s body.

**Stem Cells** – The “parent cell.” Every type of blood cell in the body begins its life as a stem cell. The stem cells then divide and form the different cells that make up the blood and immune system.

**Stem Cell Harvest** – The collection of healthy stem cells from the circulating blood stream.

**Thrombocytopenia** – Low platelet count.

**White Blood Cells** – Cells that help fight infection and disease.