



The
BLOOD &
MARROW
TRANSPLANT
PROGRAM
and You



A Guide for Recipients of Allogeneic 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 treatment 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 donor's stem cells to help your body recover from the treatment. Stem Cell Transplantation allows us to give 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.

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

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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. These physicians, nurses and other health care specialists are experts in all aspects of bone marrow and peripheral blood stem cell transplant. They will be with 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 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.

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.



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

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 ALLOGENEIC TRANSPLANT

WHAT IS ALLOGENEIC TRANSPLANT?

In an allogeneic transplant, the patient receives bone marrow or peripheral blood stem cells from another person. This person may be a sibling or an unrelated donor. This is different from an autologous transplant in which some of the patient's own marrow or peripheral blood stem cells are removed and then given back following high-dose therapy. In an allogeneic transplant, the donor's stem cells are collected and then infused into the patient following the patient's high-dose chemotherapy.

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 bone marrow/peripheral blood stem cell transplant may be used are: Hodgkin's Disease, Non-Hodgkin's Lymphoma, Multiple Myeloma, Acute Leukemia, Chronic Leukemia, Aplastic Anemia, and Myelodysplastic syndromes.

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 donor'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 transfused into the patient following high dose chemotherapy. The donor may experience some discomfort or soreness with this procedure, but usually he or she can resume normal activity in a couple of days.

In a peripheral blood stem cell transplant, the stem cells are collected from the circulating blood. 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 donor 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 into the circulating blood. The donor's blood is drawn and a special blood processing system concentrates the stem cells. These cells are eventually transfused into the patient following high dose chemotherapy. The donor experiences no surgical pain.

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

HOW ARE TRANSPLANT RECIPIENTS (PATIENTS) 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.

WHO CAN BE A DONOR?

Anyone in good health, whose blood "antigens" match yours can be a donor. But finding that person can be a challenge. There may be a match in your own family. Siblings may share your genetic make-up and are the most frequent type of related match. Less frequently, we may discover that a parent or child shares your genetic make-up. If a match is not found within your family, a search begins within the general population.

The Blood and Marrow Transplant (BMT) Program is a member of the National Marrow Donor Program (NMDP) which has access to more than 15 million volunteer donors worldwide. There are also other smaller national and international registries. Your transplant coordinator can give you more information about the search process.

HOW ARE DONORS MATCHED?

A small sample of blood taken from the potential donor is compared with your blood through a series of tests. Cells have structures on their surface called human leukocyte antigens

(HLAs) which recognize whether cells belong to the body or are foreign to the person. When your antigen sites match those of a donor, your body is less likely to see that person's blood cells as foreign and reject them.

HLA tissue typing continues to improve. Today, sophisticated lab techniques are producing much better matches for unrelated donor transplants. The University of Maryland is fortunate to have one of the most advanced HLA labs in the country.

WHAT DETERMINES IF A “MATCH” WILL BE SUCCESSFUL?

The closer the match, the more likely the donated bone marrow or peripheral blood stem cells will be accepted into your body. However, even with close HLA matches, subtle differences in other structures on the cell membrane may cause rejection (your immune system attacks the bone marrow cells) or graft-vs.-host disease (the donor's immune system attacks your body). A number of new drugs are helping to counteract graft-vs.-host disease. These medications have made it possible for some less-than-perfect matches to succeed. Rejection and graft-vs.-host disease should further be discussed with your transplant physician.

HOW IS AN ALLOGENEIC STEM CELL TRANSPLANT PERFORMED?

Stem Cell Collection Donors can have stem cells collected either peripherally or through a bone marrow harvest.

For a peripheral blood stem cell collection, donors are hooked up to a special blood processing machine. His or her stem cells are collected either through the donor's veins or through a catheter inserted into a large vein near the heart that would

be placed (and also removed) the day of collection. Related donors will come to our hospital on the day of collection for this procedure. Unrelated donors' peripheral blood stem cells will be collected at a collection center close to their home and hand couried to our center for transplant. The stem cells would be collected in a similar fashion to that of the related donor.

While about 20–30 units of blood is processed during the collection, only about 1 unit of blood is outside the body at any one time. As the donor's blood circulates outside his or her body, the machine extracts some stem cells. The donor's blood is then returned to the donor. The stem cells are processed and brought to you in your room on the transplant unit. They are given to you like a blood transfusion.

There is a possibility that bone marrow may need to be harvested from your donor to obtain enough stem cells for the transplant. The transplant team will keep you fully informed.

A bone marrow harvest involves the collection of bone marrow from your donor under general anesthesia in an operating room. Approximately 1 liter to 1½ liters of bone marrow will be removed from the hip bones in the back through multiple aspirations.

The procedure lasts about 90 minutes. Your donor will be evaluated before the bone marrow transplant through different tests to determine whether he or she is approved for anesthesia and to have the procedure done safely. For a related donor, this procedure is performed at our hospital. If your donor is unrelated, the bone marrow is collected at a facility near where the donor lives. A medical courier brings the marrow immediately to you for transfusion.



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PREPARING FOR TRANSPLANT

Both you and your donor will undergo a number of tests and procedures in preparation for the transplant. Your transplant physician will go over all of these with you. Here is a brief description of what you can expect:

FOR THE DONOR

The family member or unrelated donor whose blood matches yours will have a history and physical, blood tests and urine studies. These tests will ensure that no disease or condition precludes him or her from being a donor. Donors will also have a chest X-ray and an electrocardiogram (EKG).

Four days prior to transplant, the donor who is going to give peripheral blood stem cells begins to take a medication that helps his or her body make more blood stem cells. This process is called “mobilization.” This medication, a G-CSF (granulocyte colony stimulating factor), may cause some side-effects such as mild to moderate bone pain and headache; but these are manageable. The transplant coordinator will discuss these possible side effects with the donor.

Bone marrow donors may experience mild to moderate discomfort at the harvest sites in their hips. This is treated with pain medication. In some cases, bone marrow donors may also have their stem cells “mobilized.” This could cause similar, manageable “side-effects” mentioned above—mild to moderate bone pain and headache.

FOR THE RECIPIENT

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

Some of the tests that may be needed are:

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 or 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 function.

PET Scan A special X-ray utilizing nuclear medicine and CT scanning to determine whether or not any active cancer is present.

Pulmonary Function Test (PFT) This breathing test helps to determine the health 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 to help minimize any possible discomfort.

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.

CARING FOR YOUR CATHETER

Before your transplant, a special catheter will be inserted into the large vein near your collarbone. This device, called a central venous catheter, will be used for the infusion of stem cells and can also be used to draw blood and give you fluids, chemotherapy or other medications.

Inserting the catheter is a surgical procedure, but it is done as an outpatient on the morning of your admission for transplant. You will be asked not to eat or drink anything six hours before your catheter is placed. You and your family will be taught how to clean and flush the catheter.

THE TRANSPLANT UNIT

When you are ready for your transplant, you will be admitted to a special 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 not leave the unit unless it is 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, 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. 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 often harbor bacteria in the soil and water. For this reason they are not allowed in the unit. Visitors may bring balloons or silk flower arrangements.
7. No smoking is permitted within the hospital 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 for patients that are prepared following the diet for the immunocompromised patient guidelines given by the Transplant dietician.

Thank You!

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 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. An exercise bike, treadmill and set of stairs are also available for your use. Your nurse and physical therapist will help you create a reasonable exercise regimen. 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. Nutrition may be provided intravenously (TPN or Total Parenteral Nutrition), if you are unable to eat for an extended period.

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, mouth and throat sores, swelling of the 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

Receiving Donor Peripheral Blood Stem Cells or Bone Marrow The bone marrow or peripheral blood stem cells that have been collected from your donor are processed and brought to your room on the transplant unit. The cells are given to you like a blood transfusion through your IV line which is attached to your catheter. The transfusion generally takes 1 to 2 hours.

There may be side effects: chills, fever, hives and wheezing.

During the transplant your nurse will be with you and check your vital signs often. She or he will be on hand to handle any side effects you may have. After the peripheral blood stem cells or marrow have been transfused, you may receive other medications. These might include 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 transplanted bone marrow or stem cells “take” and begin producing blood cells. It may take up to 10–16 days after the transplant 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 to prevent bleeding.

All blood products that you receive will be irradiated to prevent graft-vs.-host disease caused by the immune cells in the transfusion. This precaution is necessary for at least 12 months after the transplant and perhaps for the rest of your life. Your doctor will give you more information about blood transfusion precautions.

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 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 in the BMT clinic.

POSSIBLE COMPLICATIONS

High-dose chemotherapy and radiation, and the low blood counts that 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 blood 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 this risk. If you develop a bacterial infection, you will be given IV antibiotics. Fungal or viral infections (which are more serious

and can be life-threatening) may also occur. These are treated with long-term IV medication. Once your white blood cell count has recovered, you will still be vulnerable to certain types of infections, such as fungus, yeast, cytomegalovirus, toxoplasmosis, herpes zoster, herpes simplex and pneumocystis carinii. You will be monitored vigilantly while in the hospital and also as an outpatient in the clinic setting.

Veno-Occlusive Disease This complication results from high doses of chemotherapy and affects the function of the liver, and occasionally the kidneys. In the early stages it can be treated with medications that prevent clotting. The severe form of this disease is very difficult to treat and may be fatal.

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.

Graft-vs.-Host Disease (GVHD) This complication, which is common in allogeneic transplants, occurs when the T cells (immune cells) in the new bone marrow or stem cells react to your body. The organs most often affected are the skin, bowel and liver. This condition can be mild, moderate or severe. If severe, GVHD can be life threatening. GVHD may develop soon after transplant (acute) or several months later (chronic). The chronic form may also affect your eyes, mouth, joints and lungs. Medications are given to prevent or minimize GVHD. You will be closely monitored for any signs of this complication.

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 “stem cell boost” may be offered, or possibly a second transplant.

Relapse Even after transplant, there is always a chance of recurrence. If the cancer returns, your physician will discuss with you and your family other possible treatment options.

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THE RECOVERY PROCESS

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YOUR FOLLOW-UP CARE

After your discharge from the hospital, you will be followed closely for several months so that any problems can be addressed quickly. You will be seen at the Roslyn and Leonard Stoler Pavilion in the Marlene and Stewart Greenebaum Cancer Center. Out-of-town patients may be required to stay in the area up to three months post-transplant, depending on the frequency of visits and potential complications encountered.

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 allogeneic transplant are usually seen 3 to 5 times per week during the first 3 months after transplant and one to two times a week from 6 to 12 months after transplant. If you have no complications, after a year you will be seen once every four months. 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 to Your Appointments It is important that you bring all medications, your medication schedule and this booklet with you during each outpatient visit. Depending on what test results show, your medications may change.

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 on 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, any 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 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



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CARING FOR YOURSELF AT HOME

Your body's immune functions are compromised after a transplant. For many months you will be less able to fight off infections and repel toxins than you were before the transplant. It is vital that you exercise certain precautions during your recovery period. You will be given a face mask at discharge to wear outdoors, and in some cases, indoors. This will help protect you from airborne germs. Following are other means for protecting yourself:

MAKING THE HOME ENVIRONMENT SAFE

Illnesses of Family Members/Friends It is important to remain as germ-free as possible at home. Inform your friends and relatives that they should not visit if they have a cold, the flu or any other illness. If someone living in your home becomes ill, you should try to have as little contact with her or him as possible. You may need to separate yourself entirely. Ask your doctor if you encounter this situation.

Plants All plants and flowers should be removed from the home after transplant. After your immune system has recovered, it is safe to be around plants, as long as you do not come in contact with the soil.

Pets Our goal is to keep you safe while your immune system is recovering. You should limit your exposure to pets as they carry parasites, viruses and fleas. Until cleared by your physician, you should not handle pet food, water or biological waste. You should also refrain from grooming your pet. Do not allow your pet to sleep in the bed with you. Please do not hug or kiss your pet. Any contact with your pet should be followed by thorough hand washing.

Toxins Some substances are particularly toxic to the bone marrow. These include paint fumes, cleaning solvents, unleaded gasoline, fertilizer and certain pesticides. Please avoid contact with these agents.

Housecleaning Certain activities such as dusting or vacuuming which stir up dust in the air are to be avoided. Go to another part of the house and wear your face mask when dusting or vacuuming is being done.

Gardening and Lawn Care These activities are STRICTLY off-limits until cleared by a physician.

CHILDREN

Immunizations If your children 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.

Handwashing Please teach proper hand washing techniques with any children that may be in contact with you. Encourage frequent hand washing, as well.

School The staff at your children's school should be informed to notify you at once if a communicable disease breaks out. If this happens, contact your physician.

Pre-school children should forego attending day care or preschool classes for at least six months after your transplant. This will decrease your exposure to colds, flu and viruses.

PERSONAL CARE

Bathing You may use either the shower or the tub, and be sure to bathe daily. Be sure the tub or shower stall is cleaned well before using it.

Hand Washing Bacteria and viruses are passed 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.

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 after approximately 6 months. 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 with a smooth texture are allowed if washed and peeled or cooked. Please refer to the diet for the immunocompromised patient that you receive in the 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!

GOING OUTDOORS

You have been in the hospital for a long time. You are understandably anxious to venture outdoors. You may do so—with some precautions.

Any time you leave home for any reason, even just to step outside to the mailbox, you need to slip on your face mask. The mask will filter the air for you and help prevent the transmission of germs. Wear your mask at all times when outdoors until your immune system has recovered.

Avoid areas where crowds gather: shopping malls, theaters, grocery stores, restaurants, churches or synagogues. Until your immune system has fully recovered, wear your mask if you expect to be in crowded places.

Do not swim until at least 12 months after the transplant. Hot tubs are especially to be avoided, as they harbor germs.

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 or graft-vs.-host disease. The timing will vary from six months to 12 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.

OVER-THE-COUNTER MEDICATIONS

Any over-the-counter medications should be cleared by your physician. Do not take aspirin or any medication that contains aspirin. Aspirin affects platelets and prolongs bleeding time. It can also irritate your stomach. This also includes unregulated herbal medications.

CARING FOR YOUR CATHETER

Your catheter will be used to draw blood and to give medication while you are an outpatient. This will eliminate the need for painful needle sticks. Continue to care for your catheter as you were instructed. Be alert to any signs of infection: fever, swelling, tenderness, redness of the arm, neck or chest on the same side of the body as the catheter, drainage, rash or bleeding. Report any of these symptoms immediately to your physician.



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 future. 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.

CULTIVATING 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 include relationships, enjoyable activities, spiritual pursuits or satisfying work. Take time now to clarify what is important to you and pursue it.

TAKING CARE OF YOUR BODY

It will take awhile for your body to recover from the 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.

Allogeneic Bone Marrow Transplant (BMT) or Peripheral Blood Stem Cell Transplant A transplant using marrow or stem cells taken from a compatible donor, either a family member or unrelated donor.

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 anticancer drugs.

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

Cytomegalovirus (CMV) An opportunistic infection. The virus is very common. Between 50% and 85% of the US population tests positive for CMV by the time they are 40 years old. A healthy immune system keeps this virus in check. When the immune defenses are weak, as they are after having a donor stem cell transplant, CMV can attack several parts of the body. Routine monitoring is done post transplant to evaluate for CMV.

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.

Graft versus Host Disease (GvHD) A condition that might occur after an allogeneic bone marrow transplant. In GvHD, the donated bone marrow or stem cells view the recipient's body as foreign, and the donated cells/bone marrow attack

the body. There are two forms of GvHD: Acute graft versus host disease (aGvHD) or Chronic graft versus host disease (cGvHD). As an allogeneic transplant recipient, you might experience either form of GvHD, both forms, or neither.

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

Human Leukocyte Antigen (HLA) A type of molecule found on the surface of most cells in the body. Human leukocyte antigens play an important part in the body's immune response to foreign substances. They make up a person's tissue type, which varies from person to person. Human leukocyte antigen tests are done before a donor stem cell or organ transplant, to find out if tissues match between the donor and the person receiving the transplant.

Immune Suppression 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).

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