Autologous
Blood and Marrow
Transplant
Program

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INTRODUCTION

This booklet provides a general overview of autologous blood and marrow transplantation in order to prepare you and your family for the procedure. Please note that any medical term featured in bold is defined in the glossary at the end of the booklet.

What is ABMT? (Autologous Blood and Marrow Transplant)

Stem cell and bone marrow transplantation is a treatment for several types of cancer. **Autologous** transplantation involves removing a portion of the patient’s own bone marrow and/or blood stem cells. This procedure allows for the administration of higher doses of **chemotherapy** than conventional treatments. This is because the reinfusion of your previously collected stem cells acts as a ‘rescue’ and helps re-grow blood cells after therapy.

Who are we?

University Health Network (UHN) (consisting of Toronto General Hospital, Toronto Western Hospital, and Princess Margaret Hospital) is an international center for patient care, research and education in a range of health care specialties. Princess Margaret Hospital is a hospital devoted primarily to cancer care. The Department of Medical Oncology includes programs in both autologous and **allogeneic** blood and marrow transplantation, which are located in the Princess Margaret Hospital site, at 610 University Avenue, Toronto, ON.

We are committed to providing exemplary patient care, as well as fostering excellence in health care delivery, research and teaching. Like the community it serves, the staff is diverse and strives to appreciate the cultural and ethnic backgrounds of our patients and their families.

HEALTH CARE TEAM

The following section will introduce you to the health care team.

**Physicians**

Since the University Health Network is a teaching facility for the University of Toronto, you will meet many different physicians during your stay. Transplant fellows are the physicians with whom you will have the most contact in the outpatient setting. They are fully trained physicians who are doing one or more years intense extra training in autotransplantation. Staff physicians Dr. Armand Keating, Dr. Michael Crump, Dr. John Kuruvilla, Dr. Christine Chen, Dr. Suzanne Trudel, Dr. Donna Reece and Dr. Vishal Kukreti will supervise your overall medical care. When you are admitted for your autologous transplant, your medical care will be provided by one of the Clinical Associates who are responsible for the autotransplant inpatients.

**Transplant Coordinators**

The transplant coordinators are registered nurses who have specialized in blood and marrow transplantation. Any issues or concerns regarding your illness, preparation, or transplant should be directed through them. Currently, the coordinators are: Denise Aus for the Leukemia/Lymphoma patients, and Andrew Winter for the Myeloma/Amyloid patients. Please see the address book at the back of this booklet for how to contact them.
Transplant Clinic Nurses

The nurses in the clinic will assist with preparations and tests, which you will have as an outpatient (e.g. Blood and bone marrow tests). They will answer any questions you and your family may have about transplant or related health concerns. The nurses can also give you information about services available in your community such as the home care program (CCAC).

Stem Cell Collection Unit

The stem (blood) cell collection unit staff are registered nurses who specialize in the collection of your peripheral blood stem cells. They will teach you about the collection process, and can assist you with any collection related issues.

Inpatient Nurses

During your inpatient stay, an experienced group of nurses will plan and provide your care. They will administer your chemotherapy, and they will hang your cells and monitor you during your marrow or blood cell reinfusion. They will provide educational and emotional support for both you and your family.

Social Worker

The social worker can help you and your family deal with the stress and maximize your coping skills to help you handle the fears and anxieties associated with different aspects of your treatment. She/he can answer questions regarding the community services available to you, and how you might benefit from them. Emotional support and counseling, referrals for practical assistance such as transportation, accommodation, financial assistance, childcare arrangements and drug benefits are also available.

Pharmacists

The pharmacists follow your daily progress in conjunction with the rest of the health care team. They make suggestions concerning your drug regimen, and can answer drug-related questions.

Clinical Trials

The Autologous Blood and Marrow Transplant Program is an academic program of the Faculty of Medicine, University of Toronto. In addition to providing the best possible care, members of the transplant team are committed to studying and improving treatments so that patients in the years to come will benefit from this knowledge. You may be asked to participate in studies involving a number of aspects of marrow or blood cell transplantation. The clinical trials coordinator will explain the particular study to you and a consent form will be given to you to read and sign, if you wish to participate. Remember, you are not obliged to participate in any of these studies. If you do not wish to join a study, you will still obtain the same level of medical care and attention as if you had participated.
THE STEPS OF AUTOLOGOUS BLOOD STEM CELL OR BONE MARROW TRANSPLANTATION

To help you understand the process of autologous blood cell or bone marrow transplantation (ABMT), we have defined four steps. These steps are: 1) eligibility and response; 2) blood stem cell collection or bone marrow harvest; 3) the transplant; 4) recovery. **The length of time to progress through these four steps can vary depending on the disease you have. In some cases, complications may arise which can delay (and possibly even prevent) further treatment.**

The following sections of the booklet will describe each step in the ABMT process.

**Step 1: Eligibility and Response**

The initial assessment appointment is an essential part of your treatment. The assessment is necessary in order for you, your family, and the transplant team members to decide whether this treatment will be beneficial for you. It is also a chance for you to seek further information and helps to choose a course of action. You are encouraged to bring family members or friends to participate in your discussion with the transplant team.

Potential transplant candidates usually require further treatment to reduce the cancer. Your referring oncologist may administer these treatments. The pre-transplant treatment can involve more than one cancer facility. Although we attempt to stay up-to-date with your health care at all facilities, communications between hospitals is sometimes delayed. We **strongly suggest** that you keep a journal(diary) of your chemotherapy names and dates, your radiation dates as well as those of any x-rays and/or CT scans. Please bring the diary to your clinic appointments: your team will find this information very useful. Also, keep an up to date list of all medications that you are on, this includes your chemotherapy drugs as well as any other prescription drugs, over the counter medications, or alternative medications (e.g. holistic, naturopathic). If you are using more than one pharmacy, make sure that one of them has the complete list of medications. This can prevent unexpected drug interactions, which might delay your treatment.

It is important that you keep us informed about any events such as chemotherapy complications or delays so that we may anticipate scheduling changes. You should communicate this information to one of the transplant coordinators. You will find their phone numbers in the address book. A final decision on the advisability of an autologous bone marrow or blood cell transplant can only be made after reviewing a considerable amount of medical information, including your response to further treatment if it is required.

**Step 2: Blood Stem Cell Collection or Bone Marrow Harvest**

Peripheral stem cell collection and bone marrow harvesting are the two procedures used to collect your stem cells. **Stem cells are thought to be the origin of all blood cells.** They live in the bone marrow and are capable of reproducing themselves and producing **red and white blood cells** as well as the **platelets** that make up the components of blood. These cells, will be **reinfused** back into you, like a blood transfusion, following high-dose chemotherapy.
Blood Cell Collection

This procedure involves collecting stem cells from your peripheral circulation (bloodstream) using a technique known as **apheresis**. Although the bone marrow contains the largest concentration of stem cells in the body, a small number of stem cells can be found in the bloodstream. There are a variety of methods that can be used to increase the number of stem cells in the bloodstream. These methods are all referred to as mobilization. Your ABMT physician chooses the method of mobilization.

**Mobilization**

The most common method of mobilization is to administer a course of outpatient chemotherapy followed by the daily injection of a medication called Neupogen that stimulates the production and release of stem cells into the bloodstream. Occasionally, injections of Neupogen alone are used to mobilize stem cells. The decision about which method to use is determined by your ABMT physician.

The Neupogen is injected with a tiny needle, it is similar to the insulin injections that diabetics sometimes use. Neupogen stimulates your bone marrow and increases the number of circulating stem cells. These injections are usually well tolerated but can cause bone pain, headaches, and flu-like symptoms. The chemotherapy you receive can cause low blood counts, nausea and vomiting, fatigue and hair loss. You will be at more risk of infection for a short period of time, between the chemotherapy and the start of collection, so check your temperature twice a day. If you develop a fever (38.3 C/101 F), you should go to your local emergency.

**The Collection Procedure**

Your coordinator will tell you what day you have to report to the Stem Cell collection Unit. This information will be given at the time of mobilization. You need to be there at 8:30 am, with all your remaining Neupogen. The nurses in the unit will draw your blood each morning, do not go to the main floor blood lab. The results of this blood work, especially a test called CD34, will determine if collection is possible.

Your blood cells will be collected through a Quinton line. The Quinton line is a plastic tube, which is inserted into a large vein in your neck or chest. The line insertion takes place using a local anaesthetic in the angiography department at Toronto General Hospital, and takes about half an hour. After you have the line inserted, the doctor will give you a report documenting the position of the Quinton Line. **Please, remember to bring this report with you to your first blood cell collection procedure.** The Quinton Line is usually removed in the Stem Cell Collection Unit following your last collection. Care of your line will be reviewed by the nurses in the Stem Cell Unit.

The area of insertion may be uncomfortable for a few days. It is recommended that you take a pain reliever such as Tylenol. Once again do not, take any medication containing aspirin (ASA). Occasionally, a patient does not need a Quinton line or it does not work correctly. In that case, IV lines are inserted into the large veins in your arms, each day of the collection.

A cell separator device (apheresis machine) is used to collect cells through the Quinton line. Each session takes three to four hours, and is usually repeated for 2-5 days. There is a small
chance that the procedure will be unsuccessful. You may bring one friend or family member to the collection unit.

Side effects are very rare. Occasionally patients have experienced lightheadedness, coldness, numbness around the lips, or cramping in the hands during collection. Some people also feel fatigued after the procedure. If you experience any of these symptoms, please tell the stem cell collection nurse as soon as possible.

Prior to the collection, please eat a meal that is high in calcium (e.g. Milk, cheese). This will help to minimize any side effects. You may also bring snacks to the collection.

We recommend you abstain from drinking alcoholic beverages during the whole stem cell collection process. Most drugs including alcohol are removed from your body by the liver. The combination of chemotherapy, Neupogen and alcohol, can put a lot of stress on your liver.

Please inform your ABMT doctor of all medications, supplements and alternative therapies that you are taking at least one week prior to blood cell collection, if you are on oral blood thinners (Warfarin, Coumadin) make sure you tell your coordinator at least a week in advance of your collection. Blood thinners and blood pressure medications may need to be changed prior to your collection. So please make sure your Coordinator knows about these medications, when you come for your mobilization chemotherapy. The collected blood cells are processed and kept in frozen storage until your transplant.

The Bone Marrow Harvest

On rare occasions, you may require a bone marrow harvest to collect stem cells. Several preparatory tests are necessary before harvesting your marrow: (1) bone marrow aspirates and biopsies done on each side of the patient’s hips—this procedure is performed in the clinic, (2) a chest x-ray, (3) an ECG (electrocardiogram), and (4) blood tests. These tests usually take place in the clinic one week before the bone marrow harvest and involve about 2 hours in total.

This is an outpatient procedure, performed in the same day surgery unit. This means that you will be admitted to one of the Short-Stay Units, either at Princess Margaret Hospital, or at Toronto General Hospital, and discharged later the same day. If you live out-of-town, and need accommodation the night before the harvest, you may wish to make a reservation at the Princess Margaret Lodge. The phone number can be found in the accommodation list at the end of the booklet. You must arrange for a responsible adult age 18 years or over to pick you up by 6:00pm. and remain with you for 24 hours after the harvest.

The harvest takes place in the Operating Room while you are under a general anaesthetic. Since you will be asleep during the harvest, you will not feel anything. The procedure is similar to having a bone marrow aspirate done. The procedure will take 1-2 hours. The marrow is extracted by placing a needle into the bones of your hips to withdraw the bone marrow. The doctor will determine how much of your bone marrow will be harvested. This usually ranges from 1 to 2 liters. Your hemoglobin is checked before you are discharged, and often you will need to be given a blood transfusion.

After the harvest, you will be cared for in the PACU (Post Anaesthesia Care Unit) until you are awake and are able to talk. You will then be transferred back to the Short-Stay Unit. You may
be sleepy for the rest of the day as a result of the anaesthetic. Your hips will be tender, and they may also be itchy (these symptoms may last a few days). A mild pain medication is usually enough to relieve the discomfort. You should be up and walking in the afternoon after your harvest and be able to eat and drink that evening. Your harvested bone marrow is processed and is kept frozen until your transplant.

**Step 3: High-Dose Chemotherapy, Radiation and Transplantation**

**Preparation for Transplant**

**Communication**

Good communication between you and your health care team is crucial throughout your entire course of treatment. Not only does it help the team understand your needs, it allows you and your family, or friends to be more involved in your care.

**Scheduling**

Since Princess Margaret Hospital and the University Health Network treat hundreds of patients daily, and our program coordinates the treatment of many patients, we are not always able to accommodate each patient’s scheduling requests. It may not always be possible, for example, to set up appointments on sequential days. However, we will try to accommodate you when possible.

**Nutrition**

Good nutrition is especially important in preparing for a transplant. Being well nourished will help you withstand the stress of the transplant. The main goal is to nourish your body and try to maintain your body weight at a normal level. Eat a well-balanced selection of foods—a variety from the four food groups of milk and milk products, fruits and vegetables, meat and meat substitutes, and breads and cereals.

During the transplant, you will experience side effects that will affect your eating habits: a poor appetite, nausea, taste changes, and a sore mouth or throat. A dietitian is available upon request to discuss appropriate dietary interventions with you. Information about nutrition for transplant patients is also available in the Patient/Family Library on the Main Floor. You will probably still be suffering from these side effects when you are discharged. They will resolve over time.

**Preparatory Tests & Procedures**

There are several tests and procedures, which are required before your transplant to ensure that your major organs are functioning well. These tests also provide a baseline for comparing changes that may occur later on. The following section outlines the most common tests and procedures. Please note that not every patient will require every test. These tests are often performed during the week of stem cell collection.

**Dental Check-up**

Since your mouth can be a source of infection during transplantation, you will need preventative dental care. We recommend that you see the oncology dental specialists at Princess Margaret Hospital for an assessment. The Transplant Program Secretary will arrange this. The cost of any
dental work that needs to be done before transplant is the patient’s responsibility. You may see your own dentist in order to take care of regular procedures such as cleaning, fillings and a review of oral hygiene techniques. Failure to do so may result in the delay of your transplant. Your dentist should contact the transplant office if he/she has any questions.

**Pulmonary Function Test**

A pulmonary function test is done to assess the functioning of your lungs prior to transplant. It provides a baseline of your lung function and needs to be measured because some chemotherapy drugs and radiation treatments may affect your lungs. This test is done in the Pulmonary Function Laboratory at either the Toronto General Hospital, or Mount Sinai Hospital and takes 1 hour to complete. It involves a moderate amount of effort on your part; you are asked to take deep breaths and blow into plastic tubes many times.

**MUGA Scan (Multi-Gated Acquisition)**

The MUGA scan is done in the Nuclear Cardiology Department at either the Toronto General Hospital, or Mount Sinai Hospital and requires an intravenous injection of a radiolabelled substance, which can be detected on x-ray. X-rays are then taken of your heart. You may be asked to perform mild exercise while the x-rays are being taken. You must not eat or drink for 2 hours prior to this scan. The entire procedure takes 90 minutes.

**Echocardiogram**

The electrocardiogram is an ultrasound of your heart. The procedure takes about 40 to 60 minutes and requires the application of gel over your left chest. You may feel slight pressure as the ultrasound instrument is rubbed over the gel. You may eat and drink prior to this test. Not all patients require this test.

**Hickman Catheter (Central Venous Catheter) (CVC)**

Throughout your transplant and for several weeks following your transplant, you will require a central venous catheter (CVC), also referred to as a double lumen Hickman Catheter. The CVC is a catheter that is inserted into a large vein in your chest, near your collarbone, before your treatment begins. It is used to administer your chemotherapy, to draw blood for tests, and to reinfuse your blood cells to you after the transplant chemotherapy. If you already have a PICC line, or a Port-a-Cath, you will still require a Hickman line.

The insertion of a CVC is similar to the insertion of the Quinton line, which is described in the section on blood cell collection procedures. It is an outpatient procedure performed under local anaesthetic in the radiology (x-ray) department at the Toronto General site.

**Additional Tests**

There are many different x-ray techniques that can be used to determine the status of your disease prior to the transplant. You will have had some of these tests before and your doctor will decide which one(s) is necessary before the transplant. These tests may be done at your referring hospital; please check with your transplant coordinator.

A CT scan is an x-ray requiring an intravenous injection of a contrast solution and/or drinking for a contrast solution at specific times prior to the scan. Different hospitals have different
instructions regarding eating and drinking before a CT scan. Please check with your hospital about any preparation for your CT scan.

A bone scan is an x-ray of your bones following an injection of a radiolabelled substance. The injection is given and the scan begins 2 1/2 hours later. The scan takes 1 hour, therefore, be prepared to spend at least 4 hours of your time at the hospital. The scan is done in the Nuclear Medicine Department at Toronto General Hospital or your referring hospital. You may eat and drink prior to this test.

A gallium scan is an X-ray requiring an injection of a radiolabelled substance. This test takes 2 separate trips to the hospital because the scan is done 72 hours after the injection. The scan takes about 2 hours to complete and is performed in the Nuclear Medicine Department. You may eat and drink before this test.

**Hospital Admission/Transplant**

Following the preparatory tests and the stem cell collection, you will be admitted to the Princess Margaret Hospital for the intensive treatment portion of the transplant. This time frame can vary for a variety of reasons. You may need more treatment. There may not be an available transplant bed. Your coordinator will be stay in contact with you about when your admission will occur. The average length of the inpatient stay is 21 days. Some patients stay longer due to complications.

We suggest you bring loose, comfortable clothing with front opening tops (pajamas, slippers, robe, sweat suit), toiletries (comb, brush, shampoo, deodorant, electric razor), stationary, pens, pencils, stamps, envelopes, light reading material, a radio or cassette player and a few items to personalize your room such as a comforter, family photos, etc.

Following admission to the hospital, you will receive the high-dose chemotherapy, followed by the reinfusion of your stem cells. A small group of patients may also receive **Total Body Irradiation (TBI)**

The purpose of autologous blood or marrow transplantation is to enable the administration of much higher doses of chemotherapy than in regular cancer treatments. Although you may have had chemotherapy before, it was not as strong as the treatment you will have for a BMT. The treatment is normally given over a period of 1-5 days. The drugs used and the total number of days will vary depending on the type of disease you have. The transplant team will discuss the details of your chemotherapy and the common side effects with you.

The chemotherapy is the **treatment** for your disease. After completion of the chemotherapy (and in some cases, total body irradiation), you will receive your preserved blood cells. This process is called “reinfusion”. The reinfusion is the actual “transplant” portion of your treatment. The stem cells help you recover from this large dose of chemotherapy.

Nausea and vomiting are a common side effect of chemotherapy, and stem cell reinfusion. You will be given medication prior to the chemotherapy, and before receiving the stem cells to reduce these effects.
The technologist will thaw the cells in a warm water bath in your room prior to the infusion. Once the blood cells have thawed, they are hung like a bag of red blood cells and reinfused into your Hickman Line. This process usually takes less than half an hour. You may experience some nausea and discomfort.

As soon as the thawed blood enters your body, you will sense an unusual taste and smell which resembles canned corn. This is due to a preserving chemical called dimethylsulfoxide (DMSO) that is mixed with your cells to protect them during the freezing process. TIP: Some people find that sucking on a hard candy during the reinfusion helps to offset the taste. Others will notice the DMSO odor in your breath and perspiration for 24-48 hours. The thawed cells will be colder than your body temperature, and may feel cold as they are reinfused back into you. Your urine may also be red for several hours after the reinfusion. This is caused by the breakdown of red blood cells that were in your stem cells and is a normal side effect of the reinfusion. Your blood pressure will be monitored throughout the infusion. A health care team member will be present during your reinfusion. A family member may also be present if you wish.

Step 4: Recovery

Following the therapy and reinfusion, you will need to spend some time recuperating in the hospital. The chemotherapy will cause your marrow to stop producing blood cells (red blood cells, white blood cells & platelets). Consequently, your blood cell counts will decrease significantly until the infused marrow or blood cells engraft (begin to grow and produce new cells). This usually takes 11 days but may take longer. Most patients will require both blood and platelet transfusions, as well as antibiotics.

During the period when your blood counts are low, you are susceptible to infection and bleeding. Other side effects include nausea, vomiting, diarrhea, hair loss, lack of energy and appetite, and a sore mouth and throat. These side effects are reviewed in more detail in the following section of the booklet.

DO NOT underestimate these side effects. They will be more intense than previously experienced. On some days, you will probably feel like staying in bed during your recuperation. This is a common feeling, which should be anticipated.

All efforts are made to prevent and treat complications, which may arise. There is, however, a risk of dying as a result of infection and/or bleeding. Your physician will discuss the estimated risk of serious complications with you.

Side Effects of Chemotherapy

Bone Marrow Suppression

As mentioned earlier, your blood counts (WBC, Hgb and Plts) will be decreased for a short time after your treatment. When necessary, you will receive transfusions of red blood cells and platelets.

Having a low white cell count makes you more susceptible to infection. Consequently, several measures will be taken during your period of recuperation to reduce the risk of infection. You
will be put on a low bacteria diet and as well, any visitors who enter your room MUST WASH THEIR HANDS with antiseptic soap at the sink located just inside your room. Family (including children), and close friends can visit, provided they are well, but they are not allowed to use the patients bathroom facilities. No cut flowers or potted plants are allowed. Your door is kept closed until your white blood cell counts recover, however you will be able to walk about the unit wearing a mask. Upon return to your room, you must dispose of the mask and wash your hands thoroughly with antiseptic soap.

Since the first symptom of infection is usually a fever, your temperature will be taken every 4 hours. If you feel like you have a fever or you experience a chill, tell your nurse right away. You will be checked daily for other signs of infection such as redness, tenderness, swelling of your Hickman catheter site, or a cough.

Having a low platelet count means you are more susceptible to bleeding. You will have platelet transfusions as necessary to prevent this from happening. Your platelet count is checked daily and you will be examined for any signs of bleeding such as bruising, blood in your urine or stool, or nose bleeds. If you notice any bleeding, let your nurse know right away. In an effort to prevent bleeding, do not use any medications containing aspirin (ASA) and shave with an electric razor.

Your Hgb (hemoglobin levels) will be checked daily as well. If necessary your doctor will order transfusions of RBC’s.(red blood cells)

Nausea & Vomiting

Nausea and vomiting are common side effects of both chemotherapy and radiation. You will receive medication to help prevent these effects.

Alopecia

Hair loss is almost certain and is a result of both the chemotherapy you will have received and the radiation. You may lose hair on areas of your body other than your head. The hair loss occurs several days after the treatments finish; it starts to grow back approximately 2 months later. You may wish to bring caps, turbans or wigs to the hospital. If you wish to purchase a wig, you can contact the PMH wig boutique (number is listed on telephone list). Unfortunately, the cost of wigs is not covered by OHIP, but may be covered by your private insurance.

Fatigue

The ABMT treatment and its side effects cause a profound decrease in your level of energy, especially in the 2-3 weeks following your chemotherapy and radiation. You will require plenty of rest and sleep. Even once you are well enough to leave the hospital, you will still be very tired. Your energy level and energy reserves will improve from week to week. You may feel like you have plenty of energy, but tire easily. This is very common. Some patients say that their energy levels did not return to normal until almost a year after the treatment, though 3 to 6 months is more common. You will need to prepare for this recovery period prior to your transplant, and make arrangements at work, with your family, etc.

Lack of Appetite
In the first few weeks following the chemotherapy and radiation, it is very common to experience a loss of appetite. Food will probably not taste right because the chemotherapy and/or radiation affect your taste buds. Furthermore, nausea and mouth sores also reduce your desire to eat. It is normal to lose a little weight during the transplant process, but you should try to maintain a healthy intake of fluids and food. It may take a couple of months before your sense of taste begins to return to normal.

**Sore Mouth or Throat**

Although not all patients experience this side effect, it is common to develop a sore or painful mouth several days after your treatment. It will usually last about 7 days. The medical term for this condition is mucositis or stomatitis. The first signs of mucositis or stomatitis are usually a dry, irritated or burning feeling of your tongue and inside your mouth. This can progress to having small ulcers on the inside of your cheeks and lips. Maintaining good oral hygiene (frequent, gentle brushing and mouth rinsing) is very important to minimize discomfort and prevent infection. Your nurse will instruct you in a self-care regimen and will provide you with special rinsing solutions. The physician will also prescribe pain medication if necessary. These sores may also develop in your throat as well.

**Memory**

Some people notice a loss of memory, concentration and/or coordination. These changes are not permanent and are most likely due to various drugs, which you receive during your treatment.

**Diarrhea**

Diarrhea can occur a few days after the chemotherapy. It usually lasts for approximately one week and should improve as your body begins its recovery. If you lose a lot of fluid due to the diarrhea it will be replaced intravenously.

**Fertility**

As you may know, patients who undergo chemotherapy have a higher incidence of becoming infertile. Undergoing a blood or bone marrow transplant can add to this effect. **Infertility may already be an issue due to previous treatment.**

**Side Effects of Radiation Treatment**

If you are receiving TBI, the sore mouth, diarrhea, nausea, and vomiting which you will experience will be severe and prolonged. Additionally, there are several conditions, which are specific to radiation treatment.

**Dry mouth**

You may experience a dry mouth as a result of a temporary decrease in the amount of saliva produced. This condition will decrease over time. Since saliva helps to flush away bacteria, a dry mouth leads to increased cavities. A return appointment to the oncology dental specialist should be arranged by the Ward Clerk, within three months of your discharge from hospital.

**Skin reaction**
A mild skin reaction is a common side effect of radiation. It looks like a sunburn and will eventually turn into a tan. Your skin may also be dry. After you have finished your radiation treatments you may use an alcohol free moisturizing lotion to help relieve the dryness.

**Emotional Well-Being**

Preparing to enter a new hospital for treatment adds stress to an already difficult situation as you adjust to the different hospital routines, and begin to establish trust in your new medical team. You will also be trying to absorb more information about the transplant procedure and its side effects in order to prepare yourself for the procedure.

**Anxiety**

Anxiety is a common reaction to this type of situation. You may be worried about many things: your family’s well-being, your future, the effects of the procedure on your career and, not uncommonly, the fear of death itself. If you have had to travel a long distance for the transplant or must commute to reach the hospital, there is the added stress of leaving familiar surroundings and the support of friends and family.

By sharing these feelings with family members, you will find that they are aware of your concerns but may be protective and do not want to demonstrate their own fears. The transplant staff is aware of the different feelings which you may be having and encourage you to share your emotions with them.

At Princess Margaret Hospital, the Psychosocial Oncology and Palliative Care Program includes Psychiatry, Psychology, Social Work, Occupational Therapy, and Chaplaincy. These professional services are available for patients and their families during this difficult time. Referrals can be made either directly at 416-946-4525, or through your ABMT doctor, nurse or social worker.

**Isolation**

While you are in hospital, you may have a sense of isolation. You are encouraged to leave the room however and walk around the unit wearing a mask. During this phase, you may feel that you are not in control of certain aspects of your care. This may lead to feelings of frustration, anger, anxiety, or depression. Due to the tiredness caused by your treatment, it may be even more difficult than usual to cope with these feelings. The isolation may also lead to feelings of loneliness, boredom, restlessness, or of being trapped. All of these reactions are normal and can be anticipated. However, due to the tiredness caused by your treatment, it may be even more difficult than usual to cope with these feelings. The team caring for you will try to keep you constantly informed about your condition.

**Sexuality**

There are many aspects of one’s sexuality which may be affected by the transplant. They include concerns about self-image, performance, infertility, and a fear of contagion. Since the transplant utilizes high dose chemotherapy and sometimes total body irradiation, it is important to be aware of the side effects, which could apply to your condition. Be sure to address your questions and concerns to your physician, nurse, or social worker so they can provide you with information and direction.
During your hospitalization, we encourage you to remain affectionate with those you love.

All of the feelings mentioned above are common experiences of transplantation. People have described their journey as an “emotional roller coaster”. You each have unique strengths and skills that will help you to cope with these feelings. Focusing on the positive aspects of every day and taking one step at a time are just two ways to deal with the stresses encountered during a transplant.

Other suggestions include:

- Practice relaxation and visualization techniques.
- Express your emotions.
- Explore “self-help” books and tapes.
- Seek medical information.
- Explore creative outlets.
- Participate in activities you enjoy.

**Wise words from the “Transplant graduates”**

“As a group of autologous blood and marrow transplant “graduates”, we feel we have something unique to offer current and prospective ABMT patients. Our experiences can be supportive, informational, and maybe even inspiration. We have each faced the challenges of the transplant in our own way. Here are some of the things that helped us through…”

Milly “My husband was with me every single day - my family made the biggest difference. I was really sick and even them just being there helped…also, I saw the psychiatrist, it was a lift I looked forward to.”

Ann “My mother came to see me every day – my husband called every day and came to see me every weekend. More than anything I held on by looking forward to being out and having a normal life again.”

Dan “I used the psychiatry and social work services in the hospital, and highly recommend the same. I decorated my room as personally as I could…pictures of my family…a print from home…a dart board. I took long showers and did as many things for myself as I could. There were times when I needed space and privacy and it was important for me to be able to tell that to my loved ones and hospital staff…I would take my phone off the hook and put a sign on my door.”

Sylvia “I wasn’t really able to concentrate on the television, I didn’t have much focus. I slept a lot and just tried to accept what was coming…the time went quickly—I made the best of it. I remember my daughter called just as I received the transplant, it’s a moment I will never forget.”

Tom “I told myself, don’t worry about things you can’t control. Many of life’s ups and downs are planned for you. I may not be able to stop them but knowing this sure makes it easier to deal with! It’s not my fault!”
Lisa “I brought my own pillow, a floral pillowcase, and afghan spread, a stuffed animal, my tape player and tapes all to make the hospital room more like my own. And then there was what I called my “wall of love”. On the wall next to my bed, I hung up every card I received, cartoons, pictures, and a calendar…for charting my counts and marking off my days. Any time I needed to, I just looked at the wall—it made such a difference.”

Ian “For me, I found doing small simple things was very important…just looking, knowing something else was going on, looking ahead, reading the paper everyday…I had lots of visitors and once I regained my appetite I had a regular supply of Hagen-Dazs.”

If you are interested in speaking to a “graduate”, please contact the social worker.
Support Services

The ABMT program offers a number of support programs, as well as being linked to a network of community services, which provide help for patients and their family and friends.

**Magic Castle:**
**Princess Margaret Hospital**
**Psychosocial Oncology and Palliative Care**
(416) 946-4501 ext.5157

The Magic Castle is a playroom for the children of PMH patients and their families who are receiving treatment at the hospital. Different from a typical daycare service, the Magic Castle provides sensitive care and support to children of all ages in a fun and safe environment. Space must be reserved in advance.

**Patient Resource Guide:**
Composed by the PMH Hematology Social Workers, this guide answers many questions you may have about your hospital stay, drug coverage, income assistance programs etc. copies can be picked up from the Psychosocial Oncology offices on the 16th floor, or from the information wall outside the Transfusion Centre on the 2nd floor.
Information Services

**Cancer Information Service**  
(1-800-263-6759)

This organization offers a toll free telephone information service. Answers to questions about all types of cancer, related issues and community resources are provided by staff and trained volunteers. Written materials are available and are mailed to the caller.

The National Cancer Institute’s computerized data base (PDQ) can also be accessed to provide specialized information about new treatments and clinical trials. English & French.

**BMT Newsletter**  
1985 Spruce Avenue  
Highland Park, Illinois 60035  
Tel: (847) 831-1913  
Fax: (847) 831-1943

An informative, up to date newsletter published six times a year by Sharon Stewart, a former BMT patient. Medical advisors are used as contributors. Write, call or fax an order to add your name to the mailing list.
Donations are gratefully accepted.

**Bayview Support Network Newsletter**  
(416) 480-6898

A quarterly educational newsletter written and created by cancer patients for other patients and their friends and families. The goal of the newsletter is to share common experiences and to help patients manage the challenges of their illness, treatment and life after cancer. Available to members. The membership fee is $10.00. Contact the office to apply. English.

**International Myeloma Foundation (IMF)**  
1 800 452 CURE

The International Myeloma Foundation is dedicated to improving quality of life of myeloma patients while working toward prevention and a cure

The IMF is a non-profit corporation governed by a Board of Directors and guided by an expert Scientific Advisory Board. It offers many programs and services such as a toll-free hotline, Internet access, workshops and regular publications.

**Toronto & District Multiple Myeloma Support Group**  
(905) 669-5652  
(416) 260-1915

A local support group open to patients, family members, care givers, and any other interested people. They offer regularly scheduled meetings.
Additional Information

Travel Arrangements

Depending on where you live, there are several programs offering assistance with travel, either by providing transportation or reimbursing all or part of your expenses. They include:

Northern Health Travel Grant

Grants from Ontario Ministry of Health are available to Northern Ontario residents who must travel more than 300km (one way) for treatment. Your referring doctor can give you an application for this grant, or you can obtain one from the nearest OHIP office. An adult relative or guardian may also be eligible for this grant when accompanying a patient who is under the age of 18 years.

Hope Air Transportation Network

Hope Air is a non-profit organization, which provides travel assistance for Canadian Citizens/landed immigrants who demonstrate financial need. Commercial, government, and private transportation companies donate the airline seats.
Contact Hope Air at:
Hope Air Transportation Network
Procter and Gamble Building
4711 Yonge Street,
Toronto, ON
M2N 6K8
TEL: (416) 222-6335
FAX: (416) 222-6930

Hospital Room

Your provincial health insurance (e.g., OHIP) covers standard accommodation (a 4 bed room) room). A semi-private room, or a private room may be requested at an additional cost. If you have extended coverage through work it may cover part or all of the costs of a semi-private or private room. You will need to verify this with your insurance carrier prior to your inpatient admission. If you request a semi-private or private room, you will be charged the additional amount when you leave the hospital (unless you have notified Patient Accounts with your insurance policy information). Please note that, depending on the number of patients admitted to the floor, we might not always be able to accommodate your requests. To discuss your situation in more detail, contact Patient Accounts.

Telephone & Television

During your inpatient stay, you may want to have a television and/or telephone in your room. There are daily or monthly charges which are applied when installed. If you have extended health insurance, it may cover these costs. Monthly rates are less expensive than daily rates.
**Lodging for Family Members**

Many of our patients' families from out-of-town make arrangements to stay with friends or family while in the city. The patient and one family member/friend may stay at the Princess Margaret Hospital Lodge at no cost. There is a shuttle service to and from the Hospital.

You can also contact your hospital social worker for assistance in arranging your accommodation. There is a list of hotels that provide discounted rates to patients and patients families on the University Health Network website([www.uhn.ca](http://www.uhn.ca)). Ask about the special hotel rates for patients and their families when making your arrangements.

**Parking**

There is a parking garage located on Murray St. just south of Princess Margaret Hospital. The current cost for this lot is $10.00 per day if you park before 9:00am. After 9:00am additional rates will apply, up to a maximum of $22.50/day.

There is metered parking on the streets around the hospital between 9:30am and 3:30pm, and after 6:30pm. Parking is restricted on University Avenue from Monday to Friday. Your car will be towed if parking rules are violated.

**Public Transportation**

The Toronto Transit Commission (TTC) provides public transportation within the city, via buses, street cars, and subway. Check with TTC for pricing. Their phone number is (416)393-4636.

**Home Care (Community Care Access Centers)**

Home care means the provision of health care services to patients at home, covered by OHIP. A multi-disciplinary team of professional and support personnel provide a variety of services. The team includes personal support workers, nurses, physiotherapists, and laboratory technicians.
**Glossary**

**A**

**Allogeneic**: bone marrow/stem cells received from a compatible donor.

**Antibodies**: proteins from the immune system, which act on antigens.

**Antigen**: substances which are foreign to an individual’s body and are acted upon by antibodies from the immune system.

**Anemia**: a below-normal level of red blood cells in the blood.

**Apheresis**: the process of removing a desired blood component from the body using a cell separator device. In ABMT, apheresis is used to harvest peripheral blood stem cells for peripheral blood transplant.

**Autologous Blood and Marrow Transplant**: a treatment for certain types of cancer in which bone marrow or peripheral blood stem cells are removed from a patient, followed by the administration of high doses of chemotherapy (and in some cases, total body irradiation therapy). The cells are then returned to the patient in order to promote the regrowth of blood cells which have been destroyed by the therapy.

**B**

**B Lymphocyte**: a type of white blood cell that develops in the bone marrow. B lymphocytes are the source of antibodies.

**Benign**: a tumor (mass of cells) which enlarges only at its site of origin and does not destroy normal cells. It is not cancerous.

**Biopsy**: the surgical removal of a small piece of tissue for laboratory examination.

**Bone Marrow**: bone marrow is the spongy tissue inside the bones which produces red blood cells, as well as most of the white blood cells and platelets. It is concentrated in the ribs, breast bone, skull, pelvis, and backbone.

**Bone Marrow Aspiration**: the removal of a small number of bone marrow cells for microscopic examination. This procedure is performed in the clinic under a local anaesthetic.

**Bone Marrow Harvest**: the removal of a portion of bone marrow cells from the pelvis for transplantation. This procedure takes place in the Operating Room under a general anaesthetic.

**Bone Marrow Transplant**: a procedure in which bone marrow which has been destroyed by high-dose chemotherapy and/or radiation therapy is replaced with new marrow either from the patient himself (autologous transplant) or from a matching donor (allogeneic transplant).
C

Cancer: a disease in which abnormal cells in some organ or tissue grow out of control. A tumor is formed by a mass of cells. Cancer is a malignant tumor – a tumor that has the potential to invade and destroy normal tissue around it. It can spread to distant parts of the body. The original tumor is called the primary tumor. When cells break off the primary tumor and establish themselves in a new site as an independent cancer, the resulting secondary tumor is called a metastasis.

Cataracts: changes in the eye lens causing cloudy vision; cataracts can be corrected by routine surgery.

Chemotherapy: the treatment of cancer through chemicals in order to interrupt the rapid reproduction of the cancer cells. The side effects of this treatment stem from the fact that the chemicals affect not only cancer cells, but also healthy ones. Toxicity is a term, which refers to the ill effects or side effects of a treatment.

Clinical Trial: clinical trials are studies, which involve volunteer participants. They are an important contribution to scientific research and evaluation of new medications and treatments. Once a new medication has been through rigorous laboratory research to ensure its safety and effectiveness, studies (clinical trials) are done on patients.

Complete Blood Count (CBC): a series of tests which examines the various components of the blood in order to help determine a patient’s general condition and the effectiveness of a treatment, including the regeneration of bone marrow after transplant.

E

Engraftment: the process during which transplant marrow begins to manufacture new blood cells in the patient’s marrow cavities after transplantation.

Erythrocyte: see red blood cell definition.

F

Fractionated Radiation: a radiation treatment in which the total dose is divided over several days.

G

Graft: tissue taken from a donor and transferred to a recipient (the donor and recipient may be the same person) as with an autologous graft.

H

Hematology: the study of blood and diseases of the blood.

Hematopoiesis: the production of blood cells in the body.
**Hemoglobin**: Hemoglobin is the molecule within the red blood cell, which bonds the oxygen.

**Hickman Catheter**: an intravenous tube.

**HLA Tissue Typing**: HLA stands for human leukocyte antigens. They appear on white blood cells and on the cells of most other tissues. HLA typing is done in order to match recipients and donors of platelets, white blood cells, and bone marrow.

**Hodgkin’s Disease**: one type of lymphoma. It starts in one area of the lymphatic system, usually a lymph node, and if untreated, can spread throughout the system. Eventually, it can involve the lungs, bones, and abdominal organs.

**Immune System**: the immune system is the body’s mechanism for fighting infections and tumors.

**Immunosuppression**: a suppression of the body’s immune response caused by the use of drugs or techniques that interfere with the immune system.

**Intravenous**: the administration of a drug or fluid substance directly into the veins.

**Leukemia**: a disease characterized by abnormalities in the blood forming tissues – the bone marrow. Abnormal immature cells grow in the bone marrow, which previously produced only normal, healthy cells. The immature cells eventually spill into the blood. Normally, these cells would pass through a series of changes to reach maturity. In cancerous cells, however, the final mature stage is not reached. Leukemia is classified on the basis of its speed of development, and the type of cell involved.

**Leukocyte**: see white blood cell definition.

**Leukopenia**: a below-normal white blood cell count.

**Lymphatic System**: part of the body’s defense against infection, composed of a network of small vessels called lymphatics and nodes called lymph nodes, along with the lymphatic tissue. The lymphatic system returns fluid from the body tissues to the blood stream. Lymph nodes are small collections of lymphocytes located along the lymphatics that filter out some of the impurities and bacteria, which may be present in the lymph fluid. The lymphatic tissue is a collection of cells called lymphocytes found in the lymph nodes, glands, and other tissues.

**Lymphoma**: an abnormal growth of cells in the lymphatic system (see Hodgkin's Lymphoma or Non-Hodgkin's Lymphoma)

**Metastasis**: a secondary tumor formed by cells, which break away from the primary tumor and establish themselves in a new site.
**Mucositis:** a sore or painful mouth which is caused by chemotherapy and/or radiation therapy. You will probably require strong pain medication to control this side effect.

**Multiple Myeloma:** a disease which begins when one type of blood cell, the plasma cell, undergoes a change in the bone marrow and begins to multiply faster than usual. The rapidly multiplying plasma cells excrete excessive amounts of a type of protein called the M or monoclonal protein. This substance accumulates in the plasma (the straw-colored liquid component of the blood).

**N**

**Neupogen:** a drug which is used to stimulate growth of your stem cells and/or white blood cells.

**Neutropenia:** a below-normal count of neutrophils which makes you more susceptible to infection.

**Neutrophils:** a sub-type of white blood cells which fights infection.

**Non-Hodgkin’s Lymphoma:** a disease, which almost always originates in one or more of the body’s lymph nodes. If the cancer cells remain confined to a few nodes, the lymphoma is localized. Generalized lymphoma refers to the condition where the abnormal cells are found throughout the lymphatic system as well as in other organs.

**O**

**Oncology:** the branch of medicine, which deals with cancer and its treatment.

**P**

**Peripheral Blood Cell Transplant:** a treatment for certain types of cancer which entails the removal of stem cells from the peripheral bloodstream followed by the administration of high-dose chemotherapy and in some cases, radiation therapy. Like bone marrow transplantation, a peripheral blood cell transplant can be either autologous (the cells are removed from the patient’s own bloodstream) or allogeneic (the cells are removed from a compatible donor. It is also referred to as blood cell transplantation.

**Plasma:** the component of the blood, which remains after all the blood cells have been removed.

**Platelet:** a type of blood cell, also known as a thrombocyte. It is a major component of the blood, which produces clots to stop bleeding.

**R**

**Radiation Therapy:** a treatment, which uses high energy radiation in order to interrupt the reproduction of cancerous cells. Like chemotherapy, radiation affects not only cancerous, but also healthy cells.

**Red Blood Cell:** a type of blood cell, also known as erythrocyte. It functions primarily to supply oxygen to the tissues and remove carbon dioxide.
**Reinfusion:** The physician will return your peripheral blood stem cells into your bloodstream via your Hickman catheter.

**Relapse:** the reappearance of disease after a period during which the disease was not detectable, and symptoms were absent.

**Remission:** the absence of detectable disease. It can be partial or complete.

**S**

**Stem Cell:** a primitive blood cell, which can become anyone of several different types of mature blood cells (red or white blood cells, or platelets).

**T**

**T-lymphocyte:** a type of white blood cell that matures in the thymus gland.

**Thrombocyte:** see platelet definition.

**Total Body Irradiation (TBI):** radiation treatment that is administered to the whole body.

**W**

**White Blood Cell:** a type of blood cell, also known as a leukocyte. The white blood cells help mobilize the body’s reaction to infection and foreign substances. There are three main types of leukocytes – the granulocyte, which destroys invading bacteria; the lymphocyte, which creates antibodies; and the monocyte, which defends against micro-organisms and removes old cells.
AUTOTRANSPLANT STAFF

Transplant Team Doctors

Dr. A. Keating  416 946-4595
Dr. M. Crump  416 946-4567
Dr. C. Chen  416 946-2827
Dr. D. Reece  416 946-2824
Dr. S. Trudel  416 946-4566
Dr. J. Kuruvilla  416 946-2821
Dr. V. Kukreti  416 946-4566
Dr. R. Tiedemann  416 946-2359

Transplant Coordinators

If you have any questions regarding the transplant process, please call:

Denise Aus:  416 946-4689
Pager Number 416 790-4585
Andrew Winter:  416 946-4583
Pager Number 416 790-7861

Transplant Secretary

If you have any questions regarding test appointment dates and times, please call:

Laura Pylyp:  416 946-4501 ext. 5082

Stem Cell Unit

416 946-4688

Social Work

If you have any questions or concerns regarding community support, drug coverage, etc, please call:

Social Work:  416 946-4525

Dietitian

If you have any questions or concerns regarding nutrition, please ask for a Dietician referral