



The
BLOOD &
MARROW
TRANSPLANT
PROGRAM
and You



A Guide for Recipients of Autologous Transplants
and Their Families

Where Hope is a Way of Life

WELCOME

Welcome to the University of Maryland Marlene and Stewart Greenebaum Cancer Center's Blood and Marrow Transplant Program.

This program provides high doses of chemotherapy and/or radiation therapy to people for whom routine treatment is less promising. After this course of therapy is finished, we give you your own stem cells to help your body recover from the treatment. Stem Cell Transplantation allows us to give a higher dose chemotherapy and/or radiation than your body could normally tolerate. These higher doses may increase the chance of getting rid of the cancer.

Before receiving high dose chemotherapy, it is very important to consider all of your individual needs. You will receive a thorough medical evaluation that includes assessment of diet, dental health, emotional, financial and spiritual needs. We have Cancer Center staff that specializes in each of these areas who will meet with you.

Once it has been determined that this treatment may be right for you, we will discuss the details of your transplant with you. Please contact us if we can be of further help to you in regards to your transplant.

University of Maryland
Marlene and Stewart Greenebaum Cancer Center
Blood and Marrow Transplant Program

TABLE OF CONTENTS

- 1. The Transplant Program | page 2**
 - Blood and Marrow Transplant Program Staff
 - Your Transplant Team
 - Important Phone Numbers
- 2. About Autologous Transplant | page 4**
 - What is an autologous transplant?
 - When is bone marrow or peripheral blood stem cell transplant an appropriate treatment?
 - What is the difference between bone marrow and peripheral blood stem cell transplant?
 - How are transplant recipients selected?
 - Autologous Transplant Timeline
- 3. Preparing for Transplant | page 6**
 - Pre-transplant Tests
 - Mobilization and Collection Phase
 - Mobilization
 - Catheter Placement
 - Collecting the Stem Cells
 - Preparing for Transplant
 - Potential Treatment Calendar for Patients
- 4. In the Hospital | page 11**
 - The Transplant Unit
 - How Protective Isolation Works
 - Nursing Care on the Unit
 - Safety Precautions
 - Hospital Services
 - Your Self-Care Responsibilities
 - Preparing Your Body for Transplant
 - The Day of Transplant
 - The Engraftment Phase
 - Possible Complications
- 5. The Recovery Process | page 15**
 - Your Follow-up Care
 - Signs and Symptoms to Report
 - Maintaining your Emotional Health
 - Emergency Numbers
- 6. Caring for Yourself at Home | page 18**
 - Children and Siblings
 - Personal Care
 - Diet and Exercise
 - School and Work
 - Alcohol, Smoking and Other Substances
 - Caring for Your Catheter
- 7. Medications | page 21**
- 8. Charting Your Future | page 23**
- 9. Glossary of Terms | page 24**
- 10. Tracking Your Blood Count | page 25**

THE TRANSPLANT PROGRAM

Welcome to the Blood and Bone Marrow Transplant Program at the University of Maryland Marlene and Stewart Greenebaum Cancer Center.

Our highly skilled team is committed to providing you and your family with complete and attentive care. Our physicians, nurses and other health care specialists are experts in all aspects of bone marrow and peripheral blood stem cell transplant. We will be here for you before, during and after the transplant to assist in meeting your needs.

YOUR TRANSPLANT TEAM

Transplant Physicians are hematology/oncology physicians specially trained in bone marrow and peripheral blood stem cell transplant. Your physician will provide your primary medical care during the transplant process. A transplant physician will see you daily while you are in the hospital. He or she will order tests, treatments, medications and will inform you and your family of your progress. Your transplant physician will address your questions or concerns. Write down your questions or concerns as you think of them so they can be addressed during the physician's visit. It is important that you report any changes in how you feel.

Fellows are physicians who are board-certified in internal medicine, working toward a specialty certification in oncology and/or hematology.

Transplant Coordinators are registered nurses who manage all the arrangements for your transplant. These include: evaluating your insurance and advocating for coverage, coordinating pre-transplant tests, providing education, and participating with other team members in decisions about your care plan.

YOUR Transplant Coordinator is your primary point of contact from the time of your initial consult to the day that you are admitted for your autologous transplant. She or he is available throughout the pre-transplant process to address any questions or concerns that may arise. The Transplant Coordinator will educate you and your family on what to expect as you move through the process and will provide education regarding certain medications that will be prescribed for you.

Transplant Navigators are valuable team members that will work with you to schedule your pre-transplant testing and help guide you through your testing days at the hospital.

Nurse Practitioners are highly skilled individuals who have special training in oncology. These practitioners work closely with the attending physicians and will be taking part in your care after you are admitted for transplant.

Registered Nurses will be your primary source of contact during your hospital stay. Together with the physicians they will plan your overall nursing care. At the University of Maryland Greenebaum Cancer Center we use a "relationship-based" model of nursing care. So, though you may have different nurses caring for you during your inpatient stay, you will have one primary nurse who will oversee your nursing care.

Apheresis Nurses are trained to collect your stem cells. They are able to do so by using an apheresis machine which will separate the stem cells from the rest of your blood so that they can be collected and stored until the date of your transplant.

Cell Component Specialists are medical technicians who are responsible for processing the stem cells taken from your blood. Using highly specialized laboratory techniques, they prepare the peripheral blood stem cell product that will be used in your transplant.

Social Workers provide links to important services including financial assistance, disability insurance, housing, transportation and support groups. At discharge they may also help coordinate your transition from the hospital to home. Your social worker will meet with you and your family during the pre-transplant evaluation to assess for any special needs. She or he also provides the emotional support and counseling that many families find invaluable in dealing with the emotional upheaval that can be involved in coping with the stressors of illness and the side-effects of treatments.

Psychiatrists are available to any of our patients at their own recommendation or by a recommendation from the transplant team. A transplant can place additional stress on you and your family in an already stressful situation.

Nutritionists monitor your food intake and help create a nutritional care plan. They are available to help you during any phase of the transplant process. The Nutritionist takes part in the Pre-Transplant Class by presenting a lecture on Food Safety for patients who are immunocompromised.



IMPORTANT PHONE NUMBERS

Emergency Number for After Hours

410-328-7609

Transplant Physician

410-328-1230

NAME _____

Transplant Coordinator

410-328-1229

NAME _____

BMT Unit/Fellows/Inpatient Nurse

410-328-3866

NAME _____

Clinic Nurse

410-328-7609

NAME _____

Nutritionist

410-328-5462

NAME _____

Social Worker

410-328-7521

NAME _____

Dental Hygienist

410-328-5940

NAME _____

Apheresis Specialist

410-328-7508

NAME _____

Financial Counselor

410-328-3398

NAME _____

Dental Hygienists evaluate your oral health by examining your mouth, teeth and gums prior to starting transplant therapy. Good dental hygiene helps prevent infections that may occur while the body's immune system is recovering.

Dentists diagnose existing or potential dental problems. Some patients need to have certain dental issues addressed prior to transplant. The dentist will make recommendations for oral care or coordinate a comprehensive dental plan if necessary.

Pharmacists work closely with the team to prepare and deliver your chemotherapy and any other drug that you may receive during your transplant. He or she is experienced in dealing with the side effects of medications that may arise and is available to answer questions you may have.

Financial Coordinators will assist you with financial matters related to your transplant, particularly with obtaining required prior authorizations for transplant services.

Radiation Oncologists, depending on your diagnosis and disease status, may meet with you to determine if radiation therapy may be beneficial.

Research and Clinical Trials are available to some of our patients. You may be asked to participate in a study that may potentially improve treatment options, increase survival rate and provide a benefit to you and/or future transplant patients. There are different clinical trials going on at various times. Your physician will discuss if any are appropriate for you.

Research Coordinators work with your physician and your Transplant Coordinator to minimize trips to the hospital, educate you on what the research study or clinical trial involves and are available to answer any questions you may have pertaining to the research study or clinical trial.

While currently not on our team, **Integrative Medicine** also known as Complementary and Alternative Medicine is gaining a greater acceptance. For example, some patients have had success with their peripheral neuropathy after seeing an acupuncturist. Please discuss with your physician prior to seeing any specialist not listed.

ABOUT AUTOLOGOUS TRANSPLANT

WHAT IS AUTOLOGOUS TRANSPLANT?

In an autologous transplant, some of the patient's own bone marrow or peripheral blood stem cells are removed and reserved. Then the patient receives high doses of chemotherapy or radiation to destroy any cancer cells. Afterward, the patient's blood cells are reinfused through a transfusion. These cells find their way to the bone marrow and begin to produce a new population of blood cells. Through this process, the patient's bone marrow and immune functioning return to normal.

WHEN IS BONE MARROW OR PERIPHERAL BLOOD STEM CELL TRANSPLANT AN APPROPRIATE TREATMENT?

Bone marrow/peripheral blood stem cell transplant is used to treat a number of life-threatening diseases. Transplant has become the standard of care in certain diseases because the procedure offers hope of a cure or extended remission when standard cancer treatment has not been able to destroy all of the cancer cells. The patient's body can withstand higher (and possibly more effective) doses of chemotherapy and/or radiation when bone marrow function can be restored with fresh bone marrow and/or stem cells.

Some of the diseases for which autologous bone marrow/peripheral blood stem cell transplant may be used are: Hodgkin's Disease, Non-Hodgkin's Lymphoma, Multiple Myeloma, and some Acute and Chronic Leukemias.

WHAT IS THE DIFFERENCE BETWEEN BONE MARROW AND PERIPHERAL BLOOD STEM CELL TRANSPLANT?

Bone marrow is the spongy tissue found inside the bones. The bone marrow is the site of stem cell production. Stem cells grow and divide and become red blood cells (which carry oxygen to body tissues), white blood cells (which help fight off infection), and platelets (which aid in blood clotting).

In a bone marrow stem cell transplant, about 5% of the bone marrow (roughly the amount that would fill a 2-liter bottle) is "harvested" from the patient's hip bone. This is the amount of marrow needed to collect enough stem cells to support the patient's transplant. These cells are pooled, processed and reinfused into the patient following high dose chemotherapy. The patient may experience some discomfort or soreness with this procedure, but usually he or she can resume normal activity in a couple of days.

Stem cells are also found at naturally low concentrations in the peripheral blood stream. The number of stem cells in the peripheral blood can be increased, however, by a "growth factor." These stem cells can be collected from the circulating blood after the patient is injected with a "growth factor" called G-CSF, Granulocyte Colony Stimulating Factor. This medication stimulates the bone marrow to produce excess quantities of stem cells which are released out of the bone marrow and into the circulating blood. The patient's blood is drawn through a central venous catheter and a special blood processing system concentrates the stem cells. This process is called apheresis. These cells are eventually reinfused into the patient following high dose chemotherapy. The patient experiences no surgical pain.

Peripheral blood stem cell transplants generally provide more stem cells and result in a more rapid recovery of white blood cells and platelets.

HOW ARE TRANSPLANT RECIPIENTS SELECTED?

Possible recipients are carefully evaluated to determine if transplant is the best treatment option. Some of the criteria considered are: age, overall medical status, type and stage of disease, and disease progression. Your transplant team will thoroughly discuss all of the risks and benefits with you and your family.

PREPARING FOR TRANSPLANT

Before the transplant you will come to the Marlene and Stewart Greenebaum Cancer Center for a series of tests. These will be used to evaluate your health and to determine if a transplant is a safe and appropriate treatment for you.

PRE-TRANSPLANT TESTS

Blood Tests Several different kinds will be done to make sure your liver, kidney and bone marrow are functioning well. Your blood may also be checked for the presence of infectious diseases. A test of “tumor markers” in your blood may be done as well to help the health team with your treatment plan.

Chest X-Ray This picture of your heart and lungs is checked for any signs of infection, cancer or heart abnormality.

EKG An electrocardiogram (EKG) shows the electrical activity of your heart.

MUGA Scan This test shows how well the heart pumps. A very low dose of radioactive material is injected into a vein, and a camera takes pictures as the dye is pumped through your heart.

Echocardiogram An alternative to the MUGA Scan, this test uses sound waves to check the heart’s functioning.

Pulmonary Function Test (PFT) This breathing test helps to determine the functioning of your lungs.

CT or CAT Scan This special kind of X-ray gives a clear, crisp picture of any part of your body. It often is used to find out if cancer is present and whether your lungs, liver and kidneys are normal. It can be taken of your head, neck, chest, abdomen and/or pelvis.

Bone Scan This test reveals any abnormalities of the bones that may suggest cancer involvement.

Bone Marrow Aspiration/Biopsy A needle placed in your hip bone draws out a small amount of bone marrow which is then tested for cancer. The area of the aspiration is numbed with medication so that you will not feel the needle.

Urine Test You will collect your own urine for a 24-hour period at home. Urine tests are done to check your kidney function, make sure you do not have an infection, and to check for the use of illicit substances and nicotine.

MOBILIZATION AND COLLECTION PHASE

When your evaluation and insurance clearance are complete, your individualized treatment schedule can be prepared. The treatment schedule prior to admission to the hospital for your transplant includes the mobilization and collection of your stem cells.

MOBILIZATION

The purpose of mobilization is to stimulate your bone marrow to produce more stem cells in order for them to be released into your blood stream. Your stem cells can be mobilized in different ways: chemotherapy in combination with a growth factor or stimulation with growth factors alone. Your transplant physician will discuss the best method for you.

CATHETER PLACEMENT

Your stem cells will be collected through a central venous catheter that will be placed in Interventional Radiology under sedation shortly before your collection. A home care nurse will visit you at home following the placement to teach you and your caregiver proper care of this line. This catheter will remain in place through your transplant. Depending on your transfusional needs at the time of discharge, the catheter may be removed just prior to discharge or shortly after.

COLLECTING THE STEM CELLS

Depending on your diagnosis and condition, either bone marrow or peripheral blood stem cells will be collected from you.

Peripheral blood stem cells are collected in a process called apheresis. You will come to the hospital for approximately two days in a row where you will be hooked up to a special blood processing machine called an apheresis machine. For about four to six hours each day, your blood will be drawn through your catheter. As about one unit of your blood circulates outside of your body, the machine will extract some of the peripheral stem cells. After the cells are collected, they will be tested to find out how many actual stem cells were collected, and will then be frozen until it is time for your transplant. Side effects of this procedure will be discussed with you, but boredom tends to be very common! So be sure to bring a book to read or a DVD to watch (a DVD player is available).

If your bone marrow is to be collected, you will be admitted to the hospital in same-day surgery. Under general anesthesia, bone marrow will be taken from your hip bones in the back area using large needles that puncture the skin and go into the bone. Only about 5 percent of the marrow is taken, and the body quickly replenishes itself. Side effects from the bone marrow collection may include mild to moderate discomfort at the harvest sites in your hips. This can be effectively managed with pain medication.

PREPARING FOR TRANSPLANT

Once you have successfully completed the mobilization and collection phase of the transplant process, you will be ready for the next step: admission for transplant.

You may feel hopeful as well as anxious as you anticipate what is to come. You will be undergoing very aggressive treatment which involves certain risks, but also offers the best possibility of a cure or prolonged remission for your disease.

Many people find that their anxiety decreases as they talk about their feelings with family, friends or other helping professionals. Being fully informed also helps people cope with the uncertainties. Feel free to contact your Transplant Social Worker with any concerns you have. She or he will counsel you or direct you to the best resources. The team is committed to you and your family's overall well-being. Please allow us to serve you.

CHEMOTHERAPY MOBILIZATION CALENDAR – FRIDAY START

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
	Diagnostic work up		Consultations and class work up			
		Follow up with the doctor. Consent for mobilization.			Mobilization to start. Cytoxan infusion for 4 – 6 hours.	Begin neupogen injections and also begin other medications for the mobilization process.
Continue Neupogen and other medications.	Continue Neupogen and other medications.	Continue Neupogen and other medications.	Continue Neupogen and other medications.	Continue Neupogen and other medications.	LINE INSERTION Continue Neupogen and other medications.	Continue Neupogen and other medications.
Continue Neupogen and other medications.	Day one of collection Possible Neupogen. Continue other medications.	Day two of collection, if needed. Neupogen.				
		Follow up with doctor. Consent for transplant.				
	Admit to the Bone Marrow Transplant Unit for high dose chemotherapy followed by stem cell infusion.					

CHEMOTHERAPY MOBILIZATION CALENDAR – MONDAY START

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
<p>*REMEMBER: 2 liters of fluid per day over next 72 hours.</p>	<p>8 AM UMD 1st Floor, Stoler Pavilion Lab work and Cytoxan infusion</p>	<p>8 AM Begin Neupogen injections, antibiotics and other medications as directed.</p> <p>*REMEMBER: Keep up fluid intake and empty bladder every 2 – 3 hours</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p>
<p>Continue Neupogen injections, antibiotics and other medications as directed.</p> <p>***REMEMBER: Do not eat or drink anything 6 hours prior to catheter placement @ 8 am tomorrow morning.</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p> <p>8 AM UMD 1st Floor, Stoler Pavilion Labs, then to Interventional Radiology for line placement</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p>	<p>Continue Neupogen injections, antibiotics and other medications as directed.</p>	<p>***REMEMBER: Take antibiotics at home BEFORE coming to hospital. BRING Neupogen with you to the hospital and await instruction.</p> <p>7 AM UMD 1st Floor, Stoler Pavilion Blood check then to room S9CO2 for stem cell collection after labs back</p>	<p>Neupogen</p> <p>Stem cell collection</p>	
			<p>1 PM UMD 1st Floor, Stoler Pavilion Follow up with Doctor</p>			
			<p>Admit to BMT unit for high dose chemotherapy</p>			



CLINIC NUMBER

Monday – Friday
8 am – 4:30 pm
410-328-7609

EMERGENCY NUMBER

After 4:30 pm and Weekends
410-328-7609

TRANSPLANT COORDINATOR NUMBER

410-328-1229

- The Neupogen is given daily until apheresis is complete. Your dose of Neupogen is weight-based. They should be given around the same time every day, in the AM.
- Continue to take antibiotics until apheresis is complete:
 - Clotrimazole 10 mg by mouth, suck on like a lozenge, after meals and bedtime
 - Acyclovir 800 mg by mouth in the morning and in the evening
 - Levofloxacin 750 mg by mouth every morning
 - Compazine 10 mg by mouth every 6 hours as needed for nausea
- Take your temperature four times a day after chemotherapy until apheresis. If your temperature is 100.4 degrees or higher, call the emergency numbers IMMEDIATELY, regardless of time of day.
- Remember to bring snacks with you on the day of apheresis.
- Increase your fluid intake for 48 hours before receiving the Cytoxan chemotherapy and for 48 hours after you have completed the Cytoxan Chemotherapy.
- Remember to eat breakfast on the day of stem cell collection.

THE TRANSPLANT UNIT

When you are ready for your transplant, you will be admitted to the transplant unit at the Marlene and Stewart Greenebaum Cancer Center. The transplant unit is located on the 9th floor of the Medical Center's Gudelsky Building and is specially designed to provide protection from infection during your recovery. The unit also offers a comfortable environment for you, your family and other loved ones. We strongly recommend that patients do not leave the unit except for diagnostic studies.

HOW PROTECTIVE ISOLATION WORKS

After receiving chemotherapy and/or radiation your white blood cell count will be low. White blood cells are needed to fight infection. To lessen the risk of infection, the air in your room is cleansed continuously using a HEPA filter.

NURSING CARE ON THE UNIT

A dedicated group of nurses will care for you during your stay. These nurses are experienced and specially trained in cancer care and blood and marrow transplant. They will teach you and your family what you need to know about your care and recovery process, as well as provide emotional support. Be sure to ask your nurse any questions you may have regarding your transplant or your recovery process.

SAFETY PRECAUTIONS

Visiting Policy The Transplant Unit is a special unit with special visitation policies. Please follow these guidelines when visiting.

1. Visiting hours are set by the patient. We recommend a maximum of two visitors in the room at one time. One visitor may stay overnight in the patient's room.
2. Because of the risk of infection, visitors must be at least 12 years of age.
3. All visitors must wash hands thoroughly each time they enter a patient's room. This helps protect the patient from bacteria or viruses.
4. Visitors are not allowed to use patients' bathrooms or eat in patients' rooms
5. To reduce the risk of infection to other patients, visitors are not permitted to roam throughout the unit. Visitors must remain with the patient. Visitors are not permitted to roam throughout the unit in an attempt to reduce the risk of infection to other patients.

6. Plants and flowers are not allowed on the unit, as they often harbor bacteria in the soil and water. Visitors may bring balloons or silk flower arrangements.
7. Smoking is not permitted within the hospital or on hospital grounds at any time. This is especially important on the transplant unit as the air must remain clean at all times.
8. Visitors may bring food items prepared according to the diet guidelines for immunocompromised patients, available from the Transplant dietician.

HOSPITAL SERVICES

The University of Maryland Medical Center is committed to making your stay as comfortable as possible. If you have any questions or concerns about your care, you may contact either your primary care nurse or your attending physician. The Transplant Unit social worker can provide emotional support and connect you with resources. For spiritual concerns, there is a hospital chaplain on call. Let your nurse know your needs. He or she will connect you with the appropriate person or service.

Telephone Service Each room on the unit is a private room that has its own telephone. Patients may make outgoing calls 24 hours a day; long-distance calls must be made collect or billed to a credit card.

Patient Mail Mail is delivered every day. While in the hospital, friends and family may write to you at:

University of Maryland
Marlene and Stewart Greenebaum Cancer Center, Gudelsky 9
22 S. Greene Street, Baltimore, MD 21201

Television Each room has a television. Ask your nurse for information.

Wifi The University of Maryland Medical Center offers free wifi hospital-wide. Patients and visitors may bring lap tops or other internet devices to take advantage of this service.

YOUR SELF-CARE RESPONSIBILITIES

You will play a key role in your own recovery. By following these suggestions, you can help lessen the risk of complications.

Hygiene It is important to keep yourself as free of germs as possible. You should take daily showers and always wash your hands after using the bathroom. Please do not use any lotions or creams, except those given to you by your nurse. The use of makeup products is discouraged as they often harbor germs and can irritate skin.

Light Exercise Moderate physical activity will help maintain your circulation, your lung and heart function, and your muscle tone. We encourage you to walk around the unit regularly; if you are receiving infusions, you can walk with an IV pole. In the Patient and Family Relaxation Room, an exercise bike and treadmill are also available for your use. Your nurse and physical therapist will help you create a reasonable exercise regime. Each time you leave your room, you will need to wear a mask.

Exercising Your Lungs Fluid build up in the lungs and infection can be avoided with proper respiratory care. You will be asked to exercise your lungs regularly using a special breathing device called an incentive spirometer. Deep breathing, plus physical exercise, will help your lungs continue to function well.

Nutrition After chemotherapy, you may have difficulty eating. Food may not taste the same or your appetite may be diminished. The transplant dietician will work with you to maintain your food intake, as good nutrition is essential to your body's recovery.

Keeping Yourself Occupied A long hospital stay can lower your spirits. It's easy to become bored and lethargic. We encourage you to keep yourself occupied by bringing from home any games, books or other activities that you enjoy. You may bring in other personal items such as photographs, posters, comforters or pillows to make your room more comfortable and home-like. The unit has a designated Patient and Family Relaxation Room equipped with a treadmill, stationary bicycle and set of stairs for your use. There is also a semi-circle of chairs to promote patient interaction and conversation.

Maintaining a Positive Attitude A positive attitude is a powerful factor in your recovery. Those who cope well with cancer tend to be active, assertive and optimistic. A positive outlook means you approach your life with hope and optimism. Being positive does not mean that you will never be discouraged or have feelings of sadness or anger about your situation. Indeed, trying to cover up "negative" thoughts or feelings can be counterproductive.

Even if you feel you are not naturally "upbeat," a fighting spirit can be developed. Support groups and individual psychotherapy have been shown to be effective in fighting depression. Ask the Team Social Worker to direct you to the appropriate resource.

PREPARING YOUR BODY FOR TRANSPLANT

Chemotherapy Depending on your disease, you may receive several different kinds of chemotherapy drugs designed to kill your type of cancer cells. These medications will be given to you in the hospital through your intravenous (IV) line. These drugs are very powerful and will also affect normal cells, possibly resulting in certain side effects. These may include nausea and vomiting, diarrhea, mouth sores, fever, hair loss, changes in taste and skin and bone marrow suppression. Your nurse will discuss all possible side effects with you and provide treatments to help lessen their impact.

Radiation Therapy Some patients also receive total body irradiation (TBI) prior to transplant. Given over several days, TBI kills off cancer cells that may be in your body, and suppresses your immune system so that you will not reject your donor's bone marrow. Immediate side effects can be nausea, vomiting, diarrhea, sore mouth and throat, swollen throat and salivary glands and hair loss. If TBI is prescribed for you, you will be taken from your hospital room to the Radiation Oncology center for treatments.

Late side effects may include cataracts of the eyes and insufficient activity of your thyroid gland, as well as diminished lung capacity. Post transplant, these possible effects will be regularly monitored.

THE DAY OF TRANSPLANT

Your bone marrow or peripheral blood stem cells, which have been processed and frozen, are brought to your room on the transplant unit. The cells are thawed at your bedside in a warm solution and then given to you through an IV line attached to your catheter. The infusion generally takes about 60 minutes.

You may experience a funny taste in your mouth or an odd smell during the procedure. This is due to the preservative dimethyl sulfoxide (DMSO) that is used in the freezing process. You may want to suck on mints or candy during this time. The smell may last up to 48 hours.

There may be other side effects: nausea, shortness of breath, stomach cramping, and wheezing. During the transplant your nurse will be with you and check your vital signs often. She or he will be present to handle side effects you may have. After the peripheral blood stem cells or marrow have been

transfused, you may receive other medications. These may be antibiotics to prevent infection or other drugs to treat nausea or vomiting. Your doctor or nurse will explain these medications to you.

THE ENGRAFTMENT PHASE

Engraftment is the period when the infused bone marrow or peripheral blood stem cells “take” and begin producing blood cells. It may take 10–16 days for engraftment to occur.

During this waiting period, your blood counts will be very low. You may need transfusions of red blood cells and platelets. Red blood cells carry oxygen to all the cells of your body, and platelets help blood to clot and prevent bleeding.

Medications may be given to speed up the production of blood cells, particularly the white blood cells needed to fight off infections. Daily blood tests and, possibly, periodic bone marrow aspirations will be done to determine if engraftment has occurred. Once your white blood cell count is high enough to fight infection, you will be discharged from the inpatient unit and seen frequently in the outpatient Stoler Pavilion or BMT clinic.

POSSIBLE COMPLICATIONS

It is important to remember that after receiving your high-dose chemotherapy, you will be immunocompromised. While your blood counts improve shortly before your discharge from the hospital, it is important to remain vigilant in protecting yourself from infection. Studies have shown that it takes the body’s immune system about three months to get

back to its “normal” function after an autologous transplant.

High-dose chemotherapy with or without radiation, and the low blood counts that occur as a result, can lead to complications. These conditions, some of which are described briefly below, can be treated but have the potential to be life-threatening. A Transplant Team member will discuss possible complications with you and keep you and your family informed of your progress.

Infection Because your white cells are suppressed, you will be at risk for developing infections. You will be particularly susceptible to bacterial infections. The infection prevention measures in the Transplant Unit are designed to lessen the risk. If you develop a bacterial infection, you will be given IV antibiotics. Fungal or viral infections (which are more serious and more life-threatening) may also occur. These infections are less likely to occur due to the short time that your counts will be down and, it is hoped, can be avoided with oral medication.

Heart and Lung Problems High-dose chemotherapy, as well as infections, may decrease the function of your heart and lungs. To monitor this condition, you will have tests before, during and after your transplant.

Lack of Engraftment Sometimes the new blood cells will not grow in your body. This means they have not successfully “engrafted.” This condition is monitored by blood counts and bone marrow aspirates. If the cells show no signs of engraftment after several weeks, a second transplant may be offered.

NOTES



■

THE RECOVERY PROCESS

5

YOUR FOLLOW-UP CARE

After your discharge from the hospital, you will be followed closely so that any problems can be dealt with quickly. You will be seen at the Roslyn and Leonard Stoler Pavilion or the BMT Outpatient Clinic in the Marlene and Stewart Greenebaum Cancer Center. Depending on how far away from the hospital you live, you may be required to stay within close proximity to the hospital at your discharge. This will be discussed with you prior to your admission for transplant.

Your outpatient visits immediately following discharge are very important. We will monitor your blood counts and physical condition, being alert to any complications.

Hours The Roslyn & Leonard Stoler Pavilion and BMT Outpatient Clinic are open Monday–Friday, 8:00 am–4:30 pm. Please call 410-328-7450 to make appointments.

Appointment Schedule Recipients of autologous transplant are usually seen 2 to 3 times during the first week after transplant and one to two times a week for the next 2 to 3 weeks after transplant. Recipients then return to their referring oncologist. This schedule may vary depending on your condition.

Emergencies A member of the Transplant Team is always on call to address any problems that may arise. During weekdays, call 410-328-7609. In the evening, on weekends or on holidays call 410-328-3866.

What to Bring with You to Your Appointments It is important that you bring all medications and your medication schedule with you on each outpatient visit as well as to bring this booklet. It is helpful to keep your medication schedule in this book, there is a place for this in section 7. Depending on what tests results show, your medications or dosages may be changed.

SIGNS AND SYMPTOMS TO REPORT

A number of symptoms are expected post-transplant: dry mouth, fatigue, a salty taste or no taste, and a loss of appetite. These will lessen in time. You should carefully monitor your symptoms and write down anything that seems unusual. (For guidance as to what to report, see the chart on the next page.) It is very important that you tell your doctor if you have a fever, any bleeding, pain, or shortness of breath.

MAINTAINING YOUR EMOTIONAL HEALTH

In the days after your transplant, you may feel emotionally drained as well as physically fatigued. This is an expected response, as you have just emerged from a very intense and stressful experience. Your family and loved ones also may experience certain emotional upheaval. Please feel free to call the Transplant Social Worker if you have any concerns about you or your family members' emotional well-being. She or he will counsel you, and if necessary, refer you to another mental health professional.

Many patients and their families have found it enormously helpful to talk with others who have shared their experience. Your social worker can direct you to support groups in your area. Research shows that expressing one's feelings can help with one's recovery.

EMERGENCY NUMBERS

410-328-7609 Regular Business Hours
8:00 am–4:30 pm

410-328-3866 After hours, weekends, and holidays

SYMPTOMS

SYMPTOMS	WHAT TO LOOK FOR	WHAT TO DO
Fever	Temperature	Temperature should read 100.4 F. Call immediately if greater than 100.4 F. If less than 100.4, retake in 2 hours. Call if greater than 100.4 F. Call within 24 hours if it continues to be less than 100.4 F, but above normal. Do not take Tylenol or aspirin unless directed by one of the transplant physicians.
Shaking Chills	Uncontrolled shaking and chills with or without a fever	Call immediately
Bleeding	Vomit or stool	Call immediately
	Nosebleed	Apply first aid measures (pinch nose, put head back, apply ice pack to nose) and if still bleeding after 15 minutes, call in.
	Eye	Call within 24 hours
	Bruises	Call within 24 hours
	Urine	Call immediately
	Vagina	Call within 24 hours or sooner if new (>6 pads within 12 hours)
Cold Symptoms	Cough	Call within 24 hours
	Shortness of breath, changes in breathing	Call immediately
	Sore throat, runny nose	Call within 24 hours
Change in levels of consciousness	Unable to wake or speak	Caregiver immediately call 911, then call BMT unit
	Severe headache	Call immediately
	Confusion	Call immediately
	Dizziness	Call immediately
Chest Pain (pulse changes)	Pain in mid chest, irregular pulse, palpitations or light-headedness	Call immediately
Abdominal Pain or Cramping	Persistent pain for over 24 hours or if severe pain	Call immediately
Central Venous Catheter	A tear or crack in catheter	Call immediately
	Unable to flush	Call immediately
	Tenderness, redness or drainage at exit site or along catheter track	Call immediately
Vomiting or Nausea	Vomit looks like coffee grounds (black) or blood is present	Call immediately
	Unable to keep medications or food down	Call within 24 hours or if you need nausea medication
Diarrhea (liquid, watery, stool without form)	Stool looks black, tarry, maroon or blood present	Call immediately
	Increase in amount and/or frequency	Call within 24 hours
Skin Rashes or Lesions	Any new symptoms/rashes, blisters or hives	Call within 24 hours
Eyes	Visual changes, blurring	Call within 24 hours
	Redness or drainage	Call within 24 hours
	Dry and itchy	Call within 24 hours
Joint Pain	Any new symptoms or if medication needed	Call within 24 hours
Indigestion	Stomach pain or gas	Call within 24 hours
Pain during Urination	Burning pain when urinating	Call immediately

NOTES



A series of horizontal lines for writing notes, starting below the dotted line and extending to the bottom of the page.

CARING FOR YOURSELF AT HOME

As your body's immune function recovers, some precautions are necessary.

CHILDREN AND SIBLINGS

Immunizations If your children or primary caregiver are scheduled to receive vaccines, inform your physician that these must be “killed” rather than “live” vaccines. Your physician may contact the transplant coordinator for more information.

PERSONAL CARE

Bathing You may use either the shower or the tub, but be sure to bathe daily. Clean the tub or shower stall well before using it.

Hand Washing Bacteria and viruses get passed on most often through the hands. Make a habit of washing your hands frequently, particularly before eating, after using the toilet and after being in contact with another person. In addition, it is important that caregivers, family and any visitors (especially children) learn proper hand washing technique and practice it frequently.

Skin Care Your skin will be sensitive after transplant. Keep your skin moist with creams, lotions or bath oil. You may use cosmetics and facial creams. Men are allowed to shave as long as blood clotting agents (platelets) are adequate. Consult your physician.

Oral Hygiene The mouth harbors many germs, which can lead to infection. It is important to take extra good care of your mouth and teeth. Brush often and use mouth wash. Visit your dentist more frequently—perhaps every three months. Contact your physician if you notice any changes in your gums, tongue, throat or roof of mouth.

Intimacy You may resume sexual relations after the transplant. Your physician or nurse will discuss with you any precautions you should take in the days immediately after discharge.

Some patients notice changes in their sex drive after transplant. This is an expected response to the stress of your illness and the treatment. Chemotherapy and irradiation can lower hormone production which can result in painful intercourse. Hormone replacement therapy or other lubricants can help with this problem. If intercourse is difficult, remaining close physically in other ways can help ease the transition.

DIET AND EXERCISE

Diet and exercise are very important as your body works to rebuild itself. The nutrients in food (especially proteins available in milk products, meat, fish and nuts) are essential for replenishing normal tissue affected by the treatment. Physical activity will help strengthen your body and brighten your mind.

You may notice a lack of appetite after the transplant. This will eventually return to normal. Until then, do your best to eat an adequate and well-balanced diet. The nutritionist can help if you are having difficulty getting enough calories.

Be careful to eat only well-cooked food. Do not eat in restaurants or fast food restaurants. Do not eat raw or under-cooked meat, poultry, fish, eggs or seafood. Raw fruits and vegetables are allowed if washed and peeled or cooked. Please refer to the diet guidelines for the immunocompromised patient that you receive in your pre-transplant class for further information.

You will feel fatigued after the transplant, but try to maintain some physical activity. Walking or cycling are especially good for enhancing your lung function. Increase your activity gradually every day, and don't give up!

SCHOOL AND WORK

You may return to work or school when your blood counts and immune cells are high enough, and you have no signs of infection. The timing will vary from six weeks to 3 months, depending on your condition. Some patients return to work on a part-time basis at first. Students often can arrange home tutoring to avoid falling behind in class. Your physician will discuss your options with you.

ALCOHOL, SMOKING AND OTHER SUBSTANCES

Your lungs are very vulnerable after transplant. Do not smoke cigarettes or use any other tobacco products, and avoid being in contact with people who are smoking.

Do not consume any alcoholic beverages unless first discussed with your physician. Alcohol may react adversely with the medications you are taking.

Never use any illegal or recreational drugs.

CHARTING YOUR FUTURE



Once you have faced a life-threatening illness, life is never quite the same again. Having cancer is a tremendous challenge. And for many, it is also a gift—an opportunity to cherish and appreciate life as never before.

There are things that you can do to enhance your well-being in the coming weeks and months. Here are some ideas:

DEAL CREATIVELY WITH FEAR

For some cancer survivors, fear becomes an unwelcome companion. Unlike other illnesses where treatment corrects the problem once and for all, cancer can be unpredictable in its course. Recurrence is a possibility, and one must find a way to live with it creatively.

Certain events may trigger feelings of apprehension; this includes anniversary events (date when the cancer was diagnosed, date when treatment was completed), troubling physical symptoms, medical appointments or the illness of a loved one. There are several ways to combat anxiety. Connect with people or groups where you feel supported. Plan fun or distracting activities. Seek counseling, if needed. Give support to others. Employ relaxation techniques, such as deep breathing or meditation. Focus on the positive, but do not deny the negative emotions as they come and go. Commit yourself to living one day at a time.

CULTIVATE HOPE

Hope is an inner quality that finds meaning in life, often despite circumstances. Hope is not the same as optimism or the conviction that things will turn out a certain way.

You cultivate hope when you pursue those things that give meaning to your life. That may be relationships, enjoyable activities, spiritual pursuits or satisfying work. Take time now to clarify what is important to you and pursue it.

TAKE CARE OF YOUR BODY

It will take awhile for your body to recover from transplant experience. You may feel fatigued for many weeks or months and this physical reality can affect your mental outlook as well. Some people actually feel “estranged” from their bodies. Others become impatient that they don’t yet feel like their “old selves.” Some have doubts that they will ever feel totally well again.

This is a good time to take gentle care of your self—especially your body. Pay attention to its signals. Exercise as much as you feel you can, but don’t overdo it. Eat well. Breathe deeply. Your body is working hard to heal. Nurture it in this process.

NOTES



■



GLOSSARY OF TERMS

Apheresis The process of removing the cells from the blood stream.

Apheresis Catheter An intravenous catheter designed for use in the removal of peripheral blood stem cells, giving drugs, nutrition and in withdrawing blood samples.

Autologous Bone Marrow Transplant (BMT) or Peripheral Blood Stem Cell Transplant A transplant using the patient’s own marrow or stem cells.

Bacteria A foreign organism (bug) that invades the body.

Bone Marrow The spongy tissue found inside bones which produces many elements of the blood.

Bone Marrow Aspirate and Biopsy A procedure which draws out some of the liquid bone marrow and a small piece of bone from the back hip area using a needle for the purpose of testing.

Bone Marrow Harvest A procedure done in the operating room to obtain the bone marrow for BMT.

Bone Marrow Transplant (BMT) Replacing existing bone marrow with other bone marrow, either one’s own or a donor’s.

Chemotherapy Treatment with anti-cancer drugs.

Communicable Disease A disease that can be given directly or indirectly from one person to another.

Engraftment The period when the transplanted bone marrow or stem cells “take” and begin to produce blood cells.

Granulocyte Colony Stimulating Factor (G-CSF) A protein that stimulates granulocytes to grow.

Immunocompromised A state in which the body’s immune system is unable to respond normally to foreign substances.

Immune System The body’s defense system against disease and foreign substances.

Incentive Spirometer An instrument that is used to assist you in keeping your lungs functioning well.

Infection The invasion of disease producing organisms within the body.

Irradiation A treatment which keeps the white blood cells in blood transfusions from hurting you.

IV (Intravenous) In the vein.

Mobilization Treatment with growth factors (G-CSF, GM-CSF) to stimulate stem cells to be released from the bone marrow into the blood stream.

Multidisciplinary Team A group of people representing several disciplines who work together with you to provide thorough care during the transplant process.

Platelets Blood cells that are responsible for clotting the blood.

Red Blood Cells (RBC) Blood Cells that carry oxygen to all parts of the body.

Stem Cells Cells capable of dividing and developing into other cells such as white blood cells, red blood cells and platelets.

White Blood Cells (WBC) Blood cells which defend against infection (also called leukocytes and granulocytes).



NOTES

**POCKET FOLDER
WITH BUSINESS CARD SLITS**



UNIVERSITY *of* MARYLAND

MARLENE AND STEWART GREENEBAUM
CANCER CENTER

umgcc.com

410-328-1229