

Blood and Marrow Transplantation Patient/Parent Handbook





Children's National

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IMPORTANT TELEPHONE NUMBERS

All members of the transplant team can be reached through the Children's National Medical Center Hospital Operator.

Blood and Marrow Transplant Clinic (8am – 5pm) (202) 476-5251

Hematology/Oncology/Blood and Marrow Transplant Unit (202) 476-5180

If your child is having a life-threatening emergency, which includes fever, chills, difficulty breathing, lethargy, persistent nausea, vomiting or diarrhea, please go directly to the Emergency Department.

Blood and Marrow Transplant Advice Line (202) 476-4267

Sick calls will be returned in 1 hour Non-urgent calls will be returned in 24 hours

Advanced Practice Providers (202) 476-6690

Blood and Marrow Transplant Physicians (202) 476-6690

Social Worker (202) 476-6749

Transplant Coordinator (202) 476-5456

Transplant Financial Coordinator (202) 476-8044

Clinical Program Coordinator (202) 476-3008

CNHS Emergency Room (202) 476-5200

Hospital Operator (202) 476-5000

Global Services (202) 476-3577

Hematology/Oncology Outpatient Clinic (202) 476-3940

Georgetown Radiation (202) 444-3320

Walgreens Pharmacy (202)-986-1467

East Pines Pharmacy (301) 459-6211

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INTRODUCTION

Welcome

to The Center for Blood and Marrow Transplantation (BMT) Program at Children's National Health System. The illness that brings you and your family to consider blood and marrow transplant has greatly affected your lives. We understand that this is a very difficult time and hope that the information in this handbook will help begin to answer your questions and address some of your concerns. All of the members of the BMT team are here to help you and your child go through transplant as smoothly as possible. We want you and your child to join us and be a part of our team. Let us know how we can make your child's hospital stay easier.

This handbook was developed by the BMT team members to help guide patients and their families throughout the transplant process. The term transplant will be used in this handbook to designate bone marrow, cord blood or peripheral blood stem cell transplants.

We understand that this is all new to you, and we believe that no question is too small or too silly to ask. We are here to help you, use this handbook to take notes, write down questions, and file any papers you are given (i.e., copies of consents). Bring this handbook to all of your visits so you can write down instructions from the medical team or refer to it for information. Although the hospital is an unusual place for a child and BMT is a serious procedure, blood and marrow transplantation at Children's National offers the hope of cure for many life-threatening childhood illnesses. The goal of the healthcare team is to provide expert medical, nursing, and emotional care for you and your child. We seek to raise the chances of a successful BMT, while working to preserve normal growth and development as much as possible. The hospital is not as comfortable as home, but we aim to provide friendly and cheerful patient- and family-centered care. The choice to have a transplant is a major decision. Each patient is unique and may react in a different way to their treatment. We encourage you to get to know other families; however, remember each patient responds and recovers differently. The entire process is complete and long. The staff will be working with you before, during and after the transplant.



CHILDREN'S NATIONAL HEALTH SYSTEM BLOOD AND MARROW TRANSPLANT PROGRAM

Children's National Health System has one of the premier stem cell and bone marrow transplantation programs in the country. This includes an 11-bed inpatient unit on the back corner of the fourth floor in the east wing of the hospital and directly across from the inpatient unit is the BMT Outpatient Clinic.

The unit employs a novel approach that provides patients with more mobility and access to activities during their stay. A specialized HEPA air-filtration system allows patients to leave their rooms to socialize and participate in functions on the unit.

Currently, the Children's National Blood and Marrow Transplant Program performs 30-40 transplants a year. A variety of bone marrow stem cell transplants are performed including those in which marrow stem cells are collected from the bone marrow or blood are used from a family member or an unrelated donor and even from the patient. In addition to these types of transplants we have special research protocols focused on the

use of alternative donors as well as selected diseases such as Neuroblastoma, Leukemia, Inborn errors of Metabolism, Thalassemia, Sickle Cell Anemia and Severe Immunodeficiency diseases.

The transplant team consists of doctors, nurses, nurse practitioners, physician assistants, social workers, pharmacists, dieticians, coordinators, child life specialists, psychologists and many others who work together to make the transplant process run as smoothly as possible. You will be included in all aspects of your child's care. In the following sections you will find a straightforward account of what to expect during a transplant.



BMT TEAM AND THEIR ROLES

This section will introduce you to the different professionals that make up the transplant team. You will come in contact with these people throughout your transplant process.



Attending Physician: These physicians are board certified in pediatric or adult hematology and/or oncology that specialize in bone marrow transplants. They oversee the medical care of your child and direct the team (fellows, nurse practitioners, and physician assistants). You will see them daily throughout your child's hospital stay. The attending BMT doctors will continue to follow your child in the clinic after discharge and will communicate often with your child's referring medical team to keep them informed. The attendings can take turns being on service and usually rotate every two weeks; however, they communicate with each other on a daily basis.

BMT Fellows: These physicians are licensed pediatricians who have completed residency training (hospital rotation) and are now training to become pediatric hematologists/oncologists. The fellows have monthly assignments on the BMT service and are on-call at night and on weekends. They will make "rounds" daily with the attending doctors and examine your child. They also help oversee your child's

care during the hospital stay. They are supervised by the attending physicians.

Nurse Practitioners/Physician Assistants: are licensed and board-certified with graduate-level training to perform physical exams, make medical diagnoses, and prescribe medicines. They work with the medical staff and team to provide an organized plan of care, follow your child's progress while in the hospital, and participate in the outpatient medical care. Their goal is to ensure that your child receives the best care throughout the transplant process.

Hospitalists: The hospitalists are physicians or nurse practitioners who provide care overnight who have experience in taking care of hemo/onc and BMT patients. Within BMT, hospitalists are on-site from 5:30pm – 6:45am providing overnight care.

Inpatient BMT Resource Nurse: These nurses are the liaisons between all members of the BMT team including the doctors, nurse practitioners, physician



assistants, clinical nurses, support services, patients, and families. These nurses provide support to the clinical nurse, child, and family, as well as coordinate the BMT discharge process.

Social Workers: The BMT social worker is specially trained to help patients and families cope with the effects of going through bone marrow transplant. Before admission to the hospital, the social worker will meet with your family to discuss any non-medical concerns or questions you may have about the transplant process. This information will be used to create an individual treatment plan. The social worker provides supportive counseling to help manage patient and family distress associated with treatment. S/he will also help families with financial assistance, transportation needs, work leave documentation, school questions and making referrals to the local Ronald McDonald House. The social worker collaborates closely with the medical team to ensure that the plan of care addresses the emotional, practical and spiritual needs of patients and families in conjunction with medical treatment.

Stem Cell Transplant Coordinator: This coordinator serves as the primary contact for financial approval of blood and marrow transplant and is the link between



the patient's family and the insurance company. The coordinator obtains insurance authorization for all testing and pre-transplant evaluations as well as authorization for the transplant. They are the liaisons between the insurance company's Case Management Department and the hospital for required follow-up medical reports. The coordinator also assists in scheduling the pre-transplant organ evaluation, central line placement and radiation if your child requires these.

Transplant Coordinator: The coordinator receives the new referrals from various doctors about patients who need a bone marrow transplant. The coordinator is responsible for serving as the liaison between the National Marrow Donor Program (NMDP) when finding an unrelated donor. The coordinator also helps scheduling work-up for the matched related donor.

Clinical Program Coordinator: This program coordinator is a nurse who will be providing education to you and your child before and after transplant. They are able to answer questions regarding your preparation for admission, care during transplant and follow-up after discharge.

ADDITIONAL MEMBERS OF THE TEAM

Hematology/Oncology/BMT Clinical Nurses:

The nurses on the transplant unit and clinic are licensed registered nurses (RN) trained in pediatrics. They have special training in hematology/oncology and BMT. They have had additional training to care specifically for children undergoing BMT by providing clinical as well as educational assistance for patients and families. These nurses coordinate the daily care of your child and provide you with resources while in the hospital to prepare you and your family for discharge. Traditional nursing shifts are 7am–7pm and 7pm–7am.

Shift Coordinators: The shift coordinators are the charge nurses on most shifts. They are responsible for the daily functions of the unit and create the nursing assignments. A charge nurse is available on the unit 24 hours a day if you have any questions or concerns specific to your child's nursing care.

Clinical Nurse Supervisors: These nurses are the nursing supervisors on the inpatient unit. One of the Clinical Supervisors is always available during business hours, Monday through Friday, on the unit for any questions or concerns regarding the nursing care in the unit in general. Please feel free to contact one of them by asking your nurse or the charge nurse.

Patient Care Technicians (PCTs) and Patient Services Associate (PSAs): The PCTs and PSAs have been specifically trained to care for children undergoing a transplant. They will take your child's vital signs, daily weight, change linen and can assist your child with bathing. They will also assist nurses with many different tasks. Like the nursing staff, the PCTs and PSAs are trained to work in either clinical setting (clinic and in-patient unit).

Case Managers: These nurses assist the team in planning your child's care to ensure you have a smooth transition home and into the outpatient setting. The managers will help identify and plan for any complex

discharge needs and coordinate these services with your insurance company and home care agencies. They will communicate with your insurance company all the necessary clinical information to cover most non-formulary drugs. Case managers will also contact you after your child has been discharged to ask about your hospital experience, check how your home care service is going, and address any concerns you might have.

Dietitian: The BMT dietician is a registered nutritionist. The dietician assesses and monitors the nutritional well-being of your child throughout the transplant process to help assure that adequate nutrition and normal growth patterns are maintained. Their role includes identifying and monitoring children who need nutritional support or diet education and identifying alternative nutritional therapy for children who are unable to eat. They also serve as a consultant in determining the need for additional nutritional support.

Pharmacists: Pharmacists working on the BMT unit are trained in the handling of chemotherapeutic agents and other supportive medications children undergoing transplant may need. In addition of the unit pharmacist, the BMT Service also has a clinical pharmacist who has completed additional training through special residency –training program in hematology/oncology. The role of the clinical pharmacist is to monitor all your child's medications for correct doses, side effects, drug interactions and drug levels in the blood. The clinical pharmacist is available to assist the BMT team and family with questions regarding drug therapy.

Physical Therapy/Occupational Therapy: A physical and occupational therapist will perform an initial screening of your child before the transplant and plan a physical strengthening and conditioning program for your child during and after BMT in order to maintain muscle strength and joint flexibility. If necessary, a treatment program

will be initiated to help your child in those areas. It is very important that your child maintain as normal a routine as possible while in the hospital to help your child feel well. Physical or occupational therapy may continue after discharge from the hospital if needed.

Child Life Specialist: A child life specialist focuses on the emotional and developmental needs of children and children's responses to the hospital. The specialists will help your child and family understand and cope with illness, treatment, and the overall hospital stay. They provide instructions and prepare children for medical procedures. This is done by therapeutic play to promote a sense of control and mastery about healthcare experiences and encourage the expression of thoughts and feelings.

Art Therapists: These therapists are specially-trained in both art therapy and clinical counseling. They provide art materials and guide the use of art in a therapeutic way to help children, teenagers, and young adults express themselves. Art therapy also encourages normalization and a sense of success and control in the hospital environment.

Music Therapists: These therapists are specially-trained in child development and children's responses to being in the hospital. They help children and their families cope with procedures and hospitalization through music.

Education Specialists: These specialists are here to assist your child with the transition from school to the hospital setting. Their primary purpose is to help students maintain academic skills during hospitalization. They have ongoing contact with home school and social work to keep ongoing communication with the school. They also help transitioning back to school when your child is able to return to school.

Pediatric Psychologists: Psychologists specialize in children's reactions and adaptation to serious illness, medical therapies, and hospitalization. They are available to provide assessment and supportive counseling before admission to BMT, including assessment of anxiety and understanding of the transplant process. The psychologist provides resources to help your family cope with hospitalization including the long hospital stay, medical procedures, and isolation. Following discharge, they are available to assist in transitioning home and the gradual return to a normal routine, including school.

Children who undergo BMT are followed carefully by our multidisciplinary team to monitor the impact of their intensive medical treatment upon growth and development. Some patients will have neuropsychological testing done prior to admission. If your child is tested, the results will be shared with you and can be shared with the child's school, if you decide this would be helpful.

Chaplain: Children's National Medical Center has a chaplain that is available for support and to assist families with any spiritual or religious concerns you may have.

PANDA Palliative Care Team: is a team of medical professionals who work in collaboration with the BMT team to provide an extra layer of support for the children, adolescents and young adults undergoing blood or marrow transplant and their families. PANDA works to prevent, reduce and soothe suffering in all forms with the goal of easing the burdens of transplant, whether physical, emotional, psychosocial or environmental.

PANDA helps patients and families to optimize quality of life by:

- Providing advanced pain and symptom management so that your child can be as comfortable as possible throughout the trajectory of BMT
- Supporting effective communication between patients/families and any involved medical teams
- Providing integrative therapies such as massage, Reiki therapy, aromatherapy, acupuncture, etc. as needed to relieve symptom distress
- Assisting with spiritual and ethical concerns
- Supporting siblings and extended family members

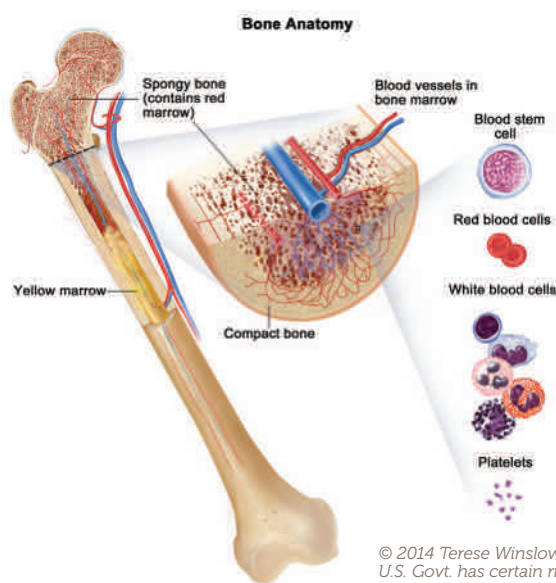
PANDA is a consultation service, so any recommendations are discussed with the primary BMT Team for safety. The PANDA Palliative Care Team works with all children admitted for BMT.

STEM CELLS, BLOOD AND THE IMMUNE SYSTEM

The information about the human body and the immune system will assist you in understanding the transplant process.

What is Bone Marrow?

The bone marrow is similar to a factory that makes blood cells. Bone marrow is a spongy substance found in the center of the bones. In the bone marrow, there are seed cells or parent cells, called stem cells. Stem cells can become any one of blood cell types; red blood cells, white blood cells, or platelets. Besides the bone marrow, stem cells are found in umbilical cord blood and in the peripheral blood. Many of the bones of your body contain bone marrow. The easiest place to obtain stem cells is from the hip bones. Stem cells will be obtained from the donor for a bone marrow transplant. In addition, the hip bones are also the location where bone marrow samples are obtained from the patient when needed for a bone marrow exam.



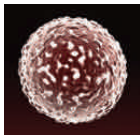
What are Blood Cells?



Red Blood Cells: The red blood cells (RBCs) carry oxygen from the lungs to all of the tissues in the body. There are two measures often used to quantify the amount of red blood cells:

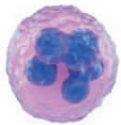
- **Hematocrit (Hct)** – this refers to the percentage or portion of the blood made up by RBCs, commonly about 33%.
- **Hemoglobin (Hgb)** – this is the amount of oxygen-carrying protein in the blood, common range is 12-16 grams/dL.

Normal ranges of hematocrit and hemoglobin are based on age and gender. However, children who have received chemotherapy and/or radiation often do not have these normal ranges. When the hemoglobin is low your child may experience symptoms of red blood cells such as fatigue, pale skin, increased heart rate, dizziness, shortness of breath. Your child may receive a blood transfusion when he/she experiences these symptoms. RBCs may take up to 12-90 days to recover post-transplant; but due to the differences in the RBC survival and the blood volume of the actual blood type switching may take several months. Transfusions are discussed in more detail in the "After Transplant" section of this handbook.



White blood cells: Many types of white blood cells (WBCs) help the body fight infection and disease. When the WBC count is low an infection can occur very easily

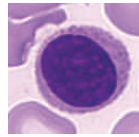
because the body has lost one part of the immune system which fights germs and viruses. There are three major types of white blood cells: neutrophils, monocytes and lymphocytes. White blood cells can take anywhere from 12-42 days to recover after transplant, but recovery times are different for each patient. The most important infection-fighting WBC is the neutrophil count. The number we look at is called your absolute neutrophil count (ANC). A healthy person has an ANC between 2,500 and 6,000. The ANC is found by multiplying the WBC count by the percent of neutrophils in the blood. For instance, if the WBC count is 8,000 and 50% of the WBCs are neutrophils, the ANC is 4,000 ($8,000 \times 0.50 = 4,000$). When the ANC drops below 1,000 it is called neutropenia. Your doctor will watch your ANC closely because the risk of infection is much higher when the ANC is below 500.



- **Neutrophils** – these cells are the body’s primary defense against harmful bacteria. They are non-specific cells that fight all bacterial infections. When neutrophils are low and the person has a fever of 100.5°F or greater, antibiotics are given to help fight the bacteria.



- **Monocytes** - these cells help in the fight against bacteria and mainly fight fungal, protozoan or parasitic infections.



- **Lymphocytes** - these cells help protect the body by making antibodies and regulating the immune system response. These cells fight all types of infections including bacterial, viral and fungal. There are two types of lymphocytes, T-cells and B-cells. T-cells recognize any foreign matter in the body and directs the immune system to attack these foreign substances. T-cells also activate the B-cells to produce antibodies that recognize a previous infection and attack the foreign substances more efficiently.

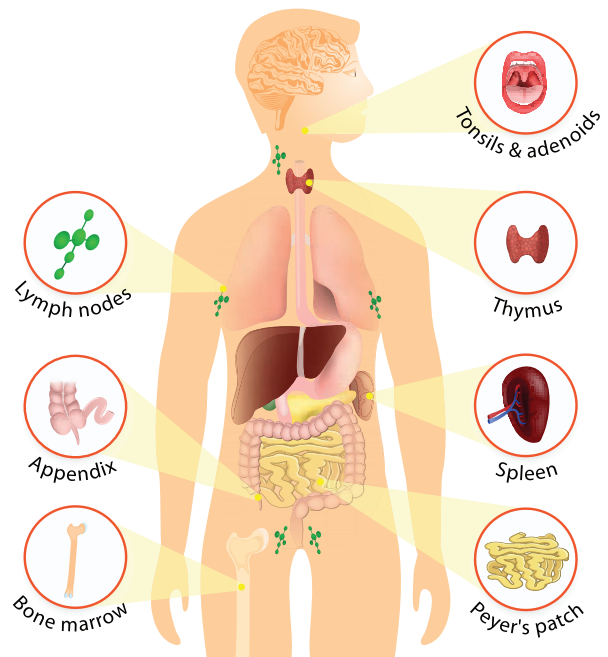


Platelets: Platelets have irregular-shapes and sticky surfaces that let them, along with other substances, form clots to stop bleeding. Platelets help prevent bruising and bleeding.

When your child has a low platelet count, or has evidence of bleeding, a platelet transfusion will be given. Petechiae are small red or purple spots on the body, caused by minor bleeds from broken capillary blood vessels. They may also appear on the skin or in the eyes when the platelet count is low. Platelets can take up to 28-90 days to recover post-transplant; again, recovery times are different for every patient.

The Immune System

The immune system is a complex system that creates the body’s defense against infection. The immune system is made up of white blood cells, the spleen, the thymus gland and lymph nodes. The immune system is able to recognize self and identify substances that belong in the body and substances that are foreign to the body. The immune system is genetically programmed to attack any foreign or “non-self” substance. Thus, in transplant, there is a risk that the new bone marrow may attack the host because it is recognized as foreign. This is known as graft versus host disease (GvHD) a topic that is discussed in more detail in the “After Transplant” section. Although all the blood cells may recover within 2 months, the immune system may take 6-18 months for full function to return.



WHAT IS STEM CELL TRANSPLANT

One goal of stem cell transplant is to replace unhealthy, failing or insufficient stem cells with normal stem cells. Another goal is to use donor stem cells to provide a source of healthy cells to make up for missing or defective blood metabolic functions. A third goal is to use a person's own stem cell to overcome the effects of chemotherapy.

Healthy stem cells are taken from a donor (can be from a family member or an unrelated individual or the patient). When stem cells are received from another person (allogeneic transplant), the new cells will identify the patient's body as foreign and will work to attack it. Therefore, the body must be prepared to accept the new marrow. A conditioning regimen or treatment is given in the form of chemotherapy, radiation, antibody therapy, or all three. This regimen empties the bone marrow space, kills any leftover cells and turns off the immune system to prevent an attack on the patient's body. The preparative regimen allows the stem cells to accept the new body. A stem cell transplant is a procedure similar to a blood transfusion. The transplanted stem cells seek out their place within the bone marrow space and begin to produce a whole new population of blood cells, including white blood cells, red blood cells, and platelets.

Until the new marrow produces healthy blood cells, your child will require support through red cell transfusions, platelet transfusions and antibiotics. Your child's immune system will not be able to fight infections initially because the immune system was suppressed or turned off during

the conditioning regimen. Special precautions will need to be taken to prevent or treat infections until the immune system is able to effectively fight infections.

Engraftment occurs when the new stem cells begin producing healthy blood cells in the bone marrow. This is first observed by a rise in your child's white blood cell count. Once your child's ANC is greater than 500 for three consecutive days engraftment has occurred. This is different from donor cell recovery; a blood test called Chimerism is sent once the patient has engrafted. The chimerism report shows what percentage of donor cells are in the blood sample. Ideally, in many diseases such as cancer, the chimerism should be 100% donor. After engraftment, your child will gradually need fewer transfusions as the new marrow is able to produce red blood cells and platelets. Complete recovery of the immune system occurs when the new lymphocytes begin to function normally. This may take six months to one year after transplant. Special blood tests indicate when recovery of the immune systems occurs. After the immune system has recovered, your child will need to repeat the recommended childhood immunizations.

Other Body Organs

Chemotherapy and radiation may affect the function of other body organs, such as the kidneys and liver. The function of your child's different body organs is evaluated

before, during and after the transplant. For further information, please see the section on "Preparing for the transplant."

WHEN IS A STEM CELL TRANSPLANT NECESSARY?

There are many reasons stem cell transplants are offered.

This treatment can provide normal bone marrow to patients:

- Whose own stem cells are abnormal, absent or defective (e.g. Aplastic Anemia)
- Whose own stem cells have been destroyed by chemotherapy or radiation therapy in order to treat cancer (e.g. Leukemia)
- With a genetic disease that affects all of the organs in the body (e.g. Hurler Syndrome)

A stem cell transplant usually requires treatment with high doses of chemotherapy or radiation which kills the patient's stem cells and then replaces or rescues the patient with donor cells. Depending on your child's diagnosis, it may be necessary to use a less toxic chemotherapy protocol, called sub-myeloablative transplant to allow gradual engraftment of the donor cell's with subsequent progressive replacement of the host's own cells and immunity. The patient may develop full donor chimerism without the long period of waiting for engraftment and with less of the toxic effects from the conditioning regimen.

The following is a list of some diseases or disorders in which stem cell transplant may be used for treatment.

Leukemia: This is a cancer of the white blood cells that develops in the stem cells. This cancer causes abnormal growth of white blood cells which crowd out the other normal blood cells. These abnormal white blood cells remain young or immature and do not work properly. The bone marrow cannot produce red blood cells, platelets, or normal white blood cells. A stem cell transplant is necessary to treat these cancers so that healthy normal blood cells can replace ineffective cells. There are different types of leukemia usually associated with different types of white blood cells. Common types of leukemia include:

- Acute Lymphocytic Leukemia (ALL) is the most common cancer of blood in children. It affects the lymphocytes.
- Acute Myelogenous Leukemia (AML) is also called acute myelocytic leukemia. It affects the granulocytes.
- Chronic Myelogenous Leukemia (CML) is a slowly

progressing form of leukemia that is more common in adults than in children. It also affects the granulocytes.

Solid tumors: Transplants have also been used to treat a variety of malignant solid tumors such as neuroblastomas, lymphomas and brain tumors. Unlike the leukemias, these types of cancer may not directly affect the patient's stem cells. This is why an autologous transplant (where the patient receives his or her own stem cells) may be used to treat these tumors. The treatment of solid tumors may require extremely high doses of chemotherapy and radiation, higher than can be given with standard chemotherapy regimens. The patient's stem cells are damaged and unable to recover. The transplant is given as a stem cell rescue. In this case, the patient's bone marrow is removed before the treatment begins and is frozen. The child receives high doses of chemotherapy and radiation which is intended to kill the tumor. The frozen stem cells are then thawed and returned to the patient.



Aplastic Anemia: Children with this disease are lacking all types of blood cells because the stem cells no longer function. Fevers and infections develop because there are not enough white blood cells to fight off bacteria or viruses in the body. Patients may bruise or bleed because there are not enough platelets to help the blood clot. The patient may tire easily because he/she is anemic, which means there are not enough red blood cells to carry oxygen throughout the body.

Sickle Cell Disease/Thalassemia: Sickle cell disease is characterized by red blood cells that assume an abnormal, rigid, sickle shape. Sickling decreases the cells' flexibility and results in their restricted movement through blood vessels, depriving downstream tissues of oxygen. With transplantation, patients receive normal stem cells which allow the production of all types of blood cells again. Thalassemia is caused by a genetic defect that results in a decreased rate of productions of one of the globin chains that make up hemoglobin. Reduced production can cause the formation of abnormal hemoglobin molecules and this in turn causes the anemia which is the characteristic presenting symptom of Thalassemia.

Inherited Metabolic Disease: These diseases are caused by a malfunctioning or missing protein that results in the collection of abnormal material in the liver, spleen, brain and lungs. These diseases include Hurler's Syndrome, Adrenoleukodystrophy and Metachromatic Leukodystrophy. With transplantation, patients receive normal stem cells which allow for the production of the malfunctioned or missing cells.

Immune Disorders: These diseases are caused by a missing or malfunctioning T lymphocyte cells in the immune system. These diseases include severe combined immunodeficiency disease (SCID) and Wiskott Aldrich Syndrome. After transplantation, the patient's new stem cells produce properly functioning T cells which create an effective immune system.

COMMON DISEASES TREATED BY TRANSPLANT

MALIGNANCIES

Leukemias

- AML – Acute Myelogenous leukemia
- ALL - Acute Lymphoblastic leukemia
- APL - Acute Biphenotypic leukemia
- CML – Chronic Myelogenous leukemia
- JCML – Juvenile Chronic Myelogenous leukemia
- MDS – Myelodysplastic syndrome (pre-leukemic syndrome)

Solid Tumors

- Neuroblastoma
- Medulloblastoma
- Osteosarcoma
- Ewing's Sarcoma
- PNET (brain tumor)

Lymphomas

- Hodgkin's
- Non-Hodgkin's

NON-MALIGNANCIES

- Severe Combined Immunodeficiency Syndrome (SCID)
- Wiskot Aldrich Syndrome (WAS)
- Blackfan Diamond Syndrome
- Hurler's Syndrome

- Adrenoleukodystrophy
- Chronic Granulomatous Disease (CGD)
- Hyper IgM Syndrome
- Hemophagocytic lymphohistiocytosis (HLH)

Hematologic Disorders

- Aplastic Anemia
- Sickle Cell Anemia
- Thalassemia major
- Fanconi Anemia

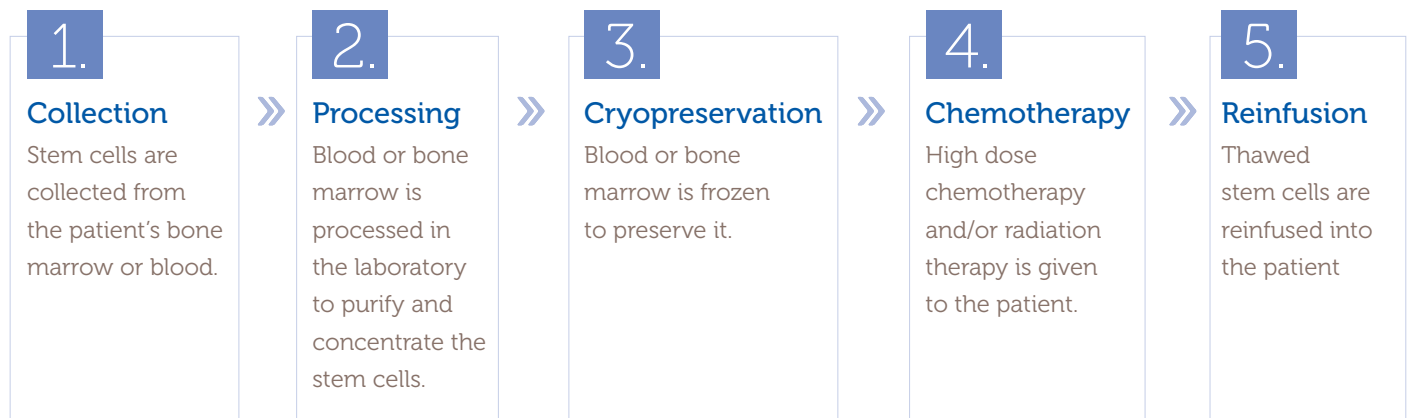


TYPES OF TRANSPLANTS

There are many types of transplants and many diseases for which it is used as treatment. These are the main types of transplants:

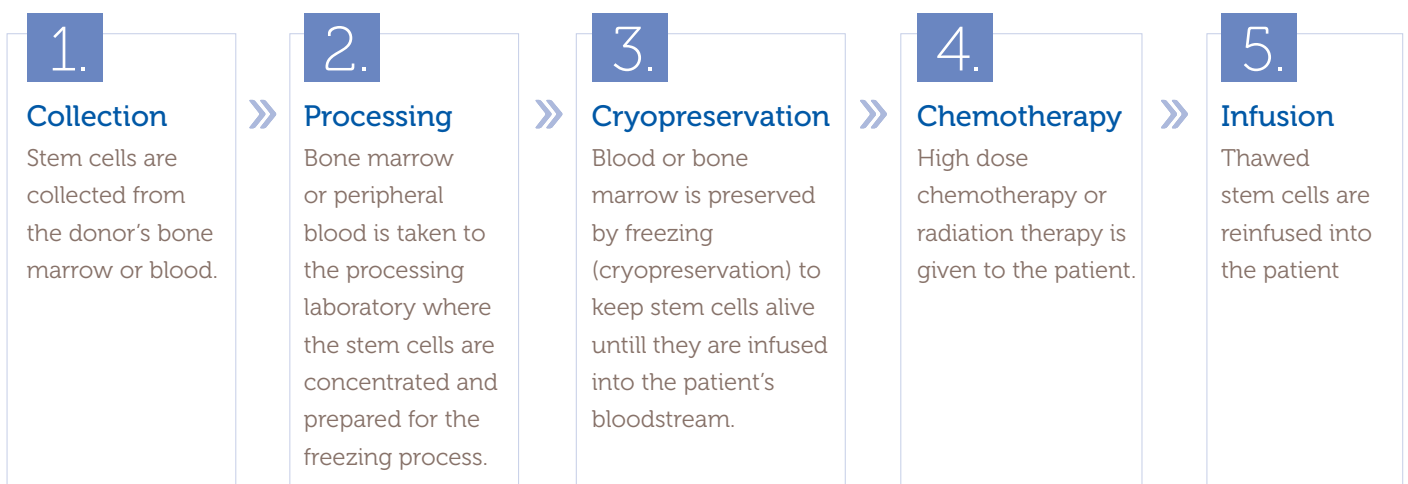
- **Autologous:** This type of transplant involves collecting your child's own stem cells and freezing it for use at a later time. After receiving high dose chemotherapy or radiation, the cells are thawed and infused into your child.

The Autologous Transplant Process



- **Allogeneic:** This type of transplant involves taking stem cells from someone other than the patient. The donor may be related or unrelated to the patient. To be a donor there is a specific test to be obtained called Human Leukocyte Antigen (HLA) tissue typing. Ideally, the donor's cells match the patient's cells to ensure that the stem cells will be accepted by the patient; however it is possible to use less than full match for transplantation. The process of tissue typing and matching is explained in detail in the following section. After your child has received high dose chemotherapy and/or radiation, the stem cells from the donor are collected and infused into your child. These types of transplants include bone marrow stem cells, peripheral blood stem cells and umbilical cord blood. Typically the stem cells are not frozen unless they are from an unrelated donor or are collected in advance.

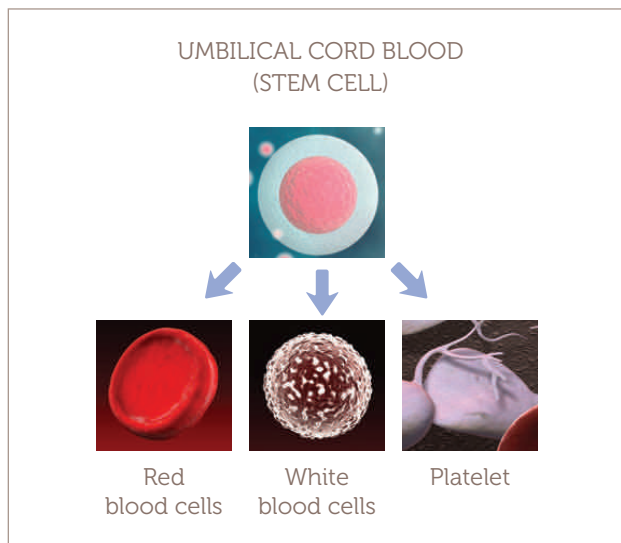
The Allogeneic Transplant Process



SOURCES OF TRANSPLANT

All blood cells come from very basic cells in the bone marrow called stem cells. These stem cells grow, divide and mature into different types of blood. After engraftment, these cells will help your child's body produce healthy blood cells. Stem cells are found in the bone marrow, peripheral blood and umbilical cord blood.

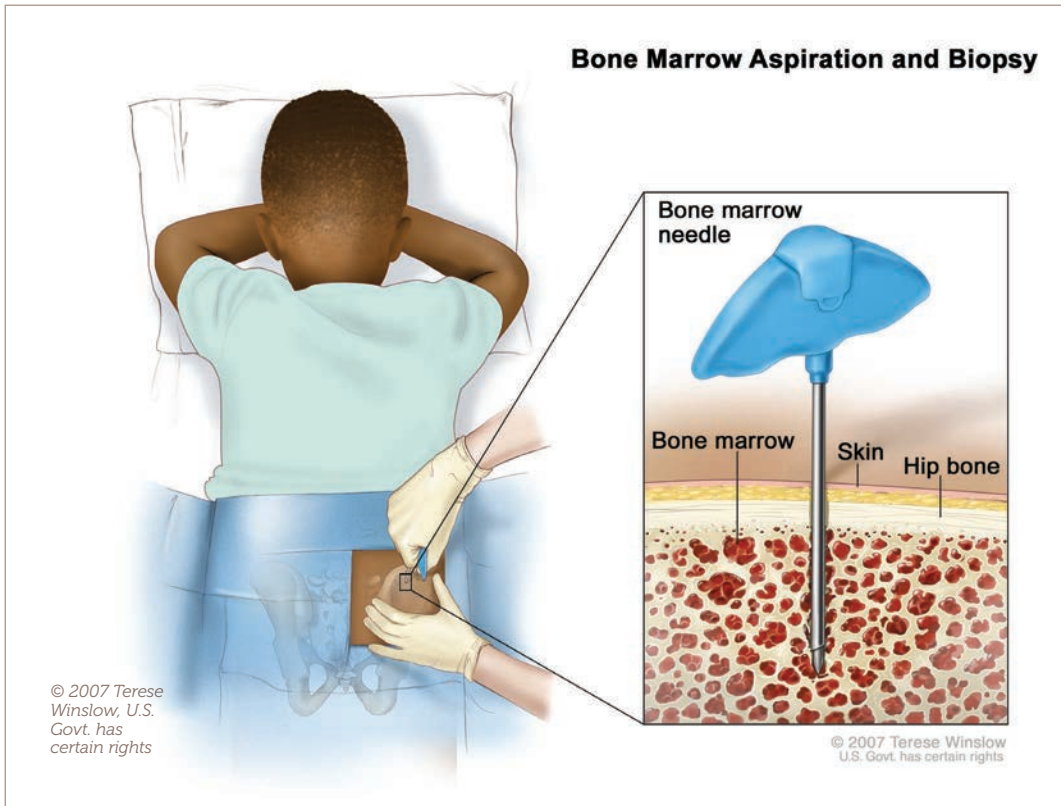
While bone marrow, peripheral blood and umbilical cord blood are considered equal in most ways, there are differences between them. The choice of which source will be used for your child will be discussed between you and the transplant team.



- **Stem cells:** The bone marrow harvest is performed in the operating room. The donor is asleep using general anesthesia. A needle is inserted into the hip or "iliac crest" where a large amount of stem cells are located. The stem cells are withdrawn through the needle with a syringe. One or two punctures on each hip through the skin and multiple bone punctures are required to harvest the needed amount of stem cells.



Bone Marrow Aspiration and Biopsy



- **Peripheral blood stem cells (PBSCs):** PBSCs are obtained by apheresis, using a special blood collection machine called a leukopheresis machine. Usually a special type of IV (catheter) is needed to allow blood to flow through the machine to collect the stem cells. If your child's veins are not large enough to obtain an adequate blood flow, he/she may need to have a special temporary catheter placed for the collection process.
- **Umbilical Cord Blood (UCB):** Umbilical cord blood is obtained from the umbilical cord and placenta after the birth of a baby. This blood is very rich in stem cells. This process poses a low health risk to the mother and the child. Only a small amount of blood can be taken from the umbilical cord and placenta, so the collected stem cells are typically used for children or small adults. The cells are frozen and then stored until an identical match is made with the product.

THE DONOR

When a child is being considered for a stem cell transplant, one of the first steps is to find out whether a family member is a suitable donor. This involves special blood studies on the patient and on his or her entire family. The standard test is called tissue typing. A second test is called high resolution DNA typing.

Human Leukocytes Antigen (HLA) Typing

HLA tissue typing is a blood test performed in order to identify the most suitable donor for a patient needing an allogeneic transplant. An antigen is a protein on the surface of the white blood cells. The HLA antigens are crucial in the recognition of self and foreign. The HLA antigens are determined by genes from each parent, resulting in two

pairs of antigens. Tissue typing is a test that identifies HLA antigens. Two groups of HLA antigens are important to tissue typing: Class I antigens and Class II antigens. Within each group, six antigens are evaluated for a possible match with your child. A perfect HLA match means that all of the donor HLA antigen types are identical to the recipients.

The following is an example of an HLA report:

A25, B38 (w4), Cw3, DR15 (DQ1, DR51) ← (inherited from mother)
A3, B7 (w6), Cw7, DR14 (DQ1, DR52) ← (inherited from father)

Inheritance Pattern of HLA Characteristics

Each potential donor will be tissue typed and these results will be compared to the patient's tissue type. The closest match is selected as the donor. A patient's best chance of finding a donor is within his or her family. Twenty-five percent of the patients who need a transplant will find a

donor within their family, related donor. For those without a family match, a search for an unrelated donor will be performed through a registry known as the National Marrow Donor Program (NMDP).

Partially-Matched Donor

A biologic parent is almost always half-matched, or haploidentical, which means half of the patient's HLA matches with his or her parent. There is a 50 percent chance that any sibling will be haploidentical with their sibling. In order for a haploidentical stem cell transplant to

work without resulting in a fatal graft-versus-host-disease (GvHD) reaction, the stem cells must be specially treated after they are collected from the donor and before they are transplanted into the patient. This treatment removes the donor T lymphocytes from the stem cells that cause

GvHD. Or the patient is given additional chemotherapy post-transplant to destroy the donor T lymphocytes. GvHD will be explained in greater detail later in this handbook. There are advantages and disadvantages to removal of the T lymphocytes from the product. The technique that is used to remove the cells reduces the risk and severity of GvHD occurring. However there is an added risk that the stem cells might not engraft. In order to improve the chances for successful engraftment, additional treatment with radiation and chemotherapy

may be added to the conditioning regimen. In some cases, children who have severe combined immunodeficiency disease (SCID) this is not used.

By removal of T cells, this may cause a delay in the recovery of the immune system, or the body's defense against infection, resulting in a higher risk of infections after transplant. T cell depleted stem cells from a parent, sibling or close relative may be considered for children who do not have an HLA-matched related or unrelated donor.

Alternative Donors

The majority of children with diseases that could be cured with a stem cell transplant will not have a matched related donor. For this reason, there are several alternative donor options.

- **Unrelated Donor** – When a related donor cannot be found, a search for an unrelated donor is conducted. An unrelated donor is an individual who is HLA matched with the patient, healthy and willing to donate stem cells.
- **Umbilical Cord Blood** – If a matched unrelated or stem cell donor is unavailable; another source of unrelated donor stem cells is umbilical cord blood

(UCB). There are many UCB banks worldwide which process and store cord blood. The cord blood, which is normally thrown away after the baby is born, contains stem cells. One potential advantage to using cord blood is that it does not have to be a perfect tissue match with the recipient. Another advantage is that there is no risk to the donor in the collection process. Disadvantages include the potential for an inadequate number of stem cells obtained during the collection. So for a large patient a large volume of cord blood would be needed and sometimes is not available. Also there is a relative delay in the recovery of marrow function post-transplant.

Selecting the Allogeneic Donor

Your BMT team will select the donor with the closest matched tissue typing to your child. Once the donor has been selected, he/she will need several blood tests to evaluate past exposure to different viruses such as cytomegalovirus (CMV), HIV and Hepatitis. For additional information on how the marrow is obtained from the donor, please see the Bone Marrow Harvest section of this handbook.

The identity of the unrelated donor will remain anonymous for the first year after transplant. Small gifts, cards and letters usually may be exchanged as long as there is no identifying information released; however, some of the international registries do not permit any

exchange of information between the donor and the recipient. Your Transplant Coordinator will be happy to help you with your paperwork and sharing information with the donor after the first year. You may thank the donor and also tell the donor about your hobbies, interests, school activities, pets, etc. You may not tell your name, address, city, state, phone number, name of the hospital or doctor or other health care providers. All letters are to be given unsealed to your Transplant Coordinator for review. If you have received a cord blood transplant, there will never be any way to correspond with the mother or family of the donated cord blood unit.

PREPARING FOR THE TRANSPLANT

Medical Evaluation

Before your child's admission to the transplant unit, the transplant team will assess his/her disease status and organ function. Your child will have several exams to ensure he/she is ready to proceed with transplant. The following is a list of some of the tests your child may receive:

- **Audiogram:** tests your child's hearing.
- **Blood work** – tests blood counts, clotting factors, salt in body and checking for evidence of virus exposure in the past.
- **Electrocardiogram (EKG) and echocardiogram:** tests heart function, as well as the rhythm and heart size.
- **Pulmonary Function tests (PFTs):** test your child's lung function. During PFTs, your child will be asked to breathe in and out of a tube to determine how well oxygen is being absorbed from his or her lungs.
- **Renal glomerular filtration rate (GFR):** tests your child's kidney function. The GFR involves injecting dye into an IV and drawing blood samples at one, two and four hours after the injection. This test measures how well your child's kidneys filter out the dye.
- **CAT Scan or MRI:** to look for disease or infection in certain parts of your child's body.
- **Bone marrow aspirate and spinal tap:** may be needed to look at disease status.
- **Dental Exam:** The mouth is examined for any teeth that may need a filling or may need to be pulled. These must be treated before transplant so they are not a source of infection later. It is important to keep the mouth clean and moisturized throughout the transplant process.
- **Ophthalmology Exam:** may be performed to evaluate your child's eyes and vision.
- **Neuropsychological Testing:** Your child may also have testing that includes intellectual, developmental and academic screening and review of school records.
- **Radiation Simulation:** If your child will be receiving total body or total lymphoid irradiation (the BMT team will let you know) as part of their pre-transplant preparative regimen a simulation will need to be done before admission. This is usually done at the time of the first appointment at the institution where radiation will be given. Our radiation is usually provided by Georgetown University Hospital. This visit will take approximately 4-6 hours and will involve meeting with the radiation oncologist (doctor who specializes in radiation therapy), the technicians and nurses who will give the treatments, and obtaining measurements of your child's body. This visit also allows your child to practice staying still in the position that will be used for the radiation treatments. If your child is too young to stay still for the treatments they will need to meet the anesthesia team as sedation will be required for the treatments. This is an important appointment that both parents/guardians should attend because you will meet the doctors and discuss the treatment methods and risks and benefits with the radiation oncologist. You will also sign consents for treatment.

Most of the tests should not cause your child any pain. The Pre-Transplant Coordinator will schedule these tests for you. It is very important to notify a member of the BMT Team immediately if any of the scheduled tests were missed. Your child will also need to be seen in the BMT clinic prior to admission. During this clinic visit, your child will have a physical exam and blood tests drawn to ensure

that your child is ready for transplant and does not have any infections.

For some children, additional evaluations by specialists in the nervous system (neurologists), hormonal glands (endocrinologists), lungs (pulmonologists) and heart (cardiologists) may be necessary. For some diseases a liver biopsy may be needed.

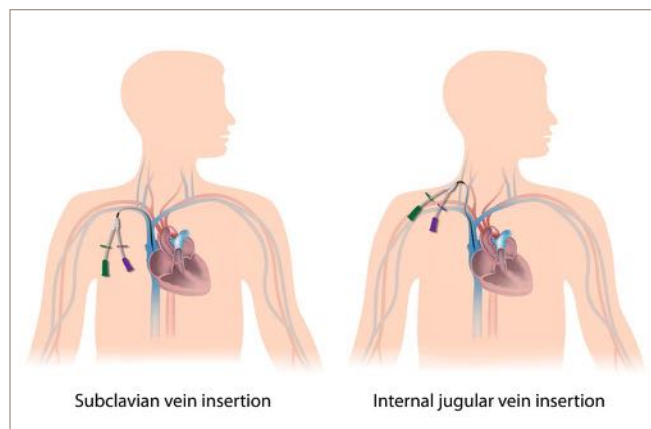
All of these evaluations will be done as an outpatient. While the pre-transplant work-up and evaluation is being completed, a tentative schedule is set for admission for transplant. This will vary depending on your child's need for additional treatment prior to transplant, whether an unrelated donor search is necessary and bed availability.

Social Isolation

Because many infections can be transmitted through casual contact, your child should stay away from ill people approximately two weeks before he/she is to be admitted to the hospital. Any suspected illness (cough, runny nose and fever) of your child should be reported to clinic as soon as possible.

If another child will be the stem cell donor, he/she may still attend school and other social outings, but will need to be kept away from people that are sick with a cold, flu or any other symptoms. Any suspected illness of the donor should be reported to the clinic as soon as possible.

Catheter Placement



Central venous catheters are special types of intravenous lines (IVs). Central venous catheters, remain in place throughout the entire transplant process and help avoid the pain and discomfort of multiple IVs and blood draws. A central venous catheter will be used to administer blood products, chemotherapy, nutrition and other medications, to draw blood required for daily tests and to infuse the stem cells. A pediatric surgeon will insert the catheter while your child is under general anesthesia. A small incision is made in the skin usually near the collar bone. The catheter is threaded into a large vein, which leads to the heart. The external end comes out of the skin in the middle of the chest. A total of two lumens are often necessary. Your child will feel some discomfort after the surgical procedure which should go away in a few days.



The central line will usually be left in place for several months after the transplant.

If a central venous catheter is not placed, then a PICC (peripherally inserted central catheter) will be placed. A PICC is inserted in an arm vein that leads towards the heart. PICCs are inserted by radiologists using ultrasound, chest radiographs and fluoroscopy to aid in their insertion and to confirm placement. Two primary caregivers will need to know how to care for your child's central line at home. Your nurses will provide classes and hands-on instruction, during your hospital stay, on how to care for your child's central line. You will be expected to know how to care for the central line before being discharged from the hospital.

Insurance Coverage

Stem cell transplantation is an expense covered by most insurance policies. You must check your policy to be sure. The Pre-Transplant Coordinator will also contact your insurance company to verify coverage and obtain approval. Medicaid covers most bone marrow transplants. Many insurance companies will require that you pay the deductible for the

calendar year. Deductibles will vary. There are incidental expenses associated with the transplant such as meals for the parent, parking, childcare for your other children, etc. Many families do not have the immediate financial reserve to meet this expense. Your social worker or pre-transplant coordinator can work with you regarding these expenses.

Psychological and Social Preparation

Your social worker will meet with you prior to transplant and discuss the major stresses of the transplant experience. Each child and family member is unique and will have individual ways of dealing with the challenges of a SCT. The social worker will try to get to know enough about your family to help you prepare for the challenges ahead. Your social worker will ask you a variety of questions about your child and family such as past medical experiences, other pressures on the family, sources of emotional support and typical ways family members cope with stress. These questions should help us understand what might make the transplant experience less difficult for all family members and help the team develop plans that fit your family as much as possible.

A few days before transplant or upon arrival to the transplant unit, the child life specialist will meet with you and your child to discuss the patient's understanding of transplant, preferred activities to create a normal environment and positive techniques. While in the clinic,

preparation for central line placement and an explanation of the transplant may be provided with the child life specialist through medical play and picture books. Specific questions or any misconceptions will be addressed at this time to help alleviate any anxiety that may be present.

A child life specialist and psychologist will also meet with the siblings to assess their understanding of the transplant process and hospitalization. The child life specialist will address concerns that the siblings may have during transplant which may include separation from parents and patient, the child's illness, length of hospitalization and visitation guidelines. The child life specialist will encourage communication between the sibling and patient throughout the transplant. If the sibling is a bone marrow donor, the child life specialist will provide teaching and education about the bone marrow harvest. The donor sibling may have special concerns that will be addressed according to each individual case.

ADMISSION TO THE STEM CELL TRANSPLANT

Upon admission to the stem cell transplant unit, a countdown period of usually five to 10 days begins. Day 0 marks the end of the countdown, which is the day of transplant. During the countdown period, the conditioning regimen is administered. This includes treatment with chemotherapy and/or radiation. Following transplant, the days are counted up (first day after transplant is Day +1).

The stem cell transplant inpatient unit is a special unit with a hepa-filtering system which filters out particles in the air. Due to this filtering system, the children are allowed to go outside their rooms to exercise but may not go outside the unit. Parents and visitors must understand that if they have or may have an infection, they risk spreading the infection to their child and other patients. For your child's safety and the safety of other patients, please observe these guidelines.

There are exceptions to this rule, if the patient needs any tests or procedures they will be allowed to go off the floor but they must wear their N95 mask. If any time during the admission the patient acquires an infection and gets placed on isolation, they must remain in their room.

Isolation procedures are designed to prevent the spread of a confirmed or suspected infectious contagious disease from one individual to another.

Parents may stay in the patient room which has a day bed, television, DVD player, phone, sink and private bathroom with a shower and bath. Children are not allowed to stay in the room overnight. During flu season, visitation policies may change per hospital policy. Each room is also equipped with a scale, so that there will be no cross contamination for the patients during their daily weight and also to ensure accuracy of the reading. The room is cleaned every day and everyone who enters the room must follow specific procedures to minimize complications associated with the transplant process.

Hand-washing

Hand washing is the best way to prevent infections. All patients and visitors must wash their hands before entering the stem cell transplant unit and again before entering the patient's room. Any time you exit the patient's room, you must rewash your hands before entering the patient's room. In addition, a person must re-wash their hands after using the bathroom, assisting the patient in the bathroom or preparing food.



Establishing a daily routine

We understand that the transplant process is a difficult one. However, we need your cooperation with the unit guidelines to aid your child's recovery. These guidelines

Daily Care

There are several routines that are done daily or several times a day to minimize those problems that may occur during the bone marrow transplant process.

- **Bathing:** Daily bathing with special soap or wipes will keep the skin germ free.
- **Mouth Care:** Mouth sores are a side effect of chemotherapy and radiation. Brushing the teeth and tongue with a soft toothbrush as well as using mouthwashes are essential to keep the mouth as clean as possible. Good mouth care can greatly reduce the severity of mouth sores.
- **Catheter Care:** Specific procedures and dressing changes will be followed to keep the catheter exit site clean.
- **Vital Signs:** Vital signs are taken around the clock every four hours starting at 8:00am. Temperature, blood pressure, heart rate, respirations and pulse oximetry will be monitored every four hours during your transplant hospitalization. It is necessary to

were developed to optimize your child's health, to decrease the risk of infection and maintain a normal daily routine as much as possible.



monitor these readings very closely. All patients are weighed at least once a day by 8AM. Fluid shifts in the body make it important to monitor weights closely.

- **School age children** should continue their lessons by weekly interaction with the educational specialists.

Visiting Policy

Children undergoing BMT have very weakened immune systems, making them open to developing life-threatening infections when exposed. Our visitation policy is intended to decrease the risk of such infections. Please keep in mind that visiting restrictions and policies may change during flu season or when deemed as necessary. Flu season usually runs from October to April. Please check with your nurse to see if different rules are in effect at this time.

ALL VISITORS will be screened, prior to entering the unit, for signs or symptoms of infections. Should you answer yes to any of the following questions, you are not allowed to visit the bone marrow transplant unit until you have recovered:

Have you had any of the following symptoms within the past 5 days?

- Fever (greater than or equal to 100°F OR feeling warm, shaking, chills, but no temperature taken)

- Cough
- Sore throat
- Body aches, chills, and fatigue
- Rash or other skin infections
- Vomiting or diarrhea

**** All visitors must be free from any of the above symptoms AND have not been in close contact with any sick individuals over the past 5 days**

- All visitors must follow posted isolation precautions.
- The BMT Team will encourage and educate your child, family and visitors of the importance of good hand washing, including not touching face, hair, or surfaces after hands are washed.

- There may not be more than four visitors, including the parents, in a patient's room or the BMT unit at a time. Prior to your admission for transplant, you will designate a total of 8 visitors. The list of visitors must be provided to the BMT team upon the day of admission. Visitors who are not on the list cannot enter the unit. All visitors must sign-in upon entering the unit and will be screened for signs of infection and must show proof of the injectable flu vaccine during flu season.
- Parents/guardians have access to their child 24 hours a day. Parents/guardians are welcome to spend the night in the room. Please observe the following guidelines:
 - Personal belongings may be kept in the room.
 - Restrooms, including showers, are available for parents and visitors outside of the child's room.
- Children Visiting the BMT Unit: Children who are not a sibling of the patient and are under the age of 16 are NOT allowed to visit. Children between the ages of 10 and 16 years old must be a sibling in order to visit. Children under the age of 10 are not allowed on the unit. Anyone under the age of 18 may not spend the night. Young children are more likely to carry diseases that could endanger the health of your transplanted child or other children in the hospital. We recommend that you pre-arrange visits with siblings with the nurse. All visitors must receive a health screen prior to visitation.
- All visitors under the age of 18 must provide proof of vaccination for Measles, Mumps, Rubella and Varicella.

- Siblings who pass the screening test may visit 12:00pm to 8:00pm daily for a maximum of 2 hours.
- Children must stay in the patient room at all times, and parents must supervise them to keep them safe. We ask that you assist your child in washing their hands. Visiting children should not be able to climb on your child's bed.

Please Note: Parents/guardians or visitors are not permitted to sit at the nurses' stations at any time. Confidential information is shared amongst staff at the nurses' stations, and it is our responsibility to maintain confidentiality for all patients.

Remember, the transplant process will span several weeks. Therefore, it is as important for the family as it is for the patient to get proper rest. For this reason it is best for the parents or caregivers to alternate their schedules if possible.



What to Pack

Planning for a stay in the hospital is never an easy task. It is even harder to try to plan for the extended stay during your child's transplant. Involve your child in the planning and preparation for the transplant period. Bring personal items to decorate your child's room to make it feel more like

their room at home. Posters or pictures will brighten up the room. Plants, synthetic flowers and fresh flowers are not permitted in the BMT Unit or Clinic because the soil and water may carry bacteria and fungus, which may make your child ill.

Most children prefer to wear their own clothes while in the hospital for transplant. Children often have a special

blanket or stuffed animal that they also want to bring with them. Only one special stuffed animal is allowed per child. It is required that any stuffed animal or special blankets be washed in hot water and dried on high heat. Remember to clean the lint filter before and after using the drier. Wash these items at least once per week during the transplant admission.

Avoid bringing old, dusty items that can carry germs. We recommend wiping all items with disinfecting wipes at home and placing them in plastic containers. Once you get to the hospital, these containers will need to be wiped down with our special disinfecting wipes; the staff will help you find these on the day of admission.

Books should be new or only used by your child. You can bring a radio, CDs, and/or a CD player or iPod. All items will be cleaned with disinfectant before entering the room. This also applies to DVDs.

Laptops and iPads are ok as well. There is internet access called "BearAir" available in the rooms if you need it. There are also computers available to parents in the Ronald McDonald Room and family library on the second floor in the main hospital.

- **Clothes:** Bring your child's favorite pajamas, t-shirts or night shirts. Laundry facilities are located within the hospital. Patient gowns can be provided if your child prefers them. We recommend loose-fitting clothing that allows easy access to the central line. All clothing must be changed at least once daily after their bath or shower. We suggest that your child's clothes be washed in hot water and dried on high heat until 100 days after the transplant.
- **Linen:** You may bring special or favorite blankets, pillows or comforters; however if these become soiled, your child will have to use hospital linen until you can

wash them. Linens, such as towels, washcloths, pillow cases and flat sheets, are in the cabinet outside your child's room. We expect your child's bed to be changed at least once a day, unless soiled, this includes linens from home, so please plan accordingly if you would like to bring them in. Please talk to your nurse or PCT about a good time to bathe your child and have their linens changed. The hospital provides pillows, but if your child has a special pillow, it should be newly purchased and in plastic until it is brought into the BMT room.

- **Toys:** Toys, games, puzzles and dolls are welcome in the BMT unit. Please bring books and activities to entertain your child. Older children can help by making a list of things they want to bring with them. Every room in the unit is equipped with a TV and DVD players are available. There are some movies on the unit but you are welcome to bring home videos or favorite movies. Be sure to label all your possessions with your name. All items should be able to be easily cleaned.

Special Considerations for Different Ages

Infants and toddlers may not be able to tell you what they want, but you know their favorites. Bring several toys and dolls that they play with repeatedly. Because this age group has a very short attention span, you will need to pack a variety of items. Movies are also good entertainment.

Preschoolers should be able to play by themselves for short periods of time. Favorite things from home such as dolls and stuffed toys, blocks, cars and puzzles encourage preschoolers to play alone. You should also bring things to do together such as simple games or books to read.

School-aged children can help to plan ahead and make a list of things they want to do during their hospital stay. Starting simple craft projects that have several steps are good for this age group. Choosing projects that are too difficult are often discouraging. Doodle-art pictures and snap together models are good choices.

Teenagers should take responsibility for planning what they want to have available to them during their extended hospital stay. Because they will want to keep in touch with their friends, they will want to make sure they have friends' phone numbers and email addresses with them. Craft projects, video games, books and music are things they will enjoy having available.

When you are first admitted, bring the most necessary items: clothes, toiletries and a few toys. As your stay continues, you can bring additional things from home. Bring pictures of family members and other important people in your child's life. Photos help remind you and your child that there is life outside the hospital. You can also plan on switching things out from home; posters and wall décor, or favorite blankets/pillow cases.

FACILITIES AND SERVICES AT CHILDREN'S NATIONAL



Cafeteria is on the second floor of the main hospital and serves three hot meals a day plus deli sandwiches, pizza, salad bar and assorted ice cream and desserts from 6:00am until 7:00pm.

Café is located on the seventh floor of the East Tower and serves light snacks, pizza, drinks and coffee. It is open from 7:00am until 11:00pm.

Snack Bar is on the second floor near the Cafeteria and offers food and drink vending machines and is open 24 hours a day.

Coffee Bars on the second floor of the West wing and in the main lobby. They are open during business hours on weekdays.

Bathrooms for parents and visitors are available in the BMT unit. You are asked not to use the bathroom in your child's BMT room (please see the section titled "Transplant"). You may use the shower before it is cleaned for the day or after your child has used it for the day. There is also a parent shower located just outside the BMT unit. A staff member will show you where it is located upon admission.

Telephones are in various other locations throughout the hospital. The telephone in the BMT room can be used only for outgoing local calls, not long distance. You can receive both local and long distance incoming calls. Phones located at the nursing stations are for medical personnel only. You may use your cell phone within the hospital; however, there may be times that cell phones are not to be used in the patient areas of the hospital. Please respect the need for strict compliance of this rule.

Laundry Facilities

Self-serve washers and dryers are located in the Ronald McDonald room just outside of the inpatient unit on the 4th floor of the East Tower. They are available at no charge; however, detergent and fabric softener are not

provided by the hospital and must be obtained by each individual family. We recommend using detergents and softeners that are fragrance free and dye free as patients who are undergoing transplant have very sensitive skin.

Meals for Parents

Parents can purchase food from the cafeteria. The refrigerators located in the patient rooms can store food for the family. Food for BMT patients must be stored in the refrigerator located in the corner of the BMT unit between Patient Rooms 427 and 428. This refrigerator is regulated and the temperature is monitored. If you keep food in this refrigerator, please label the contents with the patients

name and date. There is also a microwave oven located next to the refrigerator for your use. Please do not leave any opened food in the patient's room for longer than one hour. There are also a variety of places to eat around the hospital including the cafeteria, café and nearby restaurants.

Family Support



Ronald McDonald Family Room is a lounge for the use of parents and siblings of children staying on the Hem/Onc Unit and the Blood and Marrow Transplant Unit. A microwave oven and refrigerator are available for heating and storing

your food. Parents can also make use of the computer, attend support groups and educational sessions, as well as

obtain educational materials in the room. Children must be supervised by an adult at all times while in this room. There are computers with internet access available for use. The washer and dryer are located in the family living room. Please note that you will need to bring your own laundry detergent as it is not provided by the hospital. There is also a Ronald McDonald representative on staff that is available to help with additional resources that you may need.

The Ronald McDonald Family Room

Operated by Ronald McDonald House Charities® of Greater Washington, DC (RMHC DC)



RMHC DC's mission is to ease the hardship of childhood illness on families. A local nonprofit, RMHC DC's programs include two Ronald McDonald Houses®, the Kids Mobile Medical Clinic/Ronald McDonald Care Mobile® and the Ronald McDonald Family Room®.

The Ronald McDonald Family Room (RMFR) is located on the Hematology/Oncology floor on the left side of the hallway just beyond the unit clerk and fire door. The RMFR is intended to be a quiet comfortable home-like place of respite for parents and other caregivers of Hematology/

Oncology patients. The room features a kitchen with a refrigerator, microwave, dishwasher, coffee maker, and dining tables, as well as a washer and dryer, computer stations, and common area.

RMHC DC staff work with Children's Social Work and Child Life Departments to provide programming in the room, from support groups and educational programs to relaxing distractions such as yoga and knitting. A monthly calendar is posted in the room.

The entire RMFR is open for up to 12 hours a day with RMHC DC staff and volunteers on-site to welcome and assist visitors and maintain the room. After hours only

the kitchen/laundry side remains accessible and visitors are asked to sign in at the unit clerk's desk and then be badged into the room by the unit clerk. Licensing requires that visitors sign in so we would greatly appreciate your cooperation.

RMHC DC relies on the generous donations of others to support our programs. We do ask those who use the room to be respectful of all by helping us conserve and stretch our resources. The RMFR staff can tell you more about how you can help.

We look forward to meeting you and to making your stay a little easier



Hospital Chapel is located on the third floor next to the bank of elevators. The chapel is open for prayer twenty-four hours a day. Children's Hospital observes many religious holidays. Notices by hospital elevators and overhead announcements will indicate the time and place of these observances.

Patient and Family Library is located on the second floor near the cafeteria. This library has an excellent choice of children's books for all ages. This library also has current information for parents on diseases, treatments, and support groups to supplement the information your physician gives you. All of the library materials are available on loan and you can visit the library directly. These books cannot be taken into your child's BMT room. Volunteer services is also available to obtain books

Interpreter Services are available if your primary language is not English, the hospital will provide translating services. Meetings using an interpreter are prearranged when possible. Each patient room is equipped with a

Cyacom ("blue") phone which offers hundreds of different languages to be translated via the phone.

Parking is available in the parking garage located underneath the hospital. The cost for parking is posted in the parking garage. The Social Workers can assist in purchasing parking coupons. Please be sure to lock your car and remove all valuables because the hospital cannot take responsibility for stolen items.

Public Transportation is provided by the Washington Metropolitan Area Transit Authority. The Metrobus stops outside the hospital's front door, on Michigan Avenue.

Metro subway station the nearest stations are Brookland/ CUA (Red Line) and Columbia Heights (Green and Yellow Lines). Regular free shuttle-bus service is available from the station to the hospital and back during business hours. To find the shuttle buses, exit the station and turn to your left. The shuttle buses stop on the circular driveway to the left of the main parking lot and Metrobus stops. Look for the Dr. Bear logo on the side of the shuttle bus or ask the bus driver to verify that it stops at Children's Hospital. You

can catch the return shuttle bus right outside the main door of the hospital on the P1 level of the parking garage. Check with the information desk in the main atrium for a shuttle bus schedule. More information about the subway and Metrobus is available at <http://www.wmata.com>.

Taxis can be called for you from the information desk on the first floor (in the atrium).

Ronald McDonald House shuttle runs twice a day between the Ronald McDonald House and Children's Hospital. Contact the Ronald McDonald House for the schedule at (202) 529-8204.



Other facilities and services

Walgreen's Pharmacy is located in the first floor atrium near the people movers to the parking lot. Walgreens is open Monday - Friday, 8:00am to 9:00pm, and Saturday and Sunday, 10:00am to 6:00pm. and offers prescription and non-prescription medications, smoking cessation items, specialty medical equipment, toiletries, gift items, and healthy food and beverages.

Children's National Medical Center is a **Non-Smoking facility**. Smoking is not permitted any place inside or around the hospital. If you wish to smoke, you must go off the hospital property.

Picnic Tables are available outside the front door of the hospital. Food may be ordered "to go" from the cafeteria and taken outside to these picnic tables in fair weather.

Automatic Teller Machine is located in the first floor atrium next to the cashier's booth. There is a second ATM machine located in the cafeteria. In addition, the cashier's window will cash personal checks up to \$25 per day for parents of inpatients only.

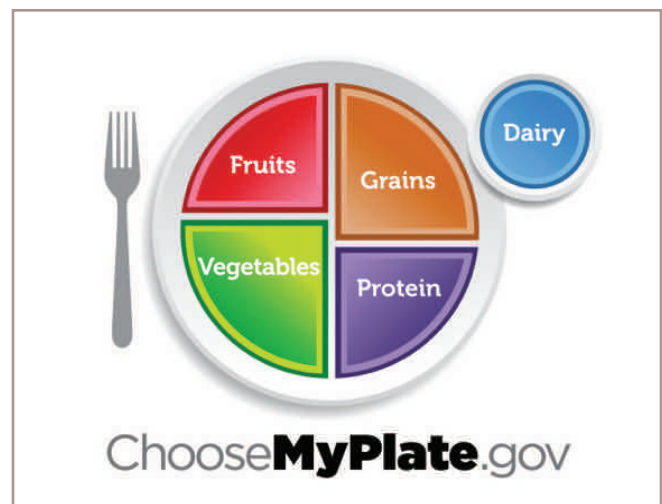
Adult Medical Services are available at our neighboring hospital, The Washington Hospital Center, which has emergency services as well as all subspecialty services available. Our medical staff is not available to provide medical care for adults. Siblings who are in the area and become ill should be seen by their pediatrician but may be seen at our Emergency Room for emergency medical care.

DIETARY CONCERNS DURING STEM CELL TRANSPLANT

Stem cell transplant patients are very susceptible to germs that could be transmitted from food and beverages. In an effort to provide a more protected environment, BMT patients are placed on a special diet upon admission. The dietitian will discuss specifics of this diet as well as some important additional information regarding safe food handling practices.

Bone Marrow Transplant Diet

The BMT diet is one in which specific foods have been excluded in an effort to reduce the risk of infection from bacteria. A low bacteria diet is a special diet that avoids foods that contain bacteria and/or are at risk of bacterial contamination. We want your child to eat as normal as possible, while keeping them safe. While on this diet, your child cannot eat leftovers, at restaurants, nor have food brought in from restaurants. Also, to prevent infection, food or beverages cannot stay at room temperature for more than one hour. Besides minimizing the risk of infection, the goals of this diet are to promote growth and prevent loss of lean body tissues providing adequate but not excessive calories and/or protein. Milk products (except yogurt) are initially allowed on the diet but may be restricted if diarrhea and vomiting occur. Your BMT team will inform you of when it is safe to have restaurant food. These diet



guidelines are temporary. They will be changed as your child's body recovers from the transplant. The special diet will be stopped when adequate engraftment occurs.

General guidelines for food during transplant:

- Don't leave meal trays sitting in patient rooms over 60 minutes without refrigeration or re-heating.
- Proper refrigeration and heating is necessary for all food.
- Follow food and safety guidelines.
- You may cook food at home and bring it to the hospital. Please follow the food safety guidelines when preparing all foods (see Tips for Food Safety below). All food must be properly washed and then fully-cooked to appropriate temperatures. If you have made something fresh and are coming into the hospital, the food must be eaten within 24 hours of preparation. You may also cook a large batch of food, portion it into smaller containers, and freeze it before bringing it into the hospital.
- You may purchase individual pre-packaged items such as canned soups, packaged cookies, puddings, juices, Lunchables™, and frozen meals. Prepared foods from the deli or deli meats are not allowed on the diet. Please ask your team if there are foods that you would like to bring in but are unsure if they are safe.

- If your child is taking any herbal supplements, health foods, vitamins or other alternative therapies, please notify the BMT team as some alternative therapies may interact with certain medications.
- Restaurant and cafeteria food is not allowed with a low bacteria diet because there is no way to make sure food is being cooked and handled properly. Foods that are not cooked or handled properly may cause infections.
- In general, it is recommended that patients having an autologous transplant continue this diet for 60 days and patients who have an allogeneic transplant follow

this diet for at least 100 days. Your child may require the diet for a longer period of time if they are on two or more immunosuppressive drugs (e.g. cyclosporine, prednisone, tacrolimus, or cellcept). Your healthcare provider will tell you how long your child needs to remain on this diet.

AUTOLOGOUS transplant follow this diet for at least 60 days.

ALLOGENEIC transplant follow this diet for at least 100 days.

The following pages list foods that are allowed and not allowed on a BMT diet.

FOODS	ALLOWED	FOODS TO AVOID
Fruits and Juices	<ul style="list-style-type: none"> ■ All canned fruits or fruit juices ■ Cooked fresh fruits ■ Unblemished, washed and peeled bananas, oranges, melons without visible mold 	<ul style="list-style-type: none"> ■ All other fresh fruits (e.g. grapefruit, berries) ■ No dried fruits (raisins, unless cooked with food) ■ No frozen fruit ■ No freeze dried fruit
Bread, Cereals and Other Starches	<ul style="list-style-type: none"> ■ All breads, hot/dry cereals, pasta, rice, cooked potatoes ■ Processed foods (e.g. potato chips, corn chips, crackers, tortilla chips) from single serving packages 	<ul style="list-style-type: none"> ■ Raw, uncooked grains ■ Sweet rolls with cream or custard filling ■ Unprocessed bran ■ Cold and hot cereals with dried fruits, nuts or coconut added after cooking ■ Raw potato
Meat and Protein Products	<ul style="list-style-type: none"> ■ Fully-cooked/canned beef, chicken, turkey, pork, fish/shellfish, seafood, hot dogs, bacon, sausage, tofu ■ Fully cooked eggs ■ Commercially packaged luncheon meats ■ Commercially packaged peanut butter ■ Cooked soy products, beans and legumes ■ Roasted nuts in individual packages 	<ul style="list-style-type: none"> ■ Raw and undercooked meats or seafood ■ Raw or partially cooked eggs including yolk, Eggnog (unless pasteurized) ■ Lox, pickled fish, sushi ■ Hard, cured salami in natural wrap ■ Meats from the deli counter ■ Jerky ■ Miso/tempeh ■ Unroasted or raw nuts
Vegetables	<ul style="list-style-type: none"> ■ Cooked vegetables (fresh or frozen) ■ Canned vegetables ■ Canned vegetable juices ■ Canned or bottled salsa 	<ul style="list-style-type: none"> ■ Raw vegetables/herbs (salads) ■ Raw vegetable juices ■ Raw or uncooked salsa ■ Prepared food from deli or salad bar
Dairy Products	<ul style="list-style-type: none"> ■ All pasteurized milk & dairy products (e.g. cheese, butter, cream) ■ Packaged cheese with pasteurized milk ■ Packaged ice cream/bars, frozen yogurt, sherbet 	<ul style="list-style-type: none"> ■ Yogurt ■ Unpasteurized dairy products (milk, cheese, yogurt, butter, cream) ■ Cheeses from deli ■ Cheese with molds (e.g. blue, gorgonzola) ■ Cheese with chili pepper or uncooked vegetables ■ Sharp cheddar, brie, feta, camembert, and farmer's cheese ■ Ice cream & yogurt from soft-serve machines ■ Freal shakes

What if my child's appetite decreases?

It is expected that your child's appetite will decrease while undergoing a transplant and may remain this way after the transplant. Some of the side effects that are common include nausea, vomiting, taste changes and a sore or dry mouth. Because of these side effects, most children will require temporary nutrition support which may include a nasogastric feeding tube or total parenteral nutrition, which is given intravenously. If needed, your medical team will discuss the best option for your child.



FOODS	ALLOWED	FOODS TO AVOID
Beverages	<ul style="list-style-type: none"> ■ Carbonated drinks or water in individual cans or bottles ■ Kool-Aid, canned fruit drinks, water, Gatorade, lemonade ■ Bottled waterx ■ Limit Coffee 	<ul style="list-style-type: none"> ■ Avoid milk drinks if demonstrates symptoms of intolerance ■ Freshly squeezed juices ■ Tea ■ Grapefruit juice
Supplements/ Formula	<ul style="list-style-type: none"> ■ Any canned or packaged supplement (e.g. Pediasure, Resource, Breeze, Ensure, Ensure Plus, etc.) ■ Lactose free infant formula, All Soy, Prosobee 	
Soups	<ul style="list-style-type: none"> ■ All canned or individual serving cans of water based soups or stews ■ Cream based soups as tolerated 	<ul style="list-style-type: none"> ■ Cold soups such as Gazpacho
Fats	<ul style="list-style-type: none"> ■ Individual serving margarine, butter ■ Salad dressings, or vegetable oils ■ Cooked gravy ■ Peanut Butter 	<ul style="list-style-type: none"> ■ Fresh or homemade salad dressing; dressings that contain aged cheese (e.g. blue, Roquefort) or raw eggs (e.g. Caesar)
Miscellaneous	<ul style="list-style-type: none"> ■ Frozen meals (e.g. Stouffers) ■ Lunchables 	<ul style="list-style-type: none"> ■ NO restaurant foods, items from the bakery or foods from hospital cafeteria ■ Foods from sidewalk vendor ■ Prepared food from vending machine ■ Fountain drinks (Slurpees, fast food)

** Do not give any type of honey to any children less than one year of age and all children with SCID until a year after transplant.

PREPARATIVE REGIMEN

Chemotherapy

Chemotherapy is used to empty the bone marrow space, kill any residual cancer cells and turn off the immune system to prevent rejection of the new bone marrow. This will allow the new bone marrow to engraft and eventually produce healthy blood cells.

There are several different medications or agents. The chemotherapy agents will be administered through your child's central line. Your child may receive one or more chemotherapy agents for several days.

Members of the BMT team will discuss your child's specific chemotherapy agents. There are several potential/possible side effects which will be discussed with you. The diagnostic testing performed before your child's transplant provides information regarding your child's ability to handle the chemotherapy medications. The BMT team is always monitoring for any side effects.



Total Body Irradiation

Total body irradiation (TBI) is given to some patients undergoing allogeneic stem cell transplants. The purpose of radiation therapy is to kill any residual cancer cells and weaken your child's immune system so that rejection of the new marrow is less likely. The radiation is usually given to the entire body. They are called "fractionated" because they are given over several days, sometimes 2 or 3 times daily. Each treatment may take from 10 to 30 minutes.

An appointment with the radiotherapist will be made one to two weeks before your child's scheduled admission to assess the amount of radiation your child needs and discuss the treatment and side effects.

The radiation treatments will be given at Georgetown University Hospital, located a short distance from Children's National Health System. On the day your child receives TBI, the nursing staff will arrange transportation by ambulance to and from this location for you. You are permitted to ride with your child in the ambulance. For

your safety, you cannot be in the room with your child during these treatments.

Having a radiation treatment is something like having an x-ray.

- It is painless.
- Your child and the clothing does not become radioactive during or after the treatments.
- Your child's body does not pass the radiation on to other people.
- Your child's lungs are sensitive to high dose radiation, so they will be covered with special lead shields for some of the treatments. These shields are made for your child in the radiation treatment.
- When your child goes for treatment, he or she will wear an N95 mask.
- Your child should not wear any jewelry during radiation treatment because the metal may increase the radiation dose to that area.

General Side Effects of Chemotherapy and Radiation

Side effects are the unwanted effects the chemotherapy and radiation have on your child's body. Some will happen quickly and disappear after several days, while others will occur more gradually and last for several weeks to years. Large doses of chemotherapy and radiation destroy many of the rapidly dividing cells in the body including abnormal and normal cells.

Areas of the body that have rapidly dividing cells include the skin, hair and digestive tract. These areas of the body often display early side effects. Early side effects include hair loss, nausea, vomiting, and diarrhea, loss of appetite, skin rashes and changes in the taste of food, oral ulcerations and weight gain. These side effects are temporary and there are medications available to lessen many of these effects. Your child's skin may become more darkened or slightly red from

radiation therapy. Your child's skin will be more sensitive to radiation therapy if any lotions or creams are on the skin during those treatments. For this reason, do not apply any lotions or creams to your child's skin during the days he/she receives radiation therapy.

After the chemotherapy and radiation therapy your child will not be able to produce white blood cells, red blood cells or platelets until the new bone marrow begins working. Before the child's new bone marrow can produce new cells, your child will have limited ability to fight infections. Decreased platelets mean your child may bruise or bleed easily. Platelet transfusions will be given as needed. Lower hemoglobin levels may make your child feel weak and tired. Red blood cells will also be transfused as needed.

MEDICATIONS

Oral and Intravenous Medications

Many medicines are given throughout the transplant period to reduce side effects and prevent infections that occur in a transplant recipient. Many of these medicines continue until the stem cells have engrafted and some continue for many weeks.

ANTIMICROBIALS: These medicines prevent and treat infections caused by bacteria, viruses or fungi. These medications include:

- **Warm Saline Rinse** is a salt mouthwash used to clean the mouth. The rinse should be swished throughout the mouth for 30 seconds and spit out at least three times a day.
- **Voriconazole/Caspofungin** are antifungal medications given by mouth or IV to prevent and treat fungal infections.
- **Acyclovir/Valacyclovir** are antiviral medications given by mouth or IV if your child has been exposed to or develops the herpes or varicella virus infection (determined from a blood test drawn before transplant).
- **Bactrim™/Pentamidine** are antibiotics used to prevent pneumonia caused by Pnuemocystis carinii. If your child is allergic to sulfa drugs Pentamidine or Atovaquone will be used.



- **Ganciclovir/Foscarnet** are antivirals that are given IV. If a patient or donor has had a previous exposure to the cytomegalovirus (CMV), one of these antivirals will be given to prevent reactivation of this infection after transplant.

ANTI-NAUSEA MEDICINES: are given to prevent or treat nausea and vomiting.

- **Zofran** is an anti-nausea medicine given either by mouth or IV. It is given before radiation therapy and chemotherapy and continued until the nausea and vomiting subsides.
- **Phenergan, Reglan, Ativan and Benadryl** are other anti-nausea medications that can be given by mouth or IV to control nausea and vomiting. There are many combinations of anti-nausea medications to give to your child to make them comfortable during their treatment. If one medicine works better for your child's nausea, please let the nurse or doctor know.

IMMUNOSUPPRESSIVE AGENTS are medications given to suppress your child's immune system. These medications prevent the new bone marrow from rejecting and are used to prevent graft-versus-host-disease (GvHD).

- **Methotrexate** is a medicine given by IV and is usually thought of as a chemotherapy agent. The dose used in BMT is much lower than doses used for chemotherapy. After an allogeneic transplant, it is used to prevent GvHD.
- **Cyclosporine/Tacrolimus** are other medications used to prevent GvHD. It is given intravenously starting two – three days prior to the stem cell transplant. As your child's discharge day gets closer it will be changed to an oral form. Your child will continue to take the medication until the risk of GvHD has lessened. These medications require blood levels to be monitored so that the appropriate dose is given to correctly prevent GvHD.
- **Mycophenolate Mofetil (MMF)** is another medication used to treat acute or chronic GvHD by suppressing your child's immune system. It is given orally with a capsule or liquid.
- **Prednisone or methylprednisolone (steroids)** may also be given IV or by mouth daily, starting in the second week following transplant and are then weaned (the amount of medicine will change) slowly if GvHD does not develop.

Other medications

- **Ursodiol** is used to maintain bile flow in the gallbladder during transplant to prevent obstruction.
- **Glutamine** is protein that helps the gastrointestinal tract regenerate; which can help hasten the recovery of mucositis. This medication is taken by mouth twice a day.
- **Progesterone** or gonadal suppression will be needed for teenage girls who experience monthly menstrual cycles. Medications will be given to prevent menses during transplant when platelets and red blood cells are low.
- **Immunoglobulin (IVIG)** is an intravenous medication that provides additional antibodies in the blood to help fight off infections. Your child may receive an infusion

of IVIG through his/her central line monthly while your child is on immunosuppressive medications or until his or her ability to fight infection returns to normal.

- **GCSF/Filgrastim** is a medication that is used to stimulate white blood cells to grow. This medication is usually given when the body fails to make the white blood cells within the first few weeks. The use of this medication varies with each patient and may not be given to every patient.



BONE MARROW HARVEST

Several weeks prior to the bone marrow harvest the related donor will have a physical exam in the BMT Clinic. During this clinic visit blood will be drawn to assess blood counts, clotting factors and blood type. These tests are needed to make sure the donor is healthy enough to donate. The child life specialist can explain what will happen during the next day, if the donor wishes.

The donor also may meet with the psychologist to discuss their feelings about donating their marrow. The consent for the bone marrow harvest is signed by the parents with the attending transplant physician. A blood transfusion may be needed in the operating room on the day of the harvest. The attending transplant physician will also obtain blood transfusion consent, in case this is needed. The consent for anesthesia will be signed with the anesthesiologist on the day of the bone marrow harvest.

The day of the bone marrow harvest the donor will be taken to the operating room and be given general anesthesia so he/she sleeps through the harvest without feeling any pain. The donor should not eat or drink for at least 8 hours before the harvest to prevent vomiting when the general anesthesia is administered. Other instructions will be given by the BMT team during the clinic visit. You will also receive a call by the surgical nurse prior to the harvest with instructions on checking in and where to go.

An intravenous (IV) line will be inserted into the donor's arm or hand so fluids, medicine and blood, if needed, can be given during the harvest.

A needle will be inserted into the hip bone or "iliac crest" where a large amount of bone marrow is located. The bone marrow will be withdrawn through the needle with a syringe. One or two punctures into the skin of each hip and multiple punctures into the hip bone are required to harvest the needed amount of bone marrow. The bone marrow is placed in a plastic blood bag after it passes through a series of filters to remove fat and bone particles. If the donor and the patient have different blood types,

the red blood cells, and the plasma will be removed in a laboratory prior to the infusion.

After the harvest, the donor will be monitored in the recovery room. Vital signs and the harvest site will be checked frequently. When the donor is fully awake he/she will be given something to drink. If the donor feels well and can drink without vomiting, he/she can go to a local residence. The donor will have a dressing at each bone marrow harvest site and these dressing should be kept dry and intact overnight. The following day, the dressing can be removed. The donor is allowed to return back to his/her normal routine as tolerated.

The donor may feel some pain at the harvest site which may last a few days. This is common following a bone marrow harvest. This pain can usually be treated with Tylenol or Tylenol with codeine. The donor may also have nausea from the anesthesia given in the operating room. The donor may also receive medication to prevent nausea in the recovery room or may be sent home with anti-nausea medication.

Other risks of the harvest are very low. They include the following:

- **Infection** – This can occur anytime a needle is placed into someone, so the harvest is performed in a sterile environment in the operating room.
- **Bleeding** – Tiny blood vessels run through the area that is being harvested. These may be cut by the harvest needles. The pressure dressing applied at the end of the harvest minimizes bleeding.



- **Numbness** – Tiny nerves also run through the harvest area and may be damaged by the needles. There may be a small area of skin numbness at the site which will go away over time.
- **Nausea** – Most patients will have some nausea for the first few hours after they wake up from anesthesia.
- **General Anesthesia** – Other side effects of anesthesia are low blood pressure, low oxygen levels and very rarely, extremely high fever. The donor will be monitored very closely for these rare complications.

Peripheral Blood Stem Cell Collection

The peripheral blood stem cell (PBSC) collection is done as an inpatient. Prior to collection the donor will receive a drug called granulocyte stimulating factor (GCSF), for several days before the stem cell collection. The growth factor will increase the number of stem cells in the donor's blood allowing greater ease in collecting the stem cells. The collection process may take one or more days depending on the number of stem cells that are collected each day. The procedure is not painful but does require your child to lie in bed for several hours during the collection.

The donor's CD34 count will be checked daily after receiving GCSF. Cells expressing CD34 are normally found on the stem cells needed for collection. Once the CD34 count is adequate the donor will be taken to Interventional Radiology for a temporary pheresis catheter placement.

After the catheter is placed, the donor will go to either the bone marrow transplant unit or the pediatric intensive care unit (PICU) where the stem cell collection procedure will occur. During this procedure the donor's blood is passed through a machine that collects the portion of the white cells containing stem cell. The remaining white cells, red cells and platelets are given back to the donor. Each stem cell collection may take four or five hours during which the donor can sleep, read or watch television. Once an adequate number of stem cells are collected, the catheter is removed and the donor is able to go home. Sometimes after the collection, a blood transfusion may be needed because with the stem cell some red blood cells are also removed in the process. The stem cells are then frozen in liquid nitrogen in the cell processing laboratory.

THE DAY OF THE TRANSPLANT

When the day of the transplant arrives we expect that you and your family will be anxious. It is important to remember that the BMT Team – doctors, nurses and other hospital staff – have done this many times before. The transplant itself is a simple, straightforward and painless procedure that is similar to a blood transfusion.



Allogeneic Transplant

Fresh stem cells can be given anytime of the day or night. Fresh bone marrow stem cells are often given very soon after they are collected. If the donor and the recipient have different blood types, then the stem cells have the red blood cells and the plasma removed before the infusion. When the stem cells have been frozen they are thawed just before they are given to the patient. This often occurs mid-morning.

The stem cells are given through the recipient's central line much like a blood transfusion. During the stem cell infusion,

the nurse will frequently check your child's blood pressure, pulse, respirations and oxygen levels. Rarely an allergic reaction may occur such as hives, chills, or a rapid heartbeat. Allergy medications, Benadryl and Hydrocortisone, are given intravenously before the transplant to prevent this type of reaction. Occasionally the patient needs medicine to decrease the amount of extra fluid in the body due to the volume of stem cells. The signs of extra fluid are increased blood pressure and/or shortness of breath.

POST TRANSPLANT

Engraftment: Waiting for the Stem Cells to Grow

It will take weeks to know whether the stem cells are accepted by your child's body. After infusion of the stem cells, the cells find their way to the marrow spaces where they begin to divide and produce mature red blood cells, white blood cells and platelets. This often takes two to four weeks to occur. One of the first signs that this has happened is the appearance of new white blood cells in

the peripheral blood circulation. This is checked with your child's blood counts every day. Engraftment occurs when the absolute neutrophil count is greater than 500 for three consecutive days. This waiting period is an anxious time for you and your child. It is possible, but unlikely, that the stem cells do not engraft. If this happens, we will discuss other treatments with you and your child.

Infections

Because your child's white blood cell count is low, his/her body's defenses against infections are weak. Organisms which do not cause infections in people with healthy defenses may cause life-threatening infections in people without white cells or other mechanisms for normal immunity. During the first weeks after the transplant, your child is at high risk for bacterial, fungal and viral infections. One of the most common signs of infection is fever. Most transplant patients have fever while waiting to engraft. Other common signs of infection may not be displayed in your child due to the low white blood cells. White blood cells are needed to display common signs of infection such as redness or puss from a skin infection. A fever in a transplant patient is very serious and often the only sign of infection. With the first sign of fever, IV antibiotics will be administered to your child. Blood cultures will also be drawn from your child's central venous line to determine the cause of the fever. Infections may develop very suddenly and be very severe. It is possible that your child may need close monitoring in the intensive care unit during the acute phase of the infection period.

Antibiotics will be continued until your child completes a full course of therapy for any bacteria he/she may have, no longer has a fever, or when the doctors are satisfied

that he/she has no infection. If your child has persistent fever he/she may have CT scans of the body to look for an infection, along with receiving anti-fungal and anti-viral medications. Transplant patients can have unusual infections because of their lowered immune system. Some viruses that cause the common cold may cause bladder infections resulting in painful urination and blood in the urine. Patients may also develop pneumonia. This can be caused by a variety of organisms including cytomegalovirus (CMV), adenovirus, pneumocystis carinii (PCP) and Legionella. All of these pneumonias give the same X-ray picture but respond to different medicines. A lung biopsy and/or bronchoscopy (looking down the windpipe and taking samples) may be needed to determine the cause. It is important to know the type of pneumonia so that the correct medications can be given. A new treatment may be available to some patients for viral infections. Virus specific t-cells can be made using the donor's blood. T cells help the body fight infection by recognizing viruses and destroying virally infected cells. Patients who have undergone a bone marrow transplant, these cells are lacking and thus cannot provide the same protection. Virus specific T-cells produced with a new method could target these viruses in a more natural way. Your BMT team will discuss with you if this is an option.



Blood tests and x-rays

After your child receives the transplant, daily blood tests will be taken. If possible, the blood tests are drawn through the central line. X-rays and others scans may be routinely ordered to gather information about an infection or a

cause of discomfort that is affecting the patient. Only necessary venipunctures (sticks) will be done. If your child had a port-a-cath, the site must be accessed so that cultures can be drawn from it with every fever.

Blood Transfusions

Almost all transplant patients require blood product transfusions while waiting for engraftment to occur. Packed red blood cells and platelet transfusions are given frequently. When your child's hemoglobin is 7.0 or less, your child will most likely receive a transfusion of packed red blood cells. Your child's platelet count will also most likely be low during this period. This means he/she is prone to bleed from a cut or bruise easily. When your

child's platelet count is 10,000 or less he/she will receive a platelet transfusion. The transfusions may differ for each patient depending on their clinical picture or if the study they are on mandates a different parameter. Your child may receive premedication's prior to a transfusion such as Benadryl or Tylenol if they have had an allergic reaction to red blood cells or platelets.

Mucositis/Pain Management

The chemotherapy and radiation therapy often cause some degree of soreness or ulcers in the throat and mouth and can extend down the entire gastrointestinal tract. This side effect may range from mild irritation to severe pain causing difficulty in swallowing. There is currently no prevention for this side effect. However, good mouth care helps to prevent other complications.

Upon admission to the BMT unit, your child will begin a mouth care regimen that is very important. Mouth care should be done through the transplant process and continue after discharge. Your child should brush his/her teeth at least twice a day with a soft bristle toothbrush and swish his/her mouth with warm saline rinse at least three times a day.

If your child begins to develop pain, a pain medication such as morphine, will be given to decrease the pain. The pain medication is usually given through a patient controlled analgesia (PCA) or nurse controlled analgesia (NCA) pump. This pump allows a continuous dose of the pain medicine to infuse and also allows the patient to receive additional doses of medicine if needed by simply pushing a button. The pump is programmed so that only a preset amount of medicine can be given to your

child. Your child will not become addicted to the pain medication because it is being used to control pain. If your child has severe mouth pain, he/she may not want to do mouth care because of the soreness. Numbing medicine may also be given to your child; that is applied on his/her gums or cheeks with a cotton tip applicator. The mouth and throat sores and pain will heal quickly after your child engrafts.

Graft-Versus-Host-Disease (GvHD)

If your child has received an allogeneic transplant, then he/she could develop GvHD. This side effect occurs in about 20-30% of the patients. The greater the difference is in matching between the donor and the recipient, the greater the risk of GvHD. The risk of developing GvHD is higher in older children and patients receiving unrelated donor transplants. GvHD can begin once the new stem cells engraft and start to produce new white blood cells. The transplanted white cells recognize they are not in their original body and consider the patient's body to be foreign territory so they launch an attack. Patient organs that experience this initial attack, or GvHD, are usually large surface organs such as the skin, liver and gut. One or all of these organs may be involved. Common signs of

GvHD include skin rash, often starting on the palms of the hands or soles of the feet, diarrhea, jaundice (a yellow skin color) and abnormal liver function tests. Members of the BMT team are constantly watching your child for any of these signs. Medications are given to prevent GvHD and other medicines may be added to control these symptoms if they occur.

Mild GvHD is beneficial for some patients, as it has been found to reduce the possibility of relapse after transplant. However, severe GvHD requires aggressive treatment. If uncontrolled, GvHD can be fatal. We will treat your child with different medications that will reduce the GvHD risk until the stem cells grow normally in your child.

Types of Manifestations of GvHD

GvHD can take two forms, acute and chronic.

- **Acute GvHD** usually occurs during the first three months after transplant. A person may develop acute GvHD that goes away when treated or the acute GvHD may become chronic GvHD.
- **Chronic GvHD** usually develops three to 18 months after the transplant and can occur even if your child did not have acute GvHD.

Patients who get acute GvHD have a 50 percent chance of developing chronic GvHD. Chronic GvHD often affect the:

- **Eyes** – causing dryness and irritation, itching, sensitivity to light

- **Skin** – causing rash and itching, stiffness or thickness, darkening or lightening of the skin, progresses to severe skin damage leading to stiff, scarred skin
- **Liver** – causing jaundice and/or hepatitis
- **Stomach and intestinal tract** – resulting in loss of appetite, cramping pain, diarrhea, dry mouth and vomiting, weight loss
- **Hair/Nails** – thinning of hair, brittleness or changes in the texture of fingernails
- **Muscles/Joints** – stiffness or decreased mobility

Prevention and Treatment

There are several medications that are used to help prevent, treat and reduce the severity of GvHD. Some of the medications include Cyclosporine or Tacrolimus, prednisone and low doses of Methotrexate. Cyclosporine or Tacrolimus, is started prior to transplant and is continued for several months after transplant. These medications may be given alone or in combination depending upon the type of transplant and the disease being treated by the transplant. It is very important these medications are taken on time. Some of the medication levels are checked frequently to assist in maintaining safe and therapeutic doses; please notify your BMT provider if any doses of your child's medications were missed. The medicines and other treatments used to treat the GvHD will also weaken your child's immune response to infections. You will need to continue to watch for signs or symptoms of infection and your child will continue to take some of the "prophylactic" medicines which are taken to prevent infection. Getting

too much sun can trigger GvHD of the skin and aggravate existing GvHD. Always have your child wear sunscreen when he or she is outside in the sun. Include the tops of the hands and feet and ears. Wear a hat and as much clothing as comfortably possible. Try to keep your child in the shade when outside. Remember, clouds do not protect you from the sun, so follow precautions even on cloudy days.

In addition to medications, a procedure known as Extracorporeal Photophoresis (ECP) may be used to treat GvHD. In ECP, blood is collected and the white blood cells are exposed to a medication and UV light which causes cell death of the angry cells that are causing the GvHD. This allows some control of the immune system and therefore control of GvHD. This treatment can be long-term; typically the treatment is twice a week for 4 weeks and then gradually to every other week, every 3 weeks and weaned off, but most patients receive treatment for at least 16 weeks.

Diet

Your child will continue to follow a BMT diet as previously explained in the Diet section of this handbook until engraftment. Your BMT team will inform you when it is safe to introduce fresh foods and restaurant foods back into your child's diet. The dietician will be available to answer your questions regarding your child's diet. Due to nausea, vomiting or mouth sores during the transplant many children are unable to eat and drink enough for adequate nutrition. Your child's oral intake will be closely monitored. If your child is no longer able to eat and drink enough, enteral nutrition will be administered via a nasogastric tube (NGT) or total parental nutrition (TPN) will be given to your child through his/her central line. Your medical team will decide which nutrition would be suited best for your child. The preferred method of

nutrition when your child is not taking food by mouth is to place a NGT in the nostril of the nose and ends in the stomach. This tube allows medications and formula to be administered without any difficulty. Patients can continue to eat and drink while the tube is in place. TPN can be administered if your child cannot tolerate the NGT with feeds or if is already experiencing signs of mucositis. When your child begins to show interest in foods again, the TPN will begin to be tapered off. When your child is eating and drinking enough for good nutrition the TPN or the enteral feeds will be stopped. Good nutrition is defined through calorie counts from a daily food intake diary. Some patients may be discharged from the hospital while still receiving enteral feeds or TPN. Parents will be taught how to give the TPN or care for the NGT at home.

Exercise

It is important for your child to continue to do some form of exercise every day. Even sitting up in the chair or taking a short walk in the hall will prevent your child from developing other complications. A physical therapist will evaluate your child upon admission for transplant and will assist in developing an exercise plan for your child.

If there are no problems identified at the time of the initial evaluation, the therapists will re-evaluate your child one to two weeks after his/her transplant to assess any change in your child's condition. A treatment program will be established at that point if a need for physical or occupational therapy is identified.

PREPARING FOR DISCHARGE AFTER TRANSPLANT

Preparation and education for discharge will begin upon admission. At least two primary caregivers will be educated on fevers, central line care, medication administration and anything specific to your child's safe care at home. You will be expected to demonstrate all skills prior to discharge.



Planning and discussion of discharge will begin when your child's new stem cells have engrafted, he/she is free from signs of infection, he/she is able to take the oral medications and he/she has no evidence of other major problems. Transition from the hospital unit to the outside world is a giant step, which can bring excitement and anxiety. The BMT team will help prepare you to care for your child so that you will feel confident at home. We like to start education early and have you practice skills often. Often a home care

company is needed to help with care for a period of time at home. A home care company will be arranged for your child if needed and provide specific education.

Transplant patients must be able to get to a hospital in less than one hour for the first 100 days after transplant. Our social worker will assist in locating a local residence near the hospital for those who qualify. Temporary housing is not always guaranteed and is offered as a first come first serve basis.

Cleaning your Home

If you are returning to your home after transplant, a complete general cleaning of your home must be done before the patient arrives home. The kitchen and bathroom areas should be cleaned with a weak mixture of bleach and water. Also wash your child's towels and bed linens including any blankets and comforters. Change all air filters (furnace or air conditioner) before your child returns home and then change them every month for one

year. Be certain all curtains and carpets have been dusted and vacuumed. Any carpets that are in bad condition may need professional cleaning or replacement. Also wipe down all hard surfaces with a bleach based cleanser. Do not have your child do any cleaning until approved by your medical team. It may be necessary to start this process before admission for transplant to ensure all tasks are complete before discharge.

Setting up a new Schedule

You will need to consider developing a new schedule for your family after transplant. Medically oriented tasks such as medications, appointments and treatments can be time consuming and will be added to other household job demands. Each person in the family may need time and encouragement to communicate their feelings regarding their new roles within the family. The demands

Clinic Visits

After transplant, your child will come to clinic frequently for checkups. As your child begins to feel better and recovers from the transplant, clinic visits will be spaced further apart.

A general schedule for checkups is as follows:

- Day 30 to 100 post transplant : 2-3 times per week
- Day 100 to 180 post transplant : weekly
- Day 180 to 1 year post transplant : monthly
- 1 year to 12 years post transplant : every three months
- Acute GVHD and on therapy : weekly
- Chronic GVHD and on therapy : every three months

The BMT team will review these topics with you in clinic:

- **Medicines:** Please bring your medicines to each clinic visit after transplant. The purpose for each medication, side effects, and schedule for taking them will be reviewed with you. Do not take medications such as Cyclosporine, Tacrolimus, or Voriconazole prior to your clinic visit so blood levels of the medication can be drawn. Once the medication levels have been drawn you will be advised as to what dose of the medication your child can take.
 - **Preventing infection:** Hand washing, social isolation (no grocery stores, school, churches, and crowds of people) and food preparation will be reviewed with you. Call the BMT Advice Line immediately for any signs of illness or fever of 100.5°F.
 - **Contact phone numbers:** On holidays, weekends or at night, please call the BMT Provider On-Call at 202-476-5000. During clinic hours, the BMT Team can be reached at 202-476-4267. Sick calls will be returned in 1 hour, non-urgent needs, such as refills will be returned in 24 hours.
 - **Blood pressure:** Some patients need to have their blood pressure checked at home. If you have been asked to
- check your child's pressure, then please bring the blood pressure record to clinic. If necessary any changes in your child's medications will be based on these readings.
- **Blood counts:** Blood will be drawn at each clinic visit. The need for a red blood cell or platelet transfusion, or a dose of GCSF (granulocyte colony stimulating factor) to increase his/her white blood cell count is based on blood counts. Blood will also be used to check drug and virus levels.
 - **Homecare Medications/IV fluids/TPN:** Your child may need IV Ganciclovir/or Foscarnet, IV fluids, and/or TPN at home. You will be taught how to give these medicines or fluids. Medicines and supplies will be sent to your home by your Homecare Company. Changes in your child's IV fluids or medicines will be made based on blood tests done in clinic. Your Homecare Company will be notified by clinic staff of any needed changes.
 - **Bone marrow aspirations:** Bone marrow aspirations will be done only as needed to check your child's engraftment. Your BMT providers will inform you of any bone marrow aspirations that must be done. They will also discuss any sedation that your child may need for the tests.
 - **Illness/Readmissions to the hospital:** Your child will be watched for side effects of the conditioning regimen, GvHD and infections. Most children are readmitted to the hospital to treat these problems. You should come to the clinic prepared for an admission to the hospital if your child is ill or has a fever.

of transplant on patients and their families are great, and we encourage you to seek help with others such as friends, relatives and neighbors who are more than happy to be called upon to help. The BMT team members are also available to assist you and you should not hesitate to ask. You may also contact your social worker with any concerns or questions.



EMOTIONAL ASPECTS OF A STEMCELL TRANSPLANT

Everyone brings their own unique experience and outlook to the BMT process. Even though it will be different for everyone who goes through it, some common feelings and concerns seem to be shared by many of the patients and their families.



Patients and families can expect that their emotions will be up and down. You may feel excited and hopeful to be starting the transplant process but at the same time, feel anxiety about what is ahead. You can expect to feel tired and frustrated, which can leave you short-tempered at times. It is natural to feel high and low along with the medical changes and even sometimes doubt your original decision about coming to transplant.

Family members often wish they could be at the hospital, at home, and at work all at the same time. Arguments arise

over what other family members are doing, or not doing. Family members may feel guilty or blame each other.

Separation from part of your family can be very hard. While at some times it may be easy, at other times it may be extremely difficult for your child to deal with staying in isolation for several months. Due to the many medications, and restrictions complying with the treatment regimen can be difficult. The hospital environment can be intense, and families get close to each other. Privacy is difficult to maintain but we will do everything we can to maintain each family's information confidential.

Siblings and Donors

Brothers and sisters often feel left out and hurt, so it is important to set aside special time for them. It helps to involve siblings in planning, telephoning, and visiting the patient.

Often, sibling donors feel unsure about donating. They want to donate yet at the same time feel apprehensive about the procedure. Many sibling donors worry unnecessarily that their bone marrow might not be “good

enough” or that they may be permanently harmed by the donation. It is important to emphasize to donors that if the patient gets sick, or the marrow doesn’t engraft, that it is not their fault. Donors also may feel they are only partially appreciated by their families and the staff. It is important to show appropriate recognition and appreciations for donors. The donor is doing the best that anyone can do for the patient.

Coping Strategies

Planning ahead seems to help the patient and their family throughout the transplant process. You may want to talk with the BMT team about your own expectations, concerns and worries.

- Please tell us how you and your child learn best and what helps you during difficult times.
- Tell us how much detail you would like to know regarding medical information and the doctor’s concerns. Some people like to anticipate all possibilities while others like to wait to find out when changes occur.
- It will be important to talk with the team about your child’s reactions to medicines, both physical and emotional, so we can know how to help.

- Remember how your child normally handles boredom, fatigue, and frustration. Help him or her to use these coping methods or to find new frustration. And remember that you will have similar feelings.
- You might want to plan ahead and explore ways to help yourself relax while at the hospital.

Conserving your energy and resources are a challenge. When friends and family want to help you, remind them that hospitalization is only the beginning of the transplant process and that you may need additional help once you return home.



YOUR ROLE ON THE TEAM

You have an important role on your child's health care team. We want to help you in any way we can and we depend on you to communicate with us. Here are some tips to help us work together.



- **Be sure to ask questions.** Bring a to do list so you do not forget any questions and be sure to clarify all information during your clinic visit.
- **Always make an appointment with our receptionist, whether your child needs an office visit or blood work.** Parents often assume that because the medical

team said, "we'll see you next Monday," they have an appointment. To get on the schedule for next week, you must talk to the appointment staff. The appointment desk phone number is: 202-476-5251. Unscheduled visits create problems and may cause delays in your child being seen.

Prevention of Infection

- **Hand-washing:** Hand-washing is essential for good health. Your child should wash his/her hands before eating, after using the bathroom, after playing outside

and any time he/she has touched a dirty object. It is also important for family and friends to wash their hands often. Commercial antibacterial soap is adequate for use.

Your child should not share towels when bathing and hand drying. You should change towels every 2-3 days.

- **Isolation:** Your child will be in “social isolation” until his/her immune system recovers and is off immune suppression. Social isolation means that you restrict contact with other people which may have an infection. This means your child should not go to any crowded places such as the grocery store, church, school, movie theaters, or restaurants. If a family member is ill, keep your child away from them as much as possible. During your clinic visit you may ask your BMT provider what activities and places would be safe for your child.
- **Wearing a Face Mask:** Wearing a face mask is not a guarantee against infection, but it may help guard against bacteria and viruses from other people. Your child will be given masks to wear when he/she is visiting the outpatient clinic or going out in public. Your child does not have to wear the mask at home, while riding in the car, or when outside in open spaces.
- **Checking Temperatures:** Your child’s temperature should be checked if he/she feels ill, chilled, shivery or “hot.” You are the expert on your child, and subtle clues that only you can pick up may be important. If your child has recently eaten or had a drink within the last 30 minutes do not take his/her temperature in their mouth. Any temperature of 100.5°F or more should be reported to the doctor immediately. Oral temperatures are ideal, if your child will not take a temperature orally please place the thermometer under their arm. Never take a rectal temperature.
- **Caring for the Central Line Catheter:** Your child may still need his/her central line after discharge so medications and blood products can be easily given. Because the catheter is a direct line into your child’s blood stream, it is important to prevent it from becoming infected. You will be taught how to care for your child’s catheter. Any redness, tenderness, or

drainage from the catheter site should be reported to the doctor immediately.

- **Cuts and sores:** Treat all cuts and sores carefully by washing them thoroughly with soap and water. Apply a topical antibiotic cream, such as Neosporin, or Polysporin and leave it open to air. If any sore becomes painful, red, swollen, or draining, call your doctor. Do not pop any blisters.
- **Immunizations:** Your child may not receive any immunizations until approved by your BMT team. Six months to a year after transplant, your BMT providers will discuss your child’s immunization schedule with you. Siblings should receive regularly scheduled immunizations. Your child cannot live in the same house with someone who has received the live oral poliovirus vaccine (OPV) for 30 days after the immunization. Ask your BMT team about any vaccines your other children may need. Avoid contact with persons who have been exposed to chicken pox or shingles. If your child is exposed, notify your BMT provider immediately. Siblings may receive the varicella vaccines; however if the sibling develops a rash after getting the vaccine the patient should be treated as having been exposed to chicken pox. Please call your BMT sick line as soon as possible if this occurs.
- **Pets and Plants:** You do not need to remove your household plants; however your child should avoid close contact with them, such as watering them or touching the dirt. Your child may play outdoors, as long as there is no construction nearby. Please make sure to wash his/her hands and face thoroughly afterwards. Your child can play with the family pet as long as the pet is healthy. Do not give your child a new pet. Always wash his/her hands after playing with the pet. If you have a cat, your child should avoid contact with the litter box or the cat’s stools. Patients should also not play with frogs, turtles or reptiles.

RECOVERY OF THE IMMUNE SYSTEM AFTER TRANSPLANT

- Your child will be at high risk for infection during the first year after transplant, but especially during the first 3 to 6 months.
- Your child's immune system will not mature until at least 1 year after transplant, or longer if he/she has graft versus host disease and is on immunosuppressive medications.
- Once your child's immune system recovers he/she will repeat all the early childhood immunizations. Your

BMT team will give you the schedule when it is time to restart them. Do not let any other physician or clinic administer these immunizations unless cleared by your BMT provider.

- Please call your BMT provider immediately if your child is exposed to anyone with chickenpox, shingles, or measles. Your child must receive an infusion of immune globulin within 2 to 3 days of exposure.



Activities of Daily Living

- **Personal Hygiene:** It is still important for your child to follow a hygiene routine after leaving the hospital. Your child's skin is the most important barrier to infection. While your child is bathing, it is a good time to inspect their skin for rashes, redness, or drainage. Your child should bathe daily or more often if needed and use a lotion for dry skin. You may use any commercial antibacterial soap and a fragrance free lotion such

as Eucerin, Lubriderm or Cetaphil. Clothes should be changed daily. You may wash his/her clothes with any commercial laundry soap – but in general it is best to use fragrance free detergent. The diaper area or anal area must be kept clean and dry. Always remember to wipe from front to back using a soft toilet tissues or wet-wipes, and wash your hands thoroughly afterwards. Keep your child's fingernails and toenails clean and short.

- **Mouth Care:** It is very important to brush your child's teeth with a soft toothbrush at least twice a day as bacteria and yeast like to grow in the mouth. Avoid dental work until approved by your doctor. When your child's platelet count is normal, a regular toothbrush should be used.
- **Sun/Ultraviolet Rays:** The chemotherapy and radiation that your child received makes the skin very sensitive to the sun so that your child may be sunburned with very little exposure. Sunlight can also make GvHD worse. Your child should avoid direct exposure to sun, especially between 10:00am and 4:00pm, when the sun's rays are strongest. If your child has to be in the sun, he/she should wear a hat, a shirt with long sleeves and long pants. Apply a sunscreen with a sun protection factor (SPF) of at least 30, thirty minutes to one hour before going outside. Reapply frequently while your child is in the sun.



- **Exercise:** Complications can be prevented by following a daily routine of exercise. A balance of rest and exercise is important. Your child needs at least 8 hours of sleep a night and should walk or have some type of light exercises everyday. Light exercise every day is better than infrequent heavy exercise. Increase your child's activity gradually. Avoid contact sports, skating, rollerblading, trampoline use or riding a bicycle until your child's doctor has approved it.

- **Diet:** A well-balanced and nutritious diet helps the body stay healthy. If your child's appetite has decreased, try to increase his/her calories by eating more frequent, smaller meals. Do not eat raw fish, meat, or eggs. Ask your doctor when your child may start to eat raw fruits or vegetables. To avoid infections, your child must not share drinking glasses or eating utensils. For more information see the nutrition section of this handbook.
- **School Re-entry:** It is very important for your child to continue with school; however, infections are easily transmitted in school rooms. We recommend home schooling during the first several months after leaving the hospital. This will vary with each patient so discuss this issue with your medical team. Your social worker can help you arrange your child's homebound schooling.
- **Bleeding:** After your child is discharged, he/she will continue to have blood counts drawn in the clinic for platelet counts. When your child's platelet count is low, he/she may bleed or bruise easily. Never give your child aspirin or ibuprofen (Advil or Motrin) because these medicines make the platelets less effective. Your doctor will continue to order platelet transfusions when your child's platelet count is low or if he/she has any signs of bleeding. If bleeding occurs, apply direct pressure to the area. For nosebleed, pinch the nostrils together for at least 10 minutes, and do not let your child lay down. Report any of the following symptoms to the BMT team immediately:
 - excessive bruising or small red or purple dots on skin
 - gum bleeding or prolonged nosebleeds
 - prolonged vaginal bleeding
 - blood in urine or black and/or bloody stools
 - headache
- **Sexual Activity:** Parents! Your teenage child may or may not have been sexually active before transplant. Even if they were not, they may be curious or have questions about this part of normal development. Please encourage them to read this section. Even kissing on the lips can be too high risk until after day 100. Sexual activity is usually safe after day 100. Before that time, there is too great a risk of infection. You may notice a decrease in sexual desire due to chemotherapy and/or radiation. This is temporary.

As you begin to be more active and regain your strength and endurance, you may find that your desire to become more sexually active increases as well. Allow yourself time to become physically and emotionally ready. Until then, you can share affection by touching and hugging. Please understand that infertility (inability to become pregnant or make

someone else pregnant) does not mean “no need for protection.” Always use a condom to protect yourself and partner from pregnancy and sexually transmitted disease. Before going home or during a clinic visit you can address this issue with your doctor. Make sure your questions about sexual activity and fertility are answered before you start.



Nutrition at Home After Transplant

■ Changes in Appetite:

Although a well-balanced diet is needed for a healthy body it may be hard to get your child to eat

enough of the foods needed to grow. Even when they feel well, children are picky eaters. For your child, whose body has to cope with growth and the side effects of treatment, eating a good diet is especially important. Not all children have trouble eating. At each clinic visit we will keep track of how much your child weighs. If your child is losing weight or seems to be gaining too much, our BMT provider will discuss these issues with you. Some tips to help your child eat include:

- **Be flexible about meals.** Small frequent meals throughout the day are often better than three larger meals. Let your child eat when he/she is hungry and don't force your child to eat if he/she is nauseated.
- **Make food fun.** Decorate it with food coloring or by making shapes your child likes. Draw faces on pancakes, or add sprinkles to desserts.
- **Let your child help with cooking** if he/she is old enough. This sometimes creates more interest in the foods prepared.
- **Praise good eating.** Try using rewards to encourage it, but do not turn mealtimes into a battle or punish your child for not eating.
- **Add calories to foods** to make every mouthful count. Try adding cheese, butter, whole milk, or granola to your child's snacks and meals.

- **Learn which foods taste different to your child** and do not serve foods that taste bad to your child. Many children complain of a metallic taste in their mouths. Providing mouth care prior to eating may help.
- **Use flavorful seasonings** like basil, oregano, or rosemary. Use bacon or onion to add flavor to vegetables.
- **Offer your child tart foods** if he likes them. Foods like lemons, limes or sweet tarts stimulate the salivary glands and help improve taste.
- **Ask to talk with the dietician** for more suggestions on ways to help your child with eating problems.

- **Nausea and Vomiting:** Some children will never have nausea or vomit once they go home; others may feel mild nausea or vomit occasionally. Most nausea and vomiting can be prevented by various medications such as Zofran®. Avoiding strong odors that may make your child feel sick may help. Children can often keep down small sips of fluid when they feel nauseated. Try giving your child one or two sips of carbonated beverages or apple juice every 15 to 30 minutes, but don't force your child to drink. Cold foods may be better than hot ones. Some parents find zip-locked plastic bags useful to keep in the car and while away from home in case your child starts vomiting. These bags won't leak or spill after being sealed and will contain the smell. Notify your doctor immediately if your child has not been able to keep anything down including his/her medications. Some signs of dehydration include: decreased number of wet diapers or times your child goes to the bathroom, strong smelling urine, no tears when your child cries; dry inside of mouth or eyes that look sunken in.

- **Healthy Eating:** Some foods like raw vegetables and raw or undercooked meats can carry a lot of bacteria. Bacteria can cause illness. Usually our bodies can kill the bacteria in foods; however, after a transplant it is harder to kill the bacteria and there is a good chance of getting sick. This is why it is important to be careful about cooking and storing food. BMT patients are not able to fight off bacteria for about six months to one year after their bone marrow transplant. Eating foods with a lot of bacteria can cause the following symptoms: nausea, vomiting, diarrhea, fever or general weakness.

- **High bacteria foods (high risk) are:** raw or undercooked poultry, meat fish, unrefrigerated milk or milk products, or rotting vegetables or fruit.
- **Low bacteria foods (low risk) are:** well-cooked meats, fish, poultry, cooked vegetables. Washed raw fruit and vegetables, well refrigerated dairy products, dairy based condiments, or pasteurized products.
- **Preventing food-borne illness:** Good hand-washing, both before and during cooking is important. In addition, clean the counter-top and cooking utensils with soap and hot water to decrease the spread of food borne illness, especially if cooking high bacteria foods.

General Tips of Food Safety

- Always wash your hands well (for at least 20 seconds) with soap and warm water before and after preparing food.
 - Use only clean utensils and work surfaces.
 - Wash fruits and vegetables well under running cold water before peeling/cutting or eating them. Use a clean vegetable scrubber to make sure that all soil is removed from the outer skin or peel. Do not wash fruits and vegetables with any rinses or soaps since produce can absorb these agents.
 - Wash and clean the tops of canned foods before opening (including drinks) and clean the can opener before and after each use.
 - Use separate cutting boards (plastic or wooden) for raw and cooked foods. Wash cutting boards after each use in hot, soapy water or in the dishwasher. Sanitize the cutting boards weekly with a dilute bleach solution, and let the board air dry.
- ** Use dilute bleach solution to clean cutting boards, kitchen counters, and refrigerator: mix 1 part household bleach to 10 parts water.**
- Thaw meat, fish, or poultry in the refrigerator away from raw fruits and vegetables. Place on a dish to catch drips. Cook defrosted meat right away and do not refreeze.
 - Always make sure that food is cooked well.
 - Eggs should be cooked until the whites and yolks are completely hard.
 - Meat (internal temperature = >150°F)
 - Poultry (internal >165°F)
 - When cooking a large batch of food, immediately portion food into smaller sealable containers if foods are not eaten right away. Store portioned foods in either the fridge or freezer. Portioned foods must be frozen within 1 hour or cooking. Portioned foods stored in the fridge must be reheated and eaten within 24 hours of cooking. Reheat foods to >165°F.
 - Never leave perishable food out of the refrigerator for more than one hour.
 - Keep cold foods cold at <40°F
 - When preparing food, never taste the food with the same utensil used for stirring.
 - When using the microwave, rotate the dish once or twice during cooking if there is no turntable since microwave cooking can leave cold spots in food where bacteria can survive.
 - Never taste a food that looks or smells strange!

Grocery Shopping

- Be careful to check the “Sell By” and “Use by” dates. Always check packaging dates on fresh meats, poultry, and seafood.
- Do not buy damaged, swollen, rusted, or deeply dented cans. Only buy packages and boxes of foods that are properly sealed.
- Buy fruits and vegetables that look and smell fresh and that are not blemished.
- Do not buy any food with mold on it.
- Do not buy yogurt and ice cream from soft-serve machines.
- Buy individually packaged foods to decrease the risk of bacterial contamination.
- Avoid prepared foods, salads, and sliced meat or sliced cheese from deli’s.
- Avoid tasting free samples.
- Avoid cracked, unrefrigerated eggs
- When shopping, buy frozen and refrigerated foods last and put the groceries away immediately when getting home.



Dining Out

Once your child is past day 100 after transplant, your child may be allowed to have restaurant or bakery foods if they have been prepared in front of you. Your child’s health care professional will determine if this is ok for your child and when your child can eat out in a restaurant. Please follow these rules for dining out.

- If eating out, eat early to avoid the crowds.
- Ask that food be prepared fresh in fast food places.
- Only drink pasteurized juice – not freshly squeezed juices.
- To be extra careful, it is recommended that raw fruits and vegetables should not be eaten when dining out.
- Ask for single-serving packets of condiments (e.g. ketchup, mustard, salad dressing) rather than using the self-serve bottles.
- Avoid high risk food sources, such as salad bars, delis, buffets, sidewalk vendors, and potluck dinners.



MEDICATIONS

Your child will be taking many different medications after transplant. It is best to develop a routine for giving your child his/her medications, such as mealtime or bedtime. You will be expected to assist your child with their medications and be familiar with their schedule at the time of discharge. A copy of your medication schedule will be provided at discharge and at each clinic visit if there are medication changes. Be sure to ask your nurse any questions about the medications your child is taking. We want you to know all the medications your child is taking. In addition, please remember:

- Do not give your child any medications that are not prescribed by your doctor including any over the counter drugs such as aspirin or laxatives or herbal remedies without permission.
- Do not allow your child to drink any alcoholic beverages such as wine, beer, or any mixed drinks.
- Bring all your child’s medications to each clinic visit.
- If your child vomits immediately after taking his/her medications, repeat the dose after the nausea has decreased but within 30 minutes. If your child is unable to keep the medication in his/her stomach for at least 30 minutes, call your provider.

- If there is a change in your insurance coverage, lapse in coverage, or change in employment status please notify us immediately so we can work together to make sure all of the medications are covered. Please **DO NOT WAIT UNTIL THE LAST MINUTE** – this could lead to missing medications that could be harmful to your child.
- If you have any questions or concerns about your child's medications call the BMT advice line at (202) 476-4267 and your call will be returned within 24 hours. If you are unable to get in touch with someone from the BMT team, please call your pharmacist and they can help facilitate refills.

Returning to normal activities after transplant

- Children are allowed to return to school between day 100 and day 180 after transplant. The time to return to school is determined by the type of transplant your child received, current medicines and complications that have been experienced. Each child is different and return to school times will vary. A letter will be sent to the school explaining special precautions for your child.
- The central catheter will be removed when he/she no longer needs it for transfusions, medications or frequent blood draws. This time frame can vary from several months to a year or longer.
- Your child will be in social isolation (avoid crowds, public places, restaurants) until recovery of his/her immune system which is usually at least 100 days after transplant. Your doctor will inform you when it is okay to resume some normal activities.
- Even when your child is off social isolation, it is very important to continue to wash hands before eating, after touching dirty items, and after using the bathroom. Use a paper towel to turn off the faucet in public restrooms after washing your hands. Carry hand-washing lotions/liquids on public outings where there are no sinks and soap to wash hands.
- Patients are not permitted to go swimming until after day 100 and until the Broviac or MedComp catheter is removed. After that time, swimming may be permitted in a private chlorinated pool. Avoid swimming in the ocean, lakes, rivers, streams, hot tubs or whirlpools until your BMT physician tells you it is safe to do so. These bodies of water can have germs that can cause infections.



When to Call the Doctor

- **Fever:** is a sign of infection. Even though your child may look or feel well, and have a normal ANC, the fact that they have recently undergone a bone marrow transplant and the normal immune system may not be working at 100%. Call your doctor in the event of a fever episode. We would like to hear from you when your child has a temperature of:

Centigrade	Farenheit
38.3°	101° or higher by mouth
37.8°	100° or higher axillary (under the arm)

OR a low-grade fever that persists for one hour

Centigrade	Farenheit
38.0°-38.2°	100.4°-100.9° by mouth
37.5°-37.7°	99.5°-99.9° axillary (under the arm)

Fevers may happen to all children. It's nothing that you did or didn't do that causes it. Most of the time BMT patients become infected with their own germs. You need to get your child checked right away. Bring them to the Children's National Emergency Department or the nearest ER agreed upon by the BMT team. Please call the BMT Advice Line on your way to the Emergency Room so we are able to assist you through the process. Delays may be harmful since a fever can be the sign of a serious blood infection. A delay in antibiotic treatment can result in a serious infection and possibly death. If you need help in reading a thermometer, we will teach you. Make sure you have a thermometer before going home. You DO NOT have to take your child's temperature every day. If your child is not acting normally, feels warm to you, or has unusual sweating, shaking chills and/or face flushing take the temperature.

Precaution: Do not take rectal temperatures. Taking temperatures this way can give a child an infection. Axillary temperatures (under the arm) are fine. Hold the thermometer under the arm (with the head of the thermometer in the arm pit) for 5 minutes and then read. Oral temperatures are fine (if your child is old enough – about 4 years). Place the thermometer under the tongue for 3 minutes and then read.

- **Pain:** Children have aches and pains like we all do. Pain that interferes with play, eating, moving or walking may be a sign of infection or another problem. If your child experiences pain like this, call for advice. You should also call if your child has pain that comes and goes, pain that doesn't interfere with daily activities but persists, or rectal pain.

- **Swelling:** Areas of swelling with or without redness, or pain can suggest an infection. Also a warm or darkened area of skin. Look at your child's skin while bathing, older children can check themselves.
- **Problems with the Broviac or MedComp Catheter:** If there is any pain, swelling, or redness at your child's Broviac or MedComp site, any problems with flushing the catheter or leaks, call the doctor.
- **Coughing:** Can be a sign of a problem. It could be a simple "cold" or it could be pneumonia. A child with an occasional cough, who is happy, eating, drinking, playing and sleeping does not have a serious problem. On the other hand, the following can be signs of pneumonia:
 - Persistent cough
 - Cough that produces yellow/green discharge
 - A cough that awakens your child from sleep
 - Tired child who's coughing
 - A cough in a child with a fever
 - A cough with rapid (fast) breathing
- **Visual Problems:** Blurry vision, red eyes and double vision are all problems that need immediate medical attention.
- **Urinary Problems:** Symptoms of a urinary tract infection are pain on urination, a feeling of urgency, frequency or blood in the urine. If your child has any of these symptoms, call us.
- **Rashes:** Your child's doctor should check any rash after a stem cell transplant. Most rashes are not a problem, but others can be signs of a serious condition. Many children in diapers will have a "diaper rash." Most of the time it is caused by irritation of urine or stool on the skin. You should still call your child's doctor. Another type of rash commonly seen in patients with low platelets is like small, pinpoint, red-purple spots which are called petechiae. Graft-versus-host disease (GvHD) can affect the skin. Many times a skin rash is the first sign of GvHD. (See section on GvHD). If your child had a matched or mismatched allogeneic bone marrow transplant they are at risk for graft-versus-host disease. Notify your child's doctor if you notice any rash.

- **Any Major Change in Activity or Behavior:** Causes for concern are a previously active child who begins to sleep or lay down all the time, or a consistently irritable child who is extremely difficult to console. Call your doctor if these occur.
- **Unusual Pallor (pale) or Fatigue (tired):** These can be signs of anemia or infection and your child will need to be evaluated.
- **Bleeding:** Bleeding can occur anywhere in the body. The gums, nose, mouth and skin are common sites. A mild nosebleed that stops easily within a few minutes is not a major concern. A bloody, oozing nose that won't stop bleeding, gum bleeding, bruising, or tiny red-purple spots on the skin (petechiae) are important. If any of these occur you should call the doctor. You should report any blood you see in your child's stool. A tarry black color of your child's stool is a sign of bleeding. Blood in the urine or emesis (vomit) should also be reported.
- **Stool Pattern:** Most children will have diarrhea (liquid stooling) once in a while. You should be concerned if your child has more than 4 diarrhea stools per day, especially if this includes abdominal pain (tummy) pain or cramping. Report any changes in stool color or if your child has liquid stools every day, or is constipated. Constipation is having hard stool or not having a bowel movement for 3 days.

Call your doctor immediately if your child has any of these:

- Fever of 100.9° or greater
- Cough, shortness of breath, difficulty breathing
- Redness, swelling or pain in your throat, eyes, ears joints or abdomen
- Nausea, vomiting, diarrhea, or signs of dehydration
- Rectal pain or burning on urinations
- Headache, dizziness or difficulty walking



- Any signs of bleeding
- Redness, tenderness or discharge from the central catheter site
- Exposure to chicken pox, shingles or measles

How to contact us:

For matters during business hours please call the Blood and Marrow Transplant Advice Line at 202-476-4267 Monday-Friday from 8:30 a.m. to 5:00 p.m. For after hours, weekends and holidays call the hospital operator at 202-476-5000 and ask to be connected to the BMT provider on-call.

LONG TERM EFFECTS

There are many possible long term side effects of transplantation. Your child may have none of these problems or may have several. Members of the BMT Team will monitor your child for these side effects.



Most problems can be controlled by medication or minor interventions. Remember, the goal is to cure your child so that he/she will have a normal life. Most children have few, or minor problems after the transplant, however it is still very important that your child have annual checkups in our Long-Term Follow Up (LTFU) Clinic with the BMT team to evaluate for any long term side effects.

- **Growth delay** – This is most often seen when children receive TBI but can occur after some chemotherapy conditioning regimens also. If abnormally slow growth is noted, your child will be referred to an Endocrinologist for an evaluation.
- **Thyroid problems** – This is seen in about 30% of patients who received TBI. Thyroid blood tests will be checked routinely. If abnormal, your child will be referred to an Endocrinologist for replacement therapy.
- **Cataracts** – This is usually related to TBI and the use of steroids. They most often form at least five years after the transplant. Your child should be seen by an ophthalmologist for yearly eye exams.
- **Hearing loss** - Antibiotics and some chemotherapeutic agents can cause hearing loss. Notify your medical team if you notice any hearing changes in your child.

- **Lung problems** – TBI and some chemotherapy can cause scar tissue to form in the lungs. Pulmonary function tests will be obtained on a routine basis. The scarring may be minimal, but may predispose your child to smoking-related lung problems. Your child should never smoke tobacco and should avoid those who do smoke.
- **Heart** – Many children who undergo BMT have received drugs that might affect the heart. TBI may add to that affect. Heart function will be closely monitored on a regular schedule.
- **Liver** – TBI and some chemotherapy can cause scar tissue to form in the liver. This scarring may never cause problems unless the liver is exposed to other toxins such as excessive alcohol and chemicals (i.e., benzene, etc).
- **Fertility** - Generally patients who receive TBI cannot have children. But there are a few reports of successful pregnancy in women who had TBI. Your child may experience some delay in puberty, and we may recommend evaluation by the Endocrinologist or other specialist for possible testosterone or estrogen therapy. Your medical team may discuss ways to preserve fertility prior to his/her bone marrow transplant.
- **Effects on the brain** – TBI and some chemotherapy may have an effect on your child’s ability to learn. This occurs more often in the very young child. Your child’s I.Q. may not necessarily change, but your child may need special tutoring to help with schoolwork. Neuropsychological testing may be performed as needed to evaluate these issues.

Tests and Evaluations

Talk with the BMT team if you have any questions or concerns about any of these potential effects. Because these systems can be affected by BMT therapy, long-term follow-up visits are very important for your child for a lifetime. Your child should be seen at a BMT center familiar with these problems. Long-term follow-up visits will include:

- Physical exam
- Echocardiogram
- Pulmonary function tests
- Thyroid blood tests
- Sex hormone blood tests
- Psychological testing for learning problems (not required for all children)
- Eye evaluations by an ophthalmologist (eye doctor)
- Immune studies (blood tests to evaluate your child’s immune system)
- Dental exams every six months
- Hearing exam

All of your child’s visits will include height and weight measurements for growth assessment. Periodic evaluations will be done to check your child’s immune system and how your child is responding to immunizations.

Potential Consults Post Stem Cell Transplantation

Annual follow-up studies may reveal health issues that need treatment. Your child will be referred to any of these services based on his/her physical exam results.

- Audiology
- Cardiology
- Dermatology
- Endocrinology
- Fertility Specialists
- Gynecology
- Hepatology
- Nephrology
- Neurology and/or Learning Support Center
- Ophthalmology
- Physical Medicine and Physical Therapy
- Pulmonology

RESOURCES

Learning that your child needs a bone marrow transplant can be overwhelming. Knowing what to expect can help you prepare, which in turn may alleviate some of the stress you feel about how transplant will affect your child and your family's life. Your child's health care providers are the best sources of medical information, and will meet with you to provide a detailed overview of what to expect. If you find conflicting information on the Internet, please talk to your BMT team about this.

Your social worker can help with organizing other aspects of your life in preparation for transplant, such as finances, housing, transportation, caregiving plan, work

leave, and school leave. There are programs inside and outside the hospital that can provide assistance with daily living expenses.

RESOURCES IN THE COMMUNITY:

Grocery Stores

Giant Food Stores

1345 Park Rd NW, Washington, DC 20010

(202) 777-1077

Open 24 hours a day (parking onsite, free hospital shuttle to stop nearby)

Target

3100 14th Street NW, Washington, DC 20010

(202) 986-1415

Open from 8:00am – 11:00pm (parking onsite, free hospital shuttle stops in front of store)

Safeway

3830 Georgia Ave NW, Washington, DC 20011

(202) 722- 4023

Open from 5:00am – midnight (free parking onsite)

Yes Organic Market

3809 12th Street NE, Washington, DC 20017

(202) 832-7715

Open from 7:00am -10:00pm (street parking)



Community Organizations:

- 1. National Marrow Donor Program (NMDP)** – a national non-profit organization that provides free information and educational materials, and offers financial assistance to eligible families going through bone marrow transplant. Visit at nmdp.org or call 888-999-6743. Ask your social worker about financial assistance programs.
- 2. Open Doors Foundation** – provides families going through transplant with one month rent or mortgage payment up to a maximum of \$2500. Ask your social worker for more information.
- 3. Ronald McDonald House** – Located at 3727 14th Street NE, the House operates as “a home away from home” for families whose children receive treatment at Children’s National Medical Center and other local hospitals. The House has 25 bedrooms, all with free wifi, including four special isolation suites for immune-compromised patients. The isolation suites have full kitchens and private bathrooms. The House also has a common kitchen, dining room, library, game room, laundry room, and outdoor playground. There is limited shuttle service to and from the hospital. Meals are provided weekly by volunteers. Because beds are limited and hospital discharge dates are often uncertain, Ronald McDonald does not take reservations. Your social worker can help you get on their waiting list if needed.
- 4. Make-A-Wish-Foundation** – grants wishes to children ages 2.5 – 18 with life-threatening illnesses. Parents and legal guardians can use the online referral to activate a wish request. Social workers help families complete the request. For more information, visit makeawish.org.
- 5. Alex’s Lemonade Stand** – a national non-profit organization that funds research on pediatric cancer provides free educational materials, and operates a travel fund for cancer patients going through transplant. The travel fund helps with transportation, lodging and food expenses. Ask your social worker about travel assistance funds. Visit alexslimonade.org for more information.

Other organizations that may be helpful include the Leukemia and Lymphoma Society, American Brain Tumor Association, Aplastic Anemia and MDS International Foundation, Histiocytosis Association, MPS Society, American Sickle Cell Anemia Association, and others.

ONLINE RESOURCES:

Blood and Marrow Transplant Information Network

www.bmtinfonet.org/

Bone Marrow Transplant Forum, BMT-TALK

To subscribe to the mailing list, send an email to listserv@listserv.acor.org. write only “SUBSCRIBE BMT-TALK” in the message body along with your first and last name.

Center for International Blood & Marrow Transplant Research

Recommended Tests and Procedures
www.cibmtr.org/ReferenceCenter/Patient/Guidelines/Documents/allo_post_transplant.pdf

Emotional Support for Transplant Patients Cancer Survivors Network

<http://csn.cancer.org/>

Employment Rights Cancer and the Americans with Disabilities Act

www.eeoc.gov/facts/cancer.html

Fertility

Resolve Support Group for infertile couples:
www.resolve.org

Help with Post-Transplant Medication Costs Patient Access Network Foundation

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

Insurance and Employment Rights

www.canceradvocacynow.org

National Bone Marrow Transport Link

www.nbmtlink.org/resources_support/support.htm

National Marrow Donor Program

http://marrow.org/Physicians/Post-Transplant_Care/Post-Transplant_Care.aspx
Search Post-Transplant Care



National Organizations

National Cancer Institute

www.cancer.gov search "Facing Forward: Life After Cancer"

National LGBT Cancer Network

www.cancer-network.org/

Pediatric

American Childhood Cancer Organization

www.acco.org

Human Growth Foundation

hgfound.org

Children's Oncology Group

www.survivorshipguidelines.org

Skin Care

Skin Cancer

www.skincancer.org

Sun Precautions Clothing

www.sunprecautions.com or Phone number 1-800-882-7860

Sun Safety

www.fda.gov, search "Sun Safety"

TIPS FOR TRANSPLANT PATIENTS AND FAMILIES

It is sometimes helpful to speak with other patients or family members who have been through the same process. Your social worker, nurse or medical team can help connect you with someone. The following tips were provided by a parent of a child who received a transplant. The parent felt that these items were important and helpful during their stay.

1. Take a lot of reading material for both parent and child. Also bring favorite toys or games, especially for older children.

2. Bring small container of detergent and softener to wash clothes.

3. Have a relative stay at least once with the child while you go out and get some rest and relaxation.

4. Write down all questions and concerns so that you can ask your medical team when they come in.

5. Keep informed of tests and procedures.

6. When going to the clinic, always keep a small bag or suitcase packed in the car.

7. Always carry extra underwear for your child.



CONCLUSIONS

The BMT team hopes the information in the handbook will answer many of your questions regarding your child's stem cell transplant. However, there will be questions and concerns that have not been addressed. Please do not hesitate to contact us. We cannot emphasize enough how important it is to report anything unusual or anything that is worrying you. It is a good idea to keep a list of your questions and discuss them with us during your clinic visits. If questions cannot wait until a clinic visit call us on the BMT Advice Line and we will help you.

GLOSSARY

Allogeneic Transplant: A transplant using a tissue matched or partially matched related or unrelated donor.

Anemia: Decreased number or insufficient function of red blood cells which causes fatigue and paleness.

Antibodies: See gamma globulin.

Antithymocyte Globulin (ATG): A protein containing drug used to treat and prevent graft versus-host disease.

Apheresis: The process of removing only selected type of blood cells from a blood donor and simultaneously returning all the others.

Autologous Transplant: A transplant using the patient's own stem cells, which are collected, sometimes treated in the laboratory and stored to be given to the patient later after treatment.

Blasts: Young, ineffective white blood cells in leukemia. There are a few normal blasts found in all marrow. Tumor blasts, though, are found in leukemia.

Bone Marrow: Spongy center of bones that is the "factory" for all blood cell in circulation.

Bone Marrow Aspirate: A procedure by which a sample of bone marrow is taken from the hip bone.

Cardiomyopathy: Heart damage that can occur after high doses of chemotherapy, causing a weakening of heart muscle and decrease in its pumping function.

Cataracts: Changes in the lens of the eye which causes cloudy vision, a condition that can occur months to years after total body irradiation and steroid therapy.

Chemotherapy: Treatment for cancer using chemical substances designed to kill cancer cells. It is used in large doses to help destroy a patient's diseased marrow in preparation for a marrow transplant.

Conditioning: The process of preparing the patient to receive donated stem cells. Often done through the use of chemotherapy and radiation therapy.

Cord Blood: The blood of newborns found in the umbilical cord and placenta. It contains large numbers of blood stem cells important for transplantation. For this reason, stem cells from the placenta and umbilical cord are collected after birth, frozen and stored.

Cystitis: An inflammatory condition of the urinary bladder. Hemorrhagic cystitis is a rare side effect of certain chemotherapy drugs (e.g. cyclophosphamide) that results in bleeding from the bladder and bloody urine.

Cytogenetics: Testing of the chromosomes (DNA) in the bone marrow or blood cells.

Donor: A volunteer (related or unrelated) who has donated stem cells for a patient.

Engraftment: Successful transplantation of donor bone marrow cells into the patient as shown by growth and differentiation of donor cells to achieve normal blood counts in the recipient.

Fungus: A type of germ, different from bacteria, which can cause life-threatening infection (examples, candida, aspergillus and other molds).



Immunoglobulin: General term for antibodies, which are proteins made by normal lymphocytes to fight infections. Transplant patients often become deficient in immunoglobulins and require intravenous replacement. This infusion may also be referred to as IVIG.

Graft-versus-Host-Disease: A condition where the donor's transplanted marrow or stem cells react against the patient's tissues. It is referred to as GvHD and most often affects the skin, gastrointestinal tract, and/or liver.

Harvesting: The procedure performed under anesthesia to remove bone marrow from the patient or a donor (bone marrow harvest) or the procedure to remove peripheral blood stem cells (PBSC harvest or pheresis).

Hematopoiesis: The formation and maturation of blood cells (red blood cells, platelets and white blood cells) from progenitor stem cells.

Hematopoietic Stem Cells: Cells with the ability to both make other stem cells (self-renew) and divide and differentiate into mature white blood cells, red blood cells, and platelets.

Hemoglobin: The protein within the red blood cell which carries oxygen. Reduced levels of this protein result in anemia.

HLA: Human Leukocyte Antigen – Proteins on cells that are determined by genes (DNA) and are used to match a recipient and donor for a bone marrow transplant.

IgG: Antibodies which fight germs, they are produced by "B" lymphocytes (a type of white cell).

Immunosuppression: A condition in which the body's ability to fight infection (immune system) is decreased.

Interstitial Pneumonia: Inflammation of the lung tissue, usually caused by a virus, or, rarely, after radiation or chemotherapy.

Irradiated Blood Products: Blood products are treated with radiation in the blood bank to inactivate or prevent T-cells from causing graft-versus-host disease in the recipient. Radiation of blood products does not make the blood radioactive and does not endanger your child in any way.

Jaundice: A yellowish color in the skin or the whites of the eyes of the eyes associated with liver inflammation.

Leukemia: Any of a group of potentially fatal diseases involving uncontrolled growth of white blood cells. Leukemias are classified based upon rapidity of course of disease and cell type affected.

Lumbar Puncture: "LP" or spinal tap is a test or procedure to remove a small amount of spinal fluid that surrounds the spinal cord in order to check for infection or leukemia. A small needle is inserted into the low back briefly to obtain fluid.

Lymphocyte: A category of white blood cells including T cells and B cells.



Lymphoma: A cancer of lymph tissue or lymph nodes.

Monoclonal Antibodies: Specially prepared antibodies made specifically to attack certain kind of cells such as T cells or leukemia. Many of the newer immune suppressive medications are monoclonal antibodies.

Mucositis: Inflammation of the mucous membranes inside the mouth, tongue, gums, throat, stomach, or intestines commonly called mouth sores.

Neuroblastoma: A solid tumor of children which, in an advanced wide-spread stage, may be treated by autologous stem cell transplant.

Neutrophil: One type of white blood cell important in fighting bacterial germs and fungi.

Peripheral Blood Stem Cells: Cells with the potential to produce all the components of blood. Peripheral Blood Stem Cells (PBSC) are obtained from “circulating” blood rather than from bone marrow.

Platelet: A component of the blood important in clotting. Inadequate amounts of platelets will lead to bleeding and bruising easily.

Protocol: A specific plan for treatment of a disease or disorder.

Red Blood Cell: A type of blood cell made in the bone marrow that carries oxygen to all parts of the body.

Rejection: The body’s refusal to accept the transplanted marrow.

Relapse: The recurrence of leukemia or other underlying disease after treatment.

Remission: The disappearance of cancer cells following treatment. Also, the period during which the reduction or disappearance of symptoms occurs.

Steroids: A type of drug used to treat certain types of leukemia’s, to reduce inflammation, or to prevent and treat graft-versus-host disease.

T Cell: A category of white blood cell (lymphocyte) responsible for regulating the immune system and protecting us from viral and fungal infections. T cells are also the cells responsible for graft rejection and graft-versus-host disease.

Total Body Irradiation: Radiation (x-rays) therapy given to the whole body in multiple fractions over several days to treat cancer, and help clear out the existing bone marrow to allow space for the transplanted marrow. “Fractionated” TBI means that the total dose is split into smaller, more frequent doses in order to reduce side effects.

Total Lymphoid Irradiation: Irradiation directed only at lymph node sites such as neck, upper midline chest, and underarms.

Transplant: A medical treatment to replace a recipient’s diseased organ or tissues with a healthy organ or tissue from a donor.

Veno-Occlusive Disease: A condition which may rarely occur in the first few weeks after HSCT caused by obstruction in the liver veins due to damage from chemotherapy and radiation.

Virus: A type of germ that causes infections, most of which are not effectively treated with antibiotics. Examples: cytomegalovirus (CMV), herpes, varicella (chickenpox), adenovirus, hepatitis.

White Blood Cell: Also called a “leukocyte,” a type of blood cell produced by the bone marrow to help fight infection.

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