MULTIPLE MYELOMA

Patient Education Manual

October 2007 Edition
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Introduction

Welcome to the Leukemia/Bone Marrow Transplant (BMT) Program of British Columbia here at Vancouver Acute of Vancouver Coastal Health (Vancouver General Hospital).

The purpose of this manual is to provide you and your family with the necessary information regarding the treatment of your Multiple Myeloma with a peripheral blood stem cell transplant.

We hope that within this manual you will find the answers to the many questions you may have. We would ask that you please bring this package with you to all your appointments.

There is a substantial amount of information contained within the following pages. We do not recommend that you try to read it in one sitting. We do however encourage you to take the time to read it at your own pace and use it as a reference guide throughout your treatment. Write down any questions that come to mind and be sure to address them with your health care team member(s) at the earliest opportunity.
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Important Telephone Numbers

These members of the BMT team can help you with your questions or put you in contact with other team members who can. We welcome you to call any of us at the following phone numbers:

BMT Coordinators:
- Mary Wong 604-875-4939
- Sheila Wong 604-875-4111, local 63432
- Valerie Campbell 604-875-4111, local 68549
- Carolyn Frew 604-875-4111, local 67486
- Fax 604-875-5678 (Mary)
- Fax 604-875-4910

Leukemia/BMT Day Care (CP6A/B) 604-875-4073
(After hours call the inpatient number)

Leukemia/BMT Inpatient (T15A) 604-875-4343

Hematology Apheresis Unit (HAU):
- Reception 604-875-4962
- Booking clerk 604-875-4626
- After Hours Call Locating 604-875-4111, ask for the HAU nurse or doctor on call

Social Workers:
- Beverly Biggs 604-875-4941
- Brad Pearson 604-875-4697

Pharmacist 604-875-4077

BMT Doctor

Medical Services Plan of BC 604-683-7151 or
Assistance Program and Fair PharmaCare 1-800-663-7100

Other Numbers: 

Leukemia/BMT Program: Who and Where We Are

We are your health care team at Vancouver General Hospital (VGH), 855 West 12th Avenue, Vancouver, BC. We are your doctors, nurses, coordinators, social workers, pharmacists, nutritionists, physiotherapists, occupational therapists, technicians and support staff. We work together to provide you with the best possible care during the course of your treatment. You may encounter us in one or more of the following areas: Daycare (CP6A/B), Inpatient unit (T15A), and Hematology Apheresis Unit (HAU). In brief these areas are:

- **Leukemia/BMT Inpatient Unit (T15A):** is located on the 15th floor of the Jim Pattison Pavilion at VGH. This unit provides 24 hour nursing and physician care with close monitoring and continuous assessment of your health care needs. Note that Multiple Myeloma patients are rarely admitted.

The following areas are located in the Krall Centre on the 6th floor of the Centennial Pavilion at VGH:

- **BMT Daycare (CP6A/B):** is the outpatient ambulatory care unit. Patients with various leukemias and related diseases are treated here. Patients are assessed and health problems/concerns are addressed. Blood counts are monitored, intravenous treatments (antibiotics, chemotherapy and other medications) and blood transfusions are given. Many other treatments and diagnostic procedures are also done in or through this department.
  
  **Hours of operation:** 8:00 am – 7:00 pm  Mon – Fri  
  8:30 am – 6:00 pm  Sat, Sun and Holidays

- **Hematology Apheresis Unit (HAU):** is the outpatient apheresis unit (CP6C). Much of your teaching and administering of G-CSF injections will take place here, as will your subsequent peripheral blood stem cell collection.
  
  **Hours of operation:** 8:00 am – 4:30 pm  Mon – Fri

  The unit is closed on weekends and holidays. There is a physician and nurse on call during closed hours. If you need to contact them, call 604-875-4111 and ask for the cell separator nurse or doctor on call.

- **BMT Daycare Program/Doctor’s Clinic (CP6D):** This is where physicians meet with their patients to assess them and discuss their disease status, treatments and progress. Hours and days of operation vary from doctor to doctor. The clinic is usually open to appointments: 
  
  **Mon-Thurs from 8:00 – 12:00 pm and 1:00 – 4:00 pm**
TREATING MULTIPLE MYELOMA WITH AUTOLOGOUS STEM CELL TRANSPLANT:

OVERVIEW

Written October 2007

Vancouver General Hospital
Treating Multiple Myeloma with Autologous Stem Cell Transplant: An Overview

The following is a brief summary of the transplant process used to treat Multiple Myeloma, from initial treatment and the collection of stem cells to and including the recovery stage. Later sections in this manual will provide you with more detailed information.

What is Multiple Myeloma?

Multiple Myeloma (MM) is a malignant cancer that starts in plasma cells (a type of white blood cell called B Lymphocytes). Plasma cells are made in the bone marrow and their normal function is to produce antibodies that help fight infection.

In myeloma, abnormal plasma cells grow continuously to form a mass, or tumor, in the marrow. These cells in turn produce abnormal antibodies that do not work properly. As these myeloma cells grow unchecked, they crowd out developing normal red, white, and platelet blood cells. Fewer red blood cells cause anemia, which leads to fatigue and shortness of breath with exercise. Fewer white blood cells cause neutropenia, which makes it harder for you to fight infection. Fewer platelets affect your ability to stop bleeding if an injury occurs (evidenced by increased bruising and nose bleeds). Myeloma cells may also attack your bones. They make substances that can cause bones to dissolve, creating pain and making bones fracture easily. In some cases, myeloma also interferes with kidney and nerve function.

Myeloma is a highly individualized disease. While there are similarities between patients, each case has its own distinct characteristics. Detailed information regarding your diagnosis of myeloma can be obtained from your physician. They will discuss with you the specific issues surrounding your diagnosis and consequent therapy. The goal of existing treatment is to slow the progress of the disease and reduce symptoms. When deciding on an appropriate treatment, your doctor will consider your age, overall health, symptoms, stage and type of myeloma.

What is Peripheral Blood Stem Cell Transplant?

Peripheral Blood Stem Cell Transplant (PBSCT), also traditionally called Bone Marrow Transplant (BMT) can be divided into two main types: Autologous and Allogeneic. The difference in these terms has to do with whom the cells are taken from.
Bone Marrow or peripheral blood stem cells taken from the patient him/herself, and given back later (reinfusion) is an **Autologous Transplant**.

Bone Marrow or peripheral blood stem cells taken from a related (sibling) or unrelated (stranger) donor is an **Allogeneic Transplant**.

Bone Marrow Transplant (BMT) is used to treat a variety of hematological diseases. It is used to replace a diseased or damaged bone marrow with a healthy, functioning marrow. This process is what makes it possible to treat your multiple myeloma with high doses of chemotherapy. Because high doses of chemotherapy will destroy the bone marrow, it will be necessary to replace your “destroyed” (damaged) bone marrow using your own (autologous) stem cells.

**Initial Treatment**

The initial therapy/treatment you receive will depend largely on how your disease is diagnosed. Because myeloma often causes thinning of the bones, some people present with bone fractures or compression of the spine. This most often requires immediate radiation therapy. Your doctors may have also elected to treat you with blood transfusions, large amounts of fluids and with bisphosphonates such as Pamidronate (Aredia®); a class of drug which helps decrease bone pain and reduce the bone destruction caused by the myeloma cells. As well, an autologous stem cell transplant has been shown to be beneficial in patients with myeloma up to the age of 70 – 75. For this reason, you have been referred to one of the physicians here at the Leukemia/Bone Marrow Transplant Program of British Columbia.

In most circumstances, the medication, which you will take during the first 2-3 months of treatment, is a drug called Dexamethasone (Decadron®). This drug is used because it allows for the control of the myeloma rapidly while plans are made for assessment in Vancouver for further treatment. Dexamethasone may be given in a number of different schedules. Most patients are given this drug at doses of between 20–40 mg for 4 days with an off treatment interval of between 4–10 days. Using this Dexamethasone schedule for a total of 28 days is referred to as “1 cycle”. We suggest patients receive at least 2-3 cycles (therefore 2-3 months) of treatment, before moving on to the next step. Again, dosing and number of cycles will depend on a patient’s specific needs and health concerns.

**Collection of Peripheral Blood Stem Cells**

Usually stem cells are collected from the peripheral blood (blood flowing through the veins) using a technique called apheresis. This is achieved using a centrifuge machine called a “cell separator”. The procedure involves removing...
whole blood from the body through an intravenous line and feeding it through the cell separator machine where the parts of the blood (red cells, white cells and plasma) are separated into layers based on their weight. The stem cell layer is then removed and kept for cryopreservation (freezing). The remaining blood is returned back to the patient through another intravenous line. The flow of blood from patient to machine and then back again is a continuous loop. The procedure is generally easy to tolerate. However, it requires the patient to lie on a bed for approximately 6-8 hours with an intravenous line in each arm. Television, music, and a caring staff are available to assist the donor/patient in their needs and to help pass the time.

Sometimes, a patient’s veins may not be big or strong enough for the intravenous needles needed for the cell separation. If this happens, it may be necessary to place a temporary intravenous-type line in a large vein such as those found in the neck. The doctor’s in the cell separator unit will explain the process to you in detail if necessary.

In order to collect stem cells from the peripheral blood, the bone marrow must be stimulated to produce these stem cells in large quantities and release them into the blood stream. To achieve this, we give the patient a stimulating hormone called G-CSF (also known as Neupogen® or Filgrastim®). This medication is given through an injection under the skin every day for 5 days. Stem cell harvesting will commence on the 5th day. For some patients who have shown a poor response to dexamethasone treatment, the doctor may prescribe a chemotherapy drug called Cyclophosphamide before G-CSF is to begin. There is more about this in the G-CSF administration section.

On your first visit to the Hematology Apheresis Unit (HAU), you will be given a tour of the unit, and the process of collecting stem cells will be explained and shown to you. Your veins will be assessed, blood work will be drawn if needed, and your height and weight recorded. A doctor will see you and provide you with a prescription for the G-CSF and a cooler pack.

You will commence your G-CSF injections, usually, within the week. Arrangements will be made to have the injections given at your GP’s office or walk-in clinic, in the HAU, or the daycare unit. You may experience some bone aches and mild fevers after a few days of taking the G-CSF. This is normal. It is essential that you notify Leukemia/BMT doctor if you develop bleeding or fevers greater than 38°C (100°F).

Following the stem cell collection, you may have a waiting period of several weeks before coming back for your transplant. You may also be required to undergo certain tests to ensure your organ function is adequate for the transplant to proceed. They include testing your kidney, heart and lung functions. Some of you may have already had these tests prior to undergoing stem cell harvesting.
Autologous Stem Cell Transplant

A few days prior to your transplant, a Hickman Line Catheter (a semi-permanent intravenous device) will be inserted. You will go either to the Angio or Cath Lab where a vascular surgeon will place the catheter into a major vein in your chest using local anesthetic (freezing). This is a relatively simple procedure and is usually done through the outpatient department. The day prior to the insertion, you will have your blood work drawn at an outpatient lab (at VGH or in your home community). A nurse from the daycare unit will contact you by phone when they have the results of your bloodwork. They will explain the procedure to you and answer any questions you may have.

You will proceed to have your chemotherapy and subsequent transplant 2 or 3 days later, in the outpatient department. Chemotherapy treatment with a drug called Melphalan will occur the day prior to transplant. This day is referred to as “day –1”, “Day 0” will be the day of your transplant. On this day, your cryopreserved stem cells will be thawed and returned to you via your Hickman intravenous catheter (much like a blood transfusion). You will be closely monitored throughout the procedure.

Please note: Prior to transplant, it is recommended that all members in your household, have the ‘flu (influenza) shot. Children in your household should be up to date with their immunization and, if due; they should also have their chicken pox vaccine before you go for transplant.

Post Transplant

Over the next 3 weeks, you will be observed carefully for potential side effects/problems. Some of these may include fever, bleeding, drug and organ toxicities, infection, sore mouth, nausea, vomiting, diarrhea and problems with eating and drinking. At the end of this period, we expect your counts to have started to recover (we call this engraftment). Some individuals may take longer to recover and will therefore require additional days of monitoring. We understand that for those individuals living outside the lower mainland, a lengthy stay outside the hospital can prove difficult. It is the patient’s responsibility to arrange for their own accommodations. We will, however, make every effort to assist you in finding a suitable place to stay. Ideally accommodations should not be further than 45 minutes away from the hospital such as with the Cancer Society Lodge or similar facilities.

Once you are doing well and you’ve been “discharged” from the hospital or outpatient department, you will return home. Follow-up monitoring and post transplant treatment will be individualized and will largely depend on your responses to the initial treatment and to the transplant. As there are numerous, and varied post transplant treatments, they are not covered in this manual.
BMT doctor and your family doctor or referring hematologist will arrange much of this.

It is important that you not only have a good understanding of what your treatment is but also, why it is being given and what the expected risks and benefits are. We strongly encourage you to discuss these with your BMT doctor, nurses or with your BMT coordinator. We all appreciate that this is a significant life issue for patients and we will ensure that the time is taken to answer your questions and concerns.
Leukemia/Bone Marrow Transplant Program

TESTS AND PROCEDURES

Written May 2007

Vancouver General Hospital
Tests and Procedures

Before undergoing your treatment, various tests and procedures are necessary to establish the present function of your heart, lungs, kidneys, etc. Throughout your treatment you will require constant monitoring. All of the tests and procedures are aimed at providing you with the best possible care.

Bone Marrow Biopsy

Bone Marrow biopsies are done to diagnose your disease and to determine the effectiveness of your treatment.

The doctor performs this procedure either in the inpatient unit or the outpatient unit. A pre-medication may be given to help you relax during this test. The skin is first cleansed with an antiseptic solution. A local anesthetic is then injected with a very fine needle to freeze the area. Once the freezing is working, a larger needle is put into the bone to take out a sample of bone marrow and a small piece of bone. You may feel some discomfort or pressure during the procedure, as the bone itself cannot be frozen. Tell the doctor if you are feeling too uncomfortable. Once the biopsy is done, you will be asked to lie on a “sandbag” for 15-20 minutes to provide pressure to the area. This helps to prevent bleeding and bruising.

Insertion of Hickman Line Catheter

Prior to beginning your treatment, a long-term intravenous catheter called a Hickman line will be inserted. The line is inserted in the “Angio” or “Cath Lab” (or sometimes in the operating room), usually under local anesthetic. You may be given some medications to help you relax before the procedure begins. A special doctor (vascular surgeon) will insert your catheter into a large vein in your chest.

The Hickman line catheter is a hollow flexible tube made of soft rubber-like material. It has several ports (openings) at the end of it. These can be used for drawing blood, infusing chemotherapy, antibiotics, blood products and other medications. It is expected that you will have your Hickman line in place for several weeks during the transplant and recovery periods.
The procedure is relatively simple and most often done through the BMT daycare unit. The day before your scheduled Hickman line insert, you will be required to go to the lab to have your blood drawn. A nurse from the BMT daycare unit will then check your blood results. You will receive a phone call from the nurse and at this time, the procedure will be fully explained to you and any questions or concerns you may have will be addressed.

The following day you will come to the outpatient department where you will have a temporary intravenous inserted into your arm prior to the procedure. An antibiotic may be given through this, to help prevent infection. The insertion procedure takes about an hour to do. You will be required to stay an additional 2 hours for monitoring, after you are transferred back to the daycare unit. It is important that you have someone available to take you home afterwards as you will be tired and may feel some of the side effects of the sedation.

**Blood Tests**

Throughout your treatment, you will have your blood drawn at various times and for many different reasons.

During the transplant and post-transplant period, blood will be taken from your Hickman line as often as every day. Your condition will be monitored and treatments adjusted according to the results of your blood tests.

**24-Hour Urine Test**

A 24-hour urine collection test will be started prior to treatment. Many of you may have already done this test when you were first diagnosed, as it is one of the tests used to help determine Multiple Myeloma. This test is used to measure your kidney function. Creatinine is a waste product put out in the urine by the kidneys. The test compares the level of creatinine in the blood with the amount of creatinine put out by the kidneys in a 24-hour period. A decreased rate of clearance indicates that the kidneys are not working as well as they should and chemotherapy treatments may have to be changed based on the results.

You will be given instructions on when the test and 24-hour period will begin. You will need to empty your bladder and throw this urine away. Make note of and record this time. After this, all urine must be saved during the next 24 hours in large plastic bottles. It’s easiest to keep these bottles in your bathroom, however, if you have to go out for an appointment, take a bottle with you. It is essential that all urine be collected during this 24-hour period. If any amount of
urine is accidentally spilled, thrown away, or mixed with stool, the test will have to be restarted. The bottles can be obtained at your local lab or at our outpatient lab at VGH (located in the Gordon & Leslie Diamond Health Care Centre). Once you have finished collecting, the bottles will be sent to the lab. Be sure to drink plenty of liquids during the test.

**Radionuclide Ventriculogram (RVG)**

A radionuclide ventriculogram (RVG) is a special type of x-ray used to look at how well the heart works. Certain chemotherapy drugs can be harmful to the heart and if the results of this test are outside normal limits, the doctor may change the dose or the type of chemotherapy.

A blood sample will be taken prior to the test, either through your Hickman or if you don’t have a line, it will be taken from your arm. Then, a small amount of radioactive material is mixed with the blood specimen and injected into a vein with a small needle. You will be asked to lie still as the machine traces the path of the injected blood on a monitor screen. From the pictures taken, the doctor can see how well the heart pumps blood and how well the heart valves work. As the amount of radiation used to tag the blood is tiny and doesn’t last long, your exposure to radiation is also very small. This procedure takes between 1-2 hours.

**Electrocardiogram (ECG)**

An electrocardiogram (ECG) records the electrical activity of the heart. It is used to diagnose possible heart problems. It is done on admission to provide a baseline. Any further ECG’s are compared to the first one. An ECG records electrical impulses; it does not send any to the patient.

An ECG can be done at a local lab, the outpatient lab at VGH, ambulatory daycare unit or the inpatient unit. During the procedure you will lie flat and quietly on the bed. Several small, flat discs will be attached to your chest, arms and legs. The wires running from the machine, called leads, are attached to the discs. The electrical activity of your heart is recorded on graph paper. The whole process takes no longer than 5-10 minutes.

**Pulmonary Function Test**

This is a study that determines how well your lungs are working by measuring how well your lungs can provide
oxygen to your body. This is a relatively simple procedure and is not uncomfortable, but for some it can be exerting. You will be required to sit in a Plexiglas booth where you will be instructed to frequently blow into special equipment while a technician takes various measurements of your lung capacity. To prevent breathing through your nose, you will be given a pair of nose clips to use. There are four tests in total and the whole procedure takes about 45-60 minutes. For one of the tests you will be asked to use an inhaler through which the technician will give you albuterol (Ventolin®). Ventolin is a bronchodilator often used by patients with asthma or bronchitis. It helps to “open up” the air passages in the lungs making it easier for air to flow through. There are very few side effects to Ventolin, however, do let the technician know whether you have a pre-existing heart condition, are taking heart medications or you are already on bronchodilators/inhalers. If you are already using bronchodilator medications such as Ventolin, do not use them before the test.

**X-Rays**

An x-ray is used to take a picture of the body or a part of the body using a small, controlled amount of radiation. You may have several x-rays before and throughout your transplant treatment. Prior to your transplant, you will have a skeletal survey and a chest x-ray done. This gives the doctors a baseline to which later x-rays taken can be compared. This allows the doctors to monitor how well you are doing with treatment.
G-CSF ADMINISTRATION FOR STEM CELL HARVESTING

Written October 2007

Vancouver General Hospital
G-CSF Administration
For Stem Cell Harvesting

In order to collect/harvest stem cells from the peripheral blood (from your veins), the bone marrow must be stimulated to produce these stem cells in large quantities and release them into the blood stream. We prime (or prepare) the bone marrow by administering G-CSF injections.

What are Stem Cells?

Stem cells (known as progenitor cells) are immature cells that grow and divide into mature red cells, white cells or platelet cells. The type of blood cells that are produced is controlled by the needs of your body. Special proteins found in the body called “growth factors” or “colony stimulating factors” (CSF) also play a role in controlling the growth of stem cells.

Stem cells are usually found inside the bone marrow spaces of large bones, such as your hipbones. They can however, travel from one bone to another by way of the blood stream. A very small percentage of the white blood cells circulating through your veins are stem cells.

What is G-CSF?

Colony stimulating factors are naturally occurring proteins, which act on the bone marrow stem cells. They stimulate the production and separation of specific cell lines (i.e. red blood cells, white blood cells and platelets). Granulocyte Colony Stimulating Factor (G-CSF also known as Neupogen® or Filgrastim®) is a recombinant protein that helps stimulate the growth of stem cells (in particular the number of neutrophils) in the bone marrow, causing their release in greater numbers into the blood stream. (Neutrophils, a type of white blood cell, are part of the body’s natural defense against infection).
How is G-CSF Given?

G-CSF will be administered daily by injection, through a tiny needle under the skin. Arrangements will be made for you to receive your injections either in the HAU, BMT daycare unit or if you prefer you may arrange to have them given at your GP’s office or walk-in clinic near to your home.

Generally, you will take G-CSF for 5 days. Stem cell collection will commence on the 5th day. On the 5th day you will have an early appointment to come early to the HAU (Hematology Apheresis Unit) and have your blood drawn in order to check your blood counts. Assuming your neutrophil count is sufficiently high, you will proceed to have your peripheral stem cells collected. In the event that your counts aren’t elevated enough, you may be prescribed additional days of G-CSF therapy.

More Information about G-CSF

Cost Reimbursement for G-CSF (Neupogen®)

- You should be registered for BC Fair PharmaCare. You can contact Fair PharmaCare (1-800-663-7100) to clarify your benefit plan and medication coverage. If you have already reached your deductible amount with Fair PharmaCare, in the present calendar year, the cost to you regarding your G-CSF may be greatly reduced.

- G-CSF is a very expensive prescription medication and is NOT paid for by the Vancouver General Hospital or the BC Cancer Agency. This is the only medication that can be used to increase blood stem cells. Generally, the cost of G-CSF for one course of treatment will be between $3000.00 and $3800.00.

- Depending on your extended benefits and your Fair PharmaCare deductible, you will need to pay for some or this entire amount “out-of-pocket”.

- You may have drug cost reimbursement through an extended health plan or funding from social assistance (Ministry of Human Resources). You should contact the insurance carrier or your financial aid worker to discuss coverage of this medication.

- If you have tried all the above and still cannot afford the medication, please contact the Leukemia/BMT Program coordinator or the program’s social worker assigned to you, to discuss this situation further.
What to look out for when injecting G-CSF

When G-CSF is injected, you may feel a slight stinging sensation at the injection site from the medication. Sometimes, injecting into a larger surface area such as the abdomen or injecting the medication slower can reduce the stinging. If you experience some pain or redness at the injection site, it should go away soon. If it does not, contact your nurse or doctor.

Sometimes a bump occurs at the injection site. Do not rub it. The bump will often go away in a few hours. If the bump persists for more than a few hours, contact the nurse or doctor.

A small amount of medication can sometimes leak out at the injection site when the needle is withdrawn. If it does, simply apply light pressure with the alcohol swab, but do not rub.

Other drugs may interact with G-CSF. It is important that you tell your doctor if you are taking any other medicines. This includes, over-the-counter drugs, naturopath/herbal remedies (including vitamins, teas, etc.), even if taken only occasionally.

Side Effects of G-CSF

Generally, therapy with G-CSF is well tolerated. Some patients have experienced discomfort that is usually reported as headache and/or aching in the bones (most often in the back and hips). If you feel discomfort, please contact your doctor or nurse for advice on how best to relieve it. Be sure to tell your nurse or doctor if you experience any symptoms that concern you while you are taking G-CSF. Never take a medication for a side effect, or for anything else, unless your nurse or doctor recommends it.

When Should You Call the Doctor?

Never hesitate to call the doctor or nurse whenever you have any symptoms that worry you or if you are concerned with any aspect of your treatment. However, if you have a fever of 38°C (100°F) or more, chills, develop a rash or symptoms of an allergic reaction, pain when urinating, bleeding, or have a problem such as a lump, swelling or bruising at the injection site that doesn’t go away, or if anything unusual about your condition occurs, contact your doctor or nurse promptly and be sure to follow the instructions you are given.
A Word about Cyclophosphamide

In the past, a chemotherapy medication, Cyclophosphamide (Cytoxan®), (sigh-kloe-FOSS-fa-mide) was used regularly for all multiple myeloma patients undergoing autologous stem cell transplant as part of the pre-harvest treatment. Cyclophosphamide is no longer used for most patients, since it has been shown that dexamethasone treatment on its own is enough to suppress the myeloma tumor load. However, there are a small percentage of patients where dexamethasone is not enough to control the myeloma or where it is felt that G-CSF alone is not sufficient to stimulate the stem cell production. For these patients, the BMT doctor may elect to prescribe Cyclophosphamide before stem cells are harvested.

How is Cyclophosphamide Given?

Cyclophosphamide is a drug used to treat many different kinds of cancer. As a chemotherapy medication, it can lower normal blood counts (called bone marrow suppression). This drug is used here because it is effective in decreasing the myeloma tumor load while minimizing bone marrow suppression.

Your Bone Marrow Transplant (BMT) doctor will arrange for you to visit the BMT daycare unit (in the Krall Centre) a few days prior to your scheduled cyclophosphamide administration. At this time, your height and weight will be recorded. A doctor will see you and will use this information to prescribe the proper dosage of cyclophosphamide for you. The cyclophosphamide infusion, additional medications and possible side effects to treatment will be explained to you and your consent for treatment will be obtained. As a conventional chemotherapy drug, Cyclophosphamide has some side effects. Among the most common are alopecia (hair loss), nausea and neutropenia (low white cells which puts you at risk for infection). You will be given prescriptions for antibiotic, anti-nausea and G-CSF medications (these are to start after you receive your cyclophosphamide).

You will receive your intravenous cyclophosphamide either in the BMT outpatient department or the HAU. The procedure will be the same in either area. A nurse will start an intravenous line in your arm. Prior to the Cyclophosphamide, you will be given fluids to help hydrate your body and medications to prevent/decrease nausea. This takes about 2-2.5 hours. The Cyclophosphamide will then be infused over another 2 hours. Finally, following this, you will receive a medication to help you pass urine. The whole process takes about 4-6 hours. Please
arrange to have someone available to take you home as you will be tired and may feel some side effects of the treatment.

Cyclophosphamide has the potential to cause kidney and bladder problems. To prevent this, it is important that you drink at least 8-12 cups water/day for at least 24 hours before and after the Cyclophosphamide infusion and that you empty your bladder often (at least every 2 hours for the first 24 hours after).

Bladder inflammation caused by cyclophosphamide resembles a urinary tract infection with symptoms including burning and frequent urination as well as visible blood or blood clots in the urine. The development of this complication is known as hemorrhagic cystitis. Treatment may include intravenous fluids and sometimes platelet transfusions to minimize bleeding, but the condition usually resolves on its own. If a bacterial or viral infection is found to be the cause of the symptoms, appropriate drug therapy is given as well.

Remember, because Cyclophosphamide will decrease your white cell count, you will be at risk for infection. Take your prescribed antibiotics as directed. You can prevent infection by washing your hands often (especially after using the bathroom) and by avoiding crowds and people who are sick.

**Note:** For patients having cyclophosphamide, G-CSF injections will start two days later and will be given daily over seven days.
PERIPHERAL BLOOD STEM CELL COLLECTION

Written October 2007

Vancouver General Hospital
Peripheral Blood Stem Cell Collection

There are two different methods of collecting stem cells.

Stem cells can be collected directly from the bone marrow spaces (most often from the hip bones). Several puncture sites are made along the bone and the cells are removed using a needle. This is known as a bone marrow harvest.

The second way (and usually the preferred way) is to give the patient Growth Factors, which promotes the growth of stem cells and causes them to be released into the blood. These stem cells can then be collected using a cell separator machine.

Collecting Stem Cell

The process by which your stem cells will be collected is called “apheresis” (a-fair-ee-sis). Two ends of tubing will connect you to a cell-separating machine during the collection. Your blood will flow out of one arm, inside the tubing, to the machine where it will spin your blood around at high speed. The spinning separates the different components of the blood into layers based on their weight. The stem cell layer will then be collected and the remaining blood will be returned to you via the other arm. The blood always stays inside the tubing set. The set and needles, which are sterile, are used only once and then discarded.

You will be attached to the cell separator machine for 6-8 hours for each collection. There will be nurses and technicians present for the entire time. During the procedure it is necessary for you to stay in bed. Each bed area has a television set to help pass the time. You may also have a friend stay with you.

Side Effects during the Apheresis Procedure

The apheresis procedure is safe, however, there are some side effects you may experience and should be aware of.

- If you have an I.V. (intravenous) needle in the inside elbow region of your arm(s) you will need to keep your arm(s) straight during the procedure. Sometimes this can be uncomfortable. Please let the nurses know so that they can assist you in getting as comfortable as possible.
• The flow of blood from your veins (and rarely the St. Paul’s catheter) can sometimes be slow and variable. In this case, the nurses may ask you to squeeze your hands to increase blood flow, change your arm position, or the nurses may adjust the lines or machine. Occasionally a needle will have to be replaced in order to get good blood flow.

• Changes in blood volume may make some people feel dizzy or light-headed. You should tell the nurses immediately if you feel anything like this.

• An anticoagulant drug is mixed with your blood as it enters the machine to keep it from clotting during the procedure. This may cause a sour taste in your mouth. The anticoagulant can also lower your blood calcium and you may experience light-headedness, nausea, muscle cramping, and/or a tingling feeling around the lips, hands or feet. You should tell the nurses immediately if you feel any of these symptoms. Oral or intravenous calcium will bring quick relief of these side effects.

• You may start to feel cold during the procedure. If you feel chilled, please let the nurses know. They can give you extra blankets and heating pads to keep you warm and comfortable.

Vein Assessment:

On your first visit to the HAU, a nurse will check your arm veins located in the elbow area to make sure that they can be used for the procedure. The cell separator machine needs a certain amount of blood flow in order to work properly. A strong vein with good blood flow is needed. If the veins are too small or delicate, the insertion of a temporary intravenous line called a “St Paul’s Catheter” may be necessary. This is a small plastic tube that will be placed into a large vein located in the side of the neck. Sometimes it is necessary (but rarely) to place this tube in the large groin vein, which drains the blood from the legs. This tube allows the blood to be easily removed and returned to your body. The tube will be inserted in the “angio-radiology” department one day prior to, or on the day of the first stem cell collection and will be removed after the collections are completed. Our goal at the HAU is to make this experience as stress free and comfortable as possible. Please let us know if there is anything we can do to assist you in this.

Frequency of Stem Cell Collections
The goal is to collect enough cells for one transplant. The targeted cell collection is usually achieved in 1-2 days. Occasionally a third day of collecting is required. The number of stem cell collections needed largely depends on the patient’s individual response to the G-CSF and apheresis treatments.

Immediately after the apheresis procedure is completed, specimens are obtained from the bag of collected stem cells. These are sent as soon as possible to a special lab where the sample will be studied and the actual stem cell count will be determined. Results of this analysis will usually be completed by 4:00 pm that same day. Once the actual count is known and reviewed by the doctor, you will be notified as to whether more stem cell collections are needed on subsequent days.

Note: Although rare, some patients do not respond well to G-CSF therapy. This means that even after additional doses of G-CSF, there will not be enough stem cells circulating in the blood to collect. Failure to collect stem cells makes autologous bone marrow transplant impossible and other treatment options will need to be considered.

Processing the Stem Cell Collection

In order to preserve the stem cells, they will need to be frozen (the process of cryopreservation). Shortly after the stem cells are collected, they are sent to a special lab called the Cryogenic Lab. There, the stem cells will be concentrated and a preservative will be added to protect the cells from the freezing process. They will then be stored in a special freezing for a maximum of 7 years.

Some Important Reminders

- The phone number for the Hematology Apheresis Unit (HAU) is 604-875-4626
- Appointment times for stem cell collections at the HAU are usually between 8:00-9:00 am
- The entire process can take up to 6-8 hours from start to finish. This makes for a very long day. You may wish to bring your own lunch and snacks. The HAU can provide juice, cookies and a limited selection of sandwiches.
- It is very important that you have breakfast before coming to the unit (one that is rich in calcium). Do not drink coffee or tea before the procedure, as you will
not be able to get up to use the washroom once you are hooked up to the machine.

- Please use the washroom facilities in the HAU just before the procedure begins. If you need to go to the bathroom during the procedure, bedpans are available. A nurse will help you with this. It is recommended that you wear comfortable and loose fitting clothing (i.e. pants with an elastic waistband may make things easier).

- You will have your own television available for your use during the apheresis procedure. Also, unless you have a St. Paul's Catheter, reading materials would be inappropriate to bring, as you will not have the use of your arms.

- Once the procedure has started, the nurses will allow one visitor to stay with you.

- Remember it is very important to notify the nurses right away if you feel light-headed, dizzy, nauseated, cold, or have tingling around the lips, fingers or toes, during the procedure. Slowing or stopping the procedure for a short time can sometimes resolve some of these symptoms.

- Important Phone numbers:
  Nursing Unit/Booking Clerk: 604-875-4626
  Reception: 604-875-4962
  After Hours Call Locating: 604-875-4111, ask for the HAU nurse or Doctor on call
AUTOLOGOUS PERIPHERAL BLOOD STEM CELL TRANSPLANT

Written October 2007

Vancouver General Hospital
Autologous Peripheral Blood Stem Cell Transplant

There are three main phases to the BMT (Bone Marrow Transplant) process:
- Pre-BMT phase
- BMT day or "reinfusion" day
- Post-BMT phase
The first two phases will be discussed in this section. The third phase: the recovery stage will be discussed in the next section.

Pre Transplant

Prior to this phase you will have had your pre-BMT diagnostic tests done and your Hickman line inserted. Please see Tests and Procedures section for information on these.

Pre-Conditioning Chemotherapy

Depending on your individual health needs, you will proceed to have your chemotherapy and subsequent transplant the outpatient or the inpatient units.

One day before your BMT, you will receive Melphalan (MEL-fa-lan), your high-dose chemotherapy. This medication, like most chemotherapy, is not without some side effects. The most immediate one is often nausea. Therefore you will be given an intravenous antinausea medication prior to the melphalan. Also, fluids/hydration will be started two hours beforehand and will continue for 2 hours after the completion of your melphalan or, if you are in the inpatient department, the hydration may continue longer.

Managing Side Effects of Melphalan

Although the side effects of treatment can be unpleasant, it is important for you to know that they are usually temporary. No two people will have the same experience with side effects. The degree of intensity of each possible side effect varies greatly from person to person and not every person will experience each side effect that is mentioned below. Outside of nausea, side effects of Melphalan generally happen within 3-7 days.
Nausea and Vomiting

Nausea and Vomiting is a very common side effect with chemotherapy. There are many different things that can trigger nausea such as motion, heartburn, food or other odours, and feeling full after eating. It is important to keep track of these triggers and to inform the doctor or nurse when they occur.

Many different anti-nausea (also called anti-emetic) medications are available to you throughout the course of your treatment. They can be prescribed for you based on your triggers. Some suggestions for coping with nausea are:

- Keep your mouth fresh by rinsing before and after meals/snacks
- Eat small, more frequent meals/snacks throughout the day.
- Avoid spicy, fried and greasy foods. Starchy, bland foods are better tolerated.
- If food odours trigger your nausea, try foods that are cool/cold. Reduce cooking odours by using a kitchen fan and keeping pots covered.
- Eat whenever your appetite is the best.
- Learn some relaxation and distraction techniques that work well for you.
- Wear loose, comfortable clothing.

Mouth and Throat Problems

Chemotherapy and/or infections can lead to a condition called mucositis. Mucositis is an inflammation of the lining of your digestive tract. Discomfort in the mouth, throat, and esophagus (the passage to the stomach) include dryness, redness, sores/ulcers, and taste changes. Mucositis may last for several days and will usually get better around the time your blood cell counts begin to recover. Taste changes may also occur due to a decreased production of saliva. Changes in the taste of food are temporary and usually return to normal within a couple of months (longer for some patients). To help you deal with these side effects, here are some tips:

- A regular mouth care routine will help minimize the discomfort. (See ‘mouth care’ section in “Guidelines for Prevention of Infection and for Healthy Living” chapter).
- Drink lots of fluids in order to help minimize mouth dryness.
- Inform the doctor/nurse if you develop sores in your mouth. Medications are available to help you with the pain and the sores.
- Choose foods that are soft, moist and easy to chew and swallow, such as ice cream, popsicles, smoothies, high protein/calorie drinks, pudding, etc.
- Many people find that hard, sour candies are very effective for metallic tastes.
Diarrhea

Chemotherapy can create changes throughout the bowel that are similar to the changes in the mouth, throat, and esophagus (as mentioned above). One side effect that commonly occurs as a result of these changes is diarrhea, gas and cramping. It is very important to let your doctor/nurse know if you are having diarrhea. Uncontrolled diarrhea can lead to complications such as dehydration.

The amount and frequency of diarrhea experienced varies from person to person. Keep the rectal area clean to prevent skin irritation. If needed, a sitz bath may be taken after bowel movements followed by a mild cream to keep the area protected.

Hair Loss

Hair loss, also known as “alopecia”, occurs because the chemotherapy treatment affects the rapidly dividing cells in the hair follicle. As a result, patients will lose most of their body hair. Areas affected will likely include the scalp, face, chest, arms, legs and pelvic area.

Adjusting to hair loss may be difficult. It is a temporary side effect, with some exceptions. Hair loss usually begins several days to a few weeks after the treatment has started. Once hair loss has begun, it will continue in a steady process. Similarly, when re-growth begins, new hair will appear at a gradual, steady rate. Hair should begin to grow back a few months after your treatment is completed.

Skin Problems

Some skin changes that can occur during and after treatment include dryness, peeling, colour changes, rashes, and itchiness. These can come and go throughout any phase of treatment.

There are a variety of possible skin reactions and the causes are numerous and are therefore not mentioned here.

However, the basics of skin care should include keeping the skin clean and moist. Mild, water-based moisturizers are helpful. Alcohol based and perfumed soaps and toiletries should be avoided.
BMT or Peripheral Stem Cell Transplant Day

This phase consists of the reinfusion of your bone marrow cells. It is often met with mixed feelings for many patients. Many will feel relieved that the pre-conditioning treatment is over and that the transplant can now finally take place.

On the day of your transplant, a technologist from the Cryogenic Lab will bring your frozen cells to the unit. They will be thawed immediately before the infusion. Many people are surprised at how straightforward and simple the re-infusion of the stem cells is. The cells are infused through the Hickman line, much like a blood transfusion. The procedure takes roughly 20-60 minutes. You may, however, experience some side effects from DMSO (Dimethyl Sulfoxide), the preservative used to protect your cells while they remain frozen. The DMSO most likely will cause a garlic-like (or oyster/cream of corn-like) taste in your mouth that will last for a few (generally 1-3) days. Some patients have found it beneficial to chew gum or suck on hard candies to lessen this effect during the transfusion. Others have noted the aroma of oranges helps as well. People around you will also notice the same distinctive garlic-like odour as the drug is expelled through your breathing. Although not due to DMSO, another side effect you may notice is that your urine may become red-coloured for 24 hours. Other side effects DMSO can cause are shortness of breath or chest tightness, wheezing, nausea, stomach pains, and tingling in your fingers. Some patients have reported feeling chilled or cold from the rapid infusion of the freshly thawed cells. These side effects occur rarely as you will be given medications 6 hours before and then 1 hour prior to the transplant to help prevent them from occurring. A nurse and doctor will be present with you in the room during the entire transplant in order to monitor you closely.

Following the bone marrow infusion, the recovery period begins. There are many aspects of the post-BMT phase and your doctor will discuss these with you. The most immediate and important features of this phase will be reviewed in the next section. These are:

- Managing low blood cell counts
- Waiting for engraftment
POST TRANSPLANT: THE RECOVERY STAGE

Written October 2007

Vancouver General Hospital
Post Transplant: The Recovery Stage

The third phase of BMT begins following the bone marrow infusion and continues throughout the recovery period. This is the longest phase of BMT. Although there are many aspects of the post-BMT period that your doctor will discuss with you, those that will be reviewed here are:

- Managing low blood cell counts
- Waiting for engraftment

Managing Low Blood Cell Counts

Until the bone marrow has engrafted, you will not be producing any normal blood cells. For this reason, white blood cells, red blood cells and platelets are too few in number to perform their usual jobs without help. Here are some of the problems that can occur with low blood cell counts and how they are dealt with.

Low White Blood Cells

White blood cells are needed to prevent infections caused by bacteria, viruses and fungi. There are several different types of white blood cells, but neutrophils are the most common type. Neutrophils fight infection by rapidly increasing in number when an infection occurs. They then surround and destroy the infection. Your “absolute neutrophil count” (ANC) is monitored closely after your treatment to give us an indication of your ability to fight infection and to indicate the beginnings of engraftment.

After you receive your transplant treatment, your white blood cell count will decrease quickly and will remain low until the new cells begin to grow. During this time, you are at great risk for developing an infection, as you will not have white blood cells to fight bacteria, viruses or fungi. Although the risk of infection decreases as the immune system recovers (white blood cell count rises), BMT patients must continue to take protective measures until the bone marrow has fully recovered.

Many precautions can be taken to prevent infection (see chapter on Guidelines for Preventing Infection and for Healthy Living). Precautions, like the protective isolation procedures and guidelines for visitors practiced on the inpatient and outpatient departments, are also for the purpose of preventing infection while you are in treatment.
One of the most common signs of infection is a fever. Most BMT patients will have an increase in temperature that may signal an infection at some point during the BMT experience. Infections can occur at any time prior to, during, and after the BMT. Because all people carry germs (organisms) in their systems naturally, infections in the transplant patient are often from the patient’s own organisms. Although infections can be quite serious, there are many approaches to treatment. Anti-bacterial, anti-viral and sometimes anti-fungal medications are prescribed during the post-BMT phase to treat these different types of infection.

To help identify an early infection it is important to let the health care team know how you are feeling. Some symptoms of an infection are:
- Fever of greater or equal to 38°Celsius (100°Fahrenheit)
- Skin tenderness
- Chills/sweating
- A burning feeling when urinating
- Rectal pain/tenderness
- A cough, sore throat or mouth pain

If any of these symptoms appear, notify your nurse or doctor immediately.

**Low Red Blood Cells**

Red blood cells contain hemoglobin that carries oxygen from the lungs to all of the cells and tissues in the body. This is what gives us our energy. When red blood cells/hemoglobin is low, you become anemic and may feel quite tired and short of breath as a result. Other symptoms may include dizziness and feeling chilled. Until the transplanted bone marrow starts making enough red blood cells on its own, you will require red blood cell transfusions to maintain your red blood cell count. Generally, when your hemoglobin count drops below 80, you will receive packed (concentrated) red blood cells (some patients may require them sooner).

**Low Platelets**

Platelets (thrombocytes) are tiny blood cell particles that help form clots and prevent bleeding. They do so by sticking to the site of a blood vessel injury, clump together, and seal off the injured blood vessel to stop bleeding. When platelets are low, you are more susceptible to bleeding. Some signs and symptoms that may occur with low platelet counts include bleeding gums, bruising and nosebleeds. While your platelets are low, there are some precautions you can take to prevent bleeding:
- Take good care of your skin and lips, as dryness may lead to cracks and bleeding.
- Use only a soft toothbrush. Do not scrub your gums vigorously.
- Avoid blowing or picking your nose.
- Use only an electric razor.
- Wear shoes or slippers at all times when you are out of bed.
- Exercise by walking or riding a stationary bike. Avoid rough activity or exercises that may cause you to injure your head or other parts of your body.

If your platelet count drops below “10” or you have bleeding issues, you will need a transfusion. Your platelet count may be checked as often as every day and you will be watched for signs of bleeding. Please notify your nurse or doctor of the following:
- Bruising
- Bleeding wounds
- Blood in your urine or stool
- Bleeding gums or nose
- Blood in any mucous/sputum that is coughed up
- Small pinpoint red or purple spots under your skin (petechiae)

**A Word about Transfusions**

You may require blood and/or platelet transfusions frequently during your treatment. With all transfusions there is the potential of having a transfusion reaction. The blood product is irradiated and leukoreduced (white cell reduced) to decrease the likelihood of a transfusion reaction. If you have had a transfusion reaction in the past, please inform your nurse or doctor. If at any time during or after a transfusion you feel warm or chilled, have shortness of breath, are dizzy, you notice hives (bumps/welts on your skin similar to giant mosquito bites) or if your skin itches, notify your nurse immediately.

**Safety of Blood Products**

Where does donated blood come from? Whole blood is collected by Canadian Blood Services from volunteer donors. All potential donors are screened by a written questionnaire and interviewed by a nurse. This donated blood is processed into its separate parts and tested for:
- Hepatitis B
- Hepatitis C
- Human Immunodeficiency Virus (HIV 1 and 2, the AIDS viruses)
- Human T Cell Lymphotripic Virus 1 and 2
- Syphilis
- West Nile Virus (summer times)
If blood is found to have any of these infections, it is disposed of and never used. Blood is never collected from this infected donor again. However, you need to be aware that blood can never be guaranteed to be 100% safe. Your doctor will discuss this further with you prior to your first transfusion. You will need to sign a blood product consent form prior to receiving any blood products.

**Engraftment**

It is during the post-BMT phase that everyone looks forward to evidence that the transplanted bone marrow/stem cells have traveled to the right place and are starting to work. After the cells have been transplanted they have to find their way to the bone marrow spaces in the centre of the large bones of the body. Only then can the transplanted bone marrow begin to produce new blood cells.

Approximately 2-3 weeks after your transplant you can expect to see signs of your bone marrow beginning to grow. We call this “engraftment”. Experts are not certain as to how this amazing process happens, just that it does. The first sign of engraftment is the production of white blood cells or platelets. This is reflected in your blood cell counts as they slowly begin to climb. Red blood cells often take a little longer to begin developing.
YOUR HEALTH CARE TEAM

Written October 2007

Vancouver General Hospital
Your Health Care Team

A large multidisciplinary team provides care of leukemia/bone marrow transplant patients. Our goal is to work with you in providing for the very best treatment of your disease.

Leukemia/BMT Doctors

Upon diagnosis and initiation of treatment with the program, you will be assigned a primary (Attending) hematologist (a doctor who specializes in diagnosing and treating conditions that arise in the blood and “blood forming tissue”, including bone marrow). This person will oversee the treatment you receive from the program and plan your long-term follow-up care.

The program is also staffed with the assistance of a group of Bone Marrow Transplant Fellows and Clinical Associates. “Fellows” are physicians who have completed training in internal medicine, hematology or oncology and who are doing further training in the leukemia/BMT field. “Clinical Associates” are general practitioners working in the leukemia/BMT field.

It is likely that you will meet several doctors from the BMT program throughout your treatment. All work in rotations that change every one to two months with the exception of the clinical associate BMT doctors (these doctors work exclusively on the BMT outpatient unit). Your medical care will be consistent regardless of changes in rotating doctors.

Every day that you are on the unit (inpatient or outpatient), the doctor(s) will review your case. If necessary they will examine you, and make any needed changes to your treatment.

Registered Nurses

Registered Nurses will work with you closely during your treatment (inpatient or outpatient). They will help you and your family learn about treatments, medications, and how to cope with side effects, hospitalization and recovery. The nurses are there to help coordinate care with you, your family, and doctors and act as a liaison between you and other health care workers. They also aim to improve the continuity of care, help you and your family stay informed and to help provide you with some control over events occurring during treatment. And finally, they will assist you with preparations to return home.
Pharmacist

There are three clinical pharmacists (two on the inpatient ward and one in the outpatient unit). These specialists assist the physicians in selecting drugs and their doses. They are also available to help you and your family learn about chemotherapy and supportive care medications. In addition they will monitor all your medications, including, if applicable, ordering and interpreting blood drug levels, to ensure that you are on the most appropriate medication at the best dose for you.

At the beginning of your transplant treatment in the outpatient unit and again at discharge, the pharmacist will provide written and verbal information regarding the discharge medications as needed. They work closely with the social worker to help sort out any financial issues that may arise with the discharge medications. The clinical pharmacists work 8-hour shifts Monday to Friday.

Social Worker

There are two Social Workers with the BMT Program. They are available to assist and provide patients and their families/support persons with practical, financial and emotional support services. The Social Worker can link you or your family with community agencies and help with practical concerns such as transportation, accommodation, financial aid, insurance and disability claims, legal issues and spiritual resources. Shortly after admission to the BMT Program, the social worker meets with the patient and family. Other meetings can be arranged on an as needed basis.

BMT Coordinators

More than likely you may have already met with one of the BMT Program’s four Coordinators, either in person, or over the phone. The Coordinators work closely with patients and their families to organize/coordinate appointments to see doctors and other health care team members, to have tests and procedures completed, and to discuss the transplant process with you.

Dietician

Proper Nutrition plays an important role in your recovery and overall care. A dietician is available to meet with you when eating becomes difficult. They can assist you in making diet changes and formulate coping strategies when side effects from treatment make meeting nutritional requirements challenging.
Physiotherapist

The physiotherapist can help you maintain your physical fitness during treatment. S/he will see you soon after you are admitted to the inpatient unit or by the request of yourself or the nurse if you are in the outpatient unit. They can assist you in planning and maintaining an activity program that is appropriate for you. Your progress will be monitored and changes are made if needed.

Occupational Therapist (OT)

The OT is available to work with you in a variety of areas, such as managing daily activities while in the hospital (inpatient or outpatient), structuring your time, personal stress management, or providing resources to build coping skills (i.e. Guiding you through a relaxation exercise). You can arrange to meet with the OT by asking your nurse.

Pastoral Care

A non-denominational interfaith Chaplain from the Pastoral Care Department is available to attend to religious and spiritual needs. Support, counseling, and sacraments are part of the care provided by chaplains. You may ask for a visit from the Chaplain through the nursing staff, day or night. You may also call directly at 604-875-4151. Specific denominational needs may be accessed through the Leukemia/BMT Chaplain. The department can provide information about churches in the area.

Psychiatrist

The Leukemia/BMT team also includes a psychiatrist, a medical doctor who specializes in difficulties with mood, thinking, and coping. Such difficulties can be due to physical, psychological, or spiritual factors, or a combination of these. Upon request, the Psychiatrist will see patients to help identify causes of any emotional difficulties and to assist in treatment.

Your Role on the Team

As a team member, you will have the most vital role to play in your care and recovery. As you know yourself best, we depend on you to report how you are feeling and any adverse or beneficial effects to treatment you are experiencing. Also, we expect to have your input and cooperation in your own recovery. We encourage you to keep some sense of independence and control over your own
care as much as possible. The activities of daily living are important ways for you to keep active and participate in your treatment and for getting well. Good Nutrition, proper hygiene and mouth care and regular activity and exercise are essential to helping you make your recovery successful and easier. See section on Basic Guidelines for Preventing Infection and for Healthy Living. In addition, it is vital that you have a caregiver to assist you through your treatment and recovery.

Choosing a Caregiver

During your treatment (whether in hospital or in the outpatient department) and even after you are discharged and return home, you will need at least one family member or a friend who can provide you with emotional and physical support. In some cases it may only be possible for you to have one caregiver with you. If this is the case, we suggest arranging occasional visits by other family members and friends who can provide support so that the care-giving task does not fall on just one person. Ideally, you would be able to arrange to have more than one caregiver, as the role can be very demanding.

Many people do successfully make it through their treatment with only one caregiver, but having two or more caregivers is a real plus. Having two caregivers allows each one to have their own time to rest and relax and have time away from the hospital and responsibility. Having more than one caregiver also allows you to share your feelings and experiences with more than one person. Caregivers can often experience a high degree of anxiety. Some of this anxiety and tension can be alleviated when the responsibility of caring for you is shared.

When choosing a caregiver, it should be someone you are comfortable around, is comfortable around you, and is able to help you through your treatment. Another consideration is whether or not the caregiver will feel comfortable in the hospital environment. The responsibilities of a caregiver include:

- Providing physical care during treatments, in hospital and at home
- Providing transportation to and from the hospital during treatment and follow-up care
- Providing emotional support
- Helping the patient with oral medications if necessary
- Identifying changes in the patient’s condition
- Obtaining medical care if needed
- Gathering information
- Keeping family and friends up-to-date about the patient’s condition
- Monitoring the number of visitors in and away from hospital
- Preparing food
Outpatient and Inpatient Information

Written October 2007

Vancouver General Hospital
Outpatient and Inpatient Information

Advancements in medical research and technology over the years have led to changes in the way multiple myeloma and other leukemias are treated today. Medical practices at Vancouver General Hospital adapt and change as new research, medications, and worldwide practices evolve.

Here at VGH most transplants for multiple myeloma patients are being performed on an outpatient basis. However some patients may find that they will experience a stay in the inpatient department at some time during the course of their treatment. This will largely depend upon the individual person’s health care needs. Our goal is to meet each patient’s needs to the best of our abilities in a timely and stress-free fashion.

The following information will provide you with an understanding of the routines and expectations of each department.
Outpatient Department Information for Patients and Families

Your transplant will occur in the outpatient department unless your physician feels that it is unsafe for you to do so. Patients who do not have a caregiver, have kidney problems, or other health care issues/needs, may require closer monitoring and therefore have their transplant in the inpatient department. Patients are discharged from the inpatient unit once it is felt that they are stable enough to resume follow-up care in the outpatient department. Your physician will discuss these matters with you.

Outpatient Ambulatory Care Unit

The Leukemia/BMT Day Care (or Ambulatory Care) unit is located in The Krall Centre, which is on the 6th floor of the Centennial Pavilion (CP). The building can be accessed from the main entrance just off of 12th Avenue, the Jim Pattison Pavilion (JPP) or from the ground floor east entrance from the back parking lot.

The unit is comprised of several treatment rooms where there are chairs, beds or stretchers for patients’ use. Call bells in each room are to be use for urgent requests only. Those patients able to walk and assist themselves are encouraged to do so.

There is a small kitchen where patients can help themselves to coffee, tea, cookies and juice. If you bring a lunch with you, it can be stored in the fridge. It is best to label your lunch bag with your name. A limited number of sandwiches are available for those patients who have an unexpected long stay and have not come prepared with a lunch.

There is a Library and a lounge with books and magazines for your reading pleasure and all treatment rooms have televisions with cable for your use.

Several washrooms are available on the unit for patient use and there is a visitor/public washroom located across from the elevators.

Please note that **Cell phone use is prohibited** on the unit and we ask that all cell phones be **turned off** while in the Centennial Pavilion. There are several areas using equipment/machinery that are sensitive to disruptions by cell phone use. The Cell Separator unit (also on the 6th floor) is one of these areas. For your convenience there are several phones available in the public areas for your use. Please be respectful and sensitive to other patients sharing the room. There is also a public telephone located in the elevator foyer.
Hours

8:00 am – 7:00 pm Mon-Fri
8:30 am – 6:00 pm Sat-Sun

Telephone number: 604-875-4073. If there is no answer in the daycare unit, please call the inpatient unit at 604-875-4343

Transportation

If you need help with transportation to and from daycare, talk to the social worker or your nurse. There is a volunteer driver program available. The social worker can also assist you in obtaining a handicapped-parking sticker for your car.

Parking

You may be dropped off at the main entrances to the JPP or CP entrances but note that there is no temporary parking at these entrances. There are 12 metered handicap parking spaces located under the ramp off w. 12th Ave. 10 metered handicap parking spaces are located off W. 10th Ave. (inner courtyard between Centennial Pavilion and Heather Pavilion and there are 20 metered parking spaces on the upper ramp at the JPP entrance. These are available on a first come, first serve basis. There are two visitor parking lots:

- The VGH parking lot is located off Laurel Street, between W. 12th and W. 13th Avenues.
- The Gordon & Leslie Diamond Health Care Centre parking lot is located off Laurel Street, between W. 12th and W. 10th Avenues.

The parking rate for both lots is $1.75 per half-hour, with a $15 daily maximum. It may be more economical to buy a 2-week or 1 month parking pass. Ask the parking attendants for more information.

What Happens in Daycare

The reasons for your visits to daycare will depend on your individual needs. Each patient is monitored and treated according to their specific history and current condition. For this reason, monitoring and treatment activities will vary from patient to patient. Your visits may include some/any of the following:

- Blood tests to monitor the growth of your new bone marrow or to assess other organ functions.
- Vital signs and weights.
- Blood and/or platelet transfusions.
- Fluid and electrolyte infusions.
- IV medications or treatments such as antibiotics, antivirals, antifungals.
- Chemotherapy such as Melphalan or Cyclophosphamide.
- Blood or bone marrow stem cell transplants and/or post transplant care.
- Bone marrow aspirates and biopsies.
- X-rays, CT scans and other diagnostic tests.
- Hickman line insertions.
- Pamidronate infusions to strengthen bones and prevent osteoporosis that can be caused by steroids.
- To have any health problems or concerns assessed and treated.

Some days you may spend several hours in daycare. If you know your stay will be long, you may want to bring your own food, drinks and anything else that will add to your comfort (i.e. Book, slippers, etc.). Hot and cold drinks are provided. Please help yourself.

Caregivers/Family members or support people who may accompany you can wait in the lounge or, space permitting, stay with you in the treatment room to assist you or keep you company. Once your treatment has started, you may relax in the designated self-care treatment area or in the lounge/Library.

**When to Call the Doctor**

If at any time throughout your outpatient treatment you experience any one of the following symptoms, call the outpatient unit during the hours of operation (or the inpatient unit after hours) immediately:

- Fever of 38°C (100°F) or higher
- Shortness of breath
- Cough
- Persistent dizziness
- Flu-like symptoms
- Bruising or bleeding
- Rash, blisters or severe skin pain/sensitivity
- Persistent nausea, vomiting
- Not able to take medications
- Diarrhea
- Pain
- Unsteady when walking
- If you have fallen
Appointments

Your first daycare appointment may be given to you before you start treatment or before you are discharged from the inpatient unit. When you arrive, please check in at the nurse’s desk. The unit clerk or nurse will sign you in and instruct you where to go.

Please note the following:

- Make all your subsequent appointments with the Unit Clerk at the front desk in daycare. It is your responsibility to make your own appointments. Daycare does not automatically make them for you.
- On your first visit to daycare, please bring all your medications and your medication administration sheet with you (if you have one).

Doctors in Daycare

In daycare the physician(s) assigned to the area will see you. You will likely see certain physicians more than others. With the exception of the Clinical Associates, all doctors rotate between the inpatient unit and the daycare unit every one to two months. Even though you may not see the same doctor(s) during every outpatient visit, rest assured, there will be a Leukemia/BMT Attending doctor and a BMT Fellow or Clinical Associate doctor monitoring your care in daycare.

Self Care

Daycare operates a self-care program in which patients learn to do as much of their own care as possible. This learning takes place under direct supervision of a nurse. This includes taking vital signs, Hickman line care which may include drawing blood specimens from the Hickman line and doing intravenous infusions of plain fluids. You or your caregiver will begin learning some of these skills either in daycare or in the inpatient unit.

Basic care of your Hickman line will be taught to you if it is felt that you will require it beyond one month after transplant. You or a family member/caregiver will need to learn to do flushing of the lines, cap changes and dressing changes before you are discharged. The sooner this learning begins, the more experienced and comfortable you will become.

In partnership with nursing care, self-care will allow you to be more involved in and in control of your health care as you recover.
Medications

It is very important that you know every medication that you are taking. Keep a list of these medications including the name of the medication, the dose and time(s) to take them. You may use your medication calendar for this purpose. Bring this list whenever you come to clinic or see your doctor so it can be reviewed. This will also give you an opportunity to ask questions about your medication.

- Do not take any medications or drugs, other than those prescribed by the BMT doctor, without checking with the BMT doctor first.
- Do not use rectal suppositories or enemas without permission from the BMT doctor.
- The use of non-prescription drugs such as marijuana, tobacco, cocaine, ecstasy, etc. can lead to serious or fatal complications. They must not be used. On all visits, have enough medication for the day in case you are delayed.
- Keep track of your medications. If you are running out of your medication please check with the doctor to see if you need to keep taking them and therefore need a refill. Do not stop any medication unless instructed by your doctor.
- If you need a prescription refill please tell the nurse and doctor when you first arrive for your appointment. Do not wait until you are on the last dose. Ask for refills at least 2 – 3 days beforehand. This allows for any unforeseen problems in getting medications to be solved before you run out.

A Word about Herbal Remedies

It is very important that your doctor knows about any herbal supplements or therapies you may be taking. Although research in this area is limited, we do know that some of these items, such as St. John’s Wort and Echinacea, may be quite harmful to a recovering leukemia/BMT patient. Be sure to discuss this area carefully with your BMT doctor.
Bloodwork

Your blood will be monitored very closely as you recover. There are two ways this can be done:

- If you have a central line (i.e. Hickman) you will be given an appointment with a nurse to have blood samples taken in daycare (or to take them yourself if you have learned this skill).
- If blood samples are taken from your arm vein, and you have no other reason to come to daycare, you will pick up your requisitions at the daycare desk and then go to the VGH Outpatient Laboratory located in the Gordon & Leslie Diamond Centre (off Laurel St. across from the Jim Pattison Pavilion) to have your blood samples taken.

Hand Washing

We cannot stress enough how important hand washing is and therefore mention it time and time again. It is the most important thing you and your caregiver(s) can do to help prevent the spread of germs and infection.

Upon entering the unit there will be liquid/gel hand cleanser by the door. All persons (patients, visitors and hospital staff) are asked to use it when entering and leaving the unit.

Isolation Procedures

When entering the unit, if you are experiencing respiratory symptoms (i.e. sore throat, sniffles and/or cough, even if it is mild), please wear a mask before you proceed to the front desk. As you enter the unit, masks can be found near the door, next to the liquid hand cleanser.

Please inform the staff, if you develop an unexplained skin rash, respiratory symptoms or other infection. Any one of these may require you to be isolated from other patients.

When isolation is necessary, you will be assigned a room to yourself (or you may share a room with another patient with the same infection). If you are isolated for respiratory symptoms/infections it will only be necessary for you and anyone accompanying you to wear a mask while outside your designated room. Strict hand washing is required when leaving your room. Staff will wear protective gear when entering.

Isolation procedures will remain in effect until it is determined that the risk to other patients has passed.
Inpatient Department Information
for Patients and Families

Inpatient Unit

The unit is located on the 15th floor of the Jim Pattison Pavilion. It consists of both single rooms and semi-private rooms. You will be assigned a bed dependent on availability. It is not guaranteed that the room you are originally given will remain your room until you are discharged from hospital. Single rooms are required for specific isolation or acutely ill patients.

Each room has a telephone, TV, and stereo system. It will have a cupboard for your personal belongings and a bathroom for your use.

All rooms have a dry erase drawing board. It can be used for pictures or messages. A calendar can also be drawn on it to help keep track of your treatment or other events. Please do not use any kind of tape on the walls, as it will damage the paint. You may borrow some reusable adhesive from the front desk.

Patients may call for assistance by using the nurse call button that is located at each bedside and in each bathroom. You will be shown how to use this when you arrive on the unit. The nursing staff change shifts at 7 a.m. and 7 p.m. Please keep non-urgent requests to a minimum during this time.

The unit has a small kitchen. There is a refrigerator and a separate freezer available for patients to keep food in. It is important that all your food is labeled with your name and room/bed number on it. Along with the fridge, the kitchen has a microwave, toaster, kettle and some dishes. Please clean up after yourself if you or your family member is heating or making you some food. This kitchen services other patients as well as you.

There is a waiting room just outside the unit doors for families and visitors.

Telephone Service

Each patient bedside has a telephone. There is a daily phone rental charge of approximately $3.42. This is subject to change. This charge does not include long-distance calls, which must be made collect, billed to a credit card or placed on a calling card. If friends or relatives want to send a useful gift, a calling card may be appreciated.
Patient Mail

While you are in the hospital, friends and relatives can write to you at the following address:

Your Name
Room Number
Vancouver General Hospital
Leukemia/BMT Unit
899 West 12th Avenue
Vancouver, BC V5Z 1M9

Television/VCR

Each room contains a television with cable access already provided. There is no charge for this. The unit has 3 mobile Televisions supplied with VCR, DVD or Nintendo capabilities. You may wish to bring in your own videos or DVDs for your viewing pleasure.

Meals

Your meals will be served to you in your room by dietary staff. Breakfast comes between 9:00 am and 9:30 am. Lunch arrives between 1:00 pm and 1:30 pm and dinner is served between 6:00 pm and 6:30 pm. You will receive a menu to mark. This will arrive with your breakfast tray and is for the following days meals. Food from home is permitted and may be labeled with your name and date and stored in the patient fridge. Unlabeled food or drink will be discarded. The dietician will visit you often while you are in hospital. She or he will assess how well you can eat, what you can eat, and will also help you to choose foods to meet your physical needs.

Visitor Guidelines

Family and friends are welcome to visit any time, if the patient agrees. The following is a list of guidelines specific to our unit. We request that all patients, families and visitors read and follow these guidelines. It is very helpful in keeping our unit operating smoothly and protecting the rights of all our patients. We appreciate your cooperation.
• All visitors are asked to check in by phoning the front desk just before entering the unit. There is a wall-mounted telephone for this purpose, located by the sink, just before the unit doors. The unit’s number is displayed above it.

• All staff and visitors **MUST** wash their hands before entering the unit and before entering and when leaving patient rooms. Instructions on the proper way to wash hands are posted above or beside the sinks.

  - Plants and flowers are not allowed in the unit as they carry a large number of bacteria and fungal spores in their water and soil. This also includes dried flowers, dried grasses, and moss. Artificial flowers, cards and balloons are welcome.

• Children are welcome on the unit, but in some situations visits from children are not advisable. Certain infections and childhood vaccinations are risky for the patient. Patients should not have any contact with children who have had an oral Polio vaccination for at least 8 weeks. (In Canada the injectable polio vaccine is most commonly used and therefore does not present an infection risk for BMT patients)

• Visitors with cold/flu symptoms of any kind, cold sores, unidentified skin rashes, and recent exposure to chicken pox virus **must not** visit on the unit.

• The visitors must use public washrooms. There is one located outside the unit across from the waiting lounge. The patient’s washroom is for **patient use only**.

  - Visitors may purchase meals in the cafeteria on the second floor of the Jim Pattison Pavilion (JPP). Hours of operation are posted outside the cafeteria. There is also a coffee shop located on the first floor of the JPP at the main entrance.

• The unit is a designated scent-free area. Visitors and patients are asked to **please avoid strong perfumes and colognes**, as many of the patients on the unit are extra sensitive to odors. Nausea is a very serious issue in our patient population.

• Smoking is allowed only in certain areas outside the hospital building. Please respect the no smoking signs posted immediately outside entrance/exit areas.

• Please limit visitors to no more than two or three in the room at a time. The rooms are small and crowd easily. Also the noise level rises easily.

Leukemia/Bone Marrow Transplant Program
One family member or friend may stay overnight. Any overnight visitors must be up and have the pull out chair and bedding put away no later than 7:30 am. Cots/chairs should not be set up in such a way that it blocks the nurse’s access to the patient and the medical equipment. For out-of-town family members needing a place to stay, please talk to the Social Worker.

If you do not want visitors or phone calls, let the nurse know so that s/he can inform the reception desk. Discuss the topic of visits and phone calls with family and friends so that they know what your wishes are. It is important to have planned rest periods.

**Protective Isolation**

Protective Isolation is set up to reduce exposure to germs that could cause an infection in patients. The ward is equipped with a special HEPA filtered positive air filtration system, which protects patients by minimizing their exposure to organisms. This allows patients to safely and freely move about the ward. The elevator areas are not HEPA filtered. Patients must wear a mask over their mouth and nose when they leave the unit for tests.

Upon admission all patients are put on room isolation for 48 hours. This is to protect the other patients in case a new patient develops respiratory symptoms (cold or flu symptoms). This simply means that for 48 hours the patient is not allowed to wander the halls of the ward and the door to the room must be kept shut. There will not be any restrictions on visitors.

Occasionally a patient will develop respiratory symptoms, or other infection, requiring him/her to be placed on special isolation precautions. S/he will remain on isolation until the cause of the symptoms is determined. Staff and visitors will be required to wear masks and gloves, and in some circumstances gowns and goggles. The isolation procedures will be posted outside the patient room. All visitors are asked to follow the isolation requirements.

**Daily Routine**

No two days will be alike during your hospital stay. There will be, however, events that are routine.

Blood samples are taken from your Hickman line every day. These samples provide important information about your progress. If you do not have a Hickman line, the samples will be taken from a vein in your arm. Most of the blood samples are taken between 5:00 am - 6:30 am. The results will be back early in the day allowing the doctors and nurses...
to plan your care. Blood samples may also be taken at other times of the day.

You will be weighed every morning before breakfast to assess body fluid balance. Your nurse will perform a complete assessment of your physical condition, early in the morning and evening shifts. Each morning the medical staff will make rounds to assess your condition. The doctor may see you more than once a day. Doctor rounds are a good time to ask questions or to set up a meeting for a longer talk. If you have trouble remembering questions you would like to ask, try writing them down. The nurses and doctors also consider your emotional status to be an important part of your regular assessments.

During each day, time must be made available for personal hygiene, mouth care, Hickman line care, medications, diagnostic tests, treatments and procedures, educational activities, meals and exercise. Another important part of your daily routine will be visits and phone calls from family and friends. Regardless of the length of your admission, from the onset, we will provide teaching and information to prepare you for your eventual discharge.

With such a busy schedule it is often necessary to find a balance that also permits some “downtime”. For health and a sense of well-being, it is important to have some time to yourself. Each of us needs some form of quiet time for recreational activities, meditation and rest. Your health care team will assist you to find this balance.

Other members of the team may also see you during the day. They include the occupational therapist, pharmacist, dietitian, physiotherapist, social worker, or doctors from other areas that have been asked to see you. Most of these meetings will occur on a drop-in basis.

**Discharge**

It is important to discuss discharge at an early stage. The health care team starts to plan your discharge as soon as you are admitted to the inpatient unit.

**When are patients discharged?** The answer to this question varies depending on the type of treatment you receive and your individual health status. The health care team ensures that you are well enough to permit monitoring on an outpatient basis before being discharged. A few criteria that need to be met are:

- There are no complications present that would stop a patient being monitored as an outpatient.
• The patient is able to eat a satisfactory diet with sufficient calories to maintain health.
• The patient has sufficient strength and mobility to attend regular outpatient clinic visits.
• The patient is able to take prescribed medications.
• The patient has a suitable place to live (preferably within 45 minutes of the hospital) while attending outpatient clinic visits.
• It is to patient’s benefit if they or their caregiver can care for the Hickman line.

Once discharged from the inpatient unit, treatment will resume in the outpatient department until such time as you are discharged from Vancouver General Hospital altogether and may be sent home.

Before you are discharged, the clinical pharmacist will see you. They will thoroughly discuss your discharge medications with you before you leave. They will review the purpose of each medication as well as the dose, time, special instructions and major side effects and drug interactions. The pharmacist will provide you with a medication calendar to help you keep track. Keep it with you at all times.

If you are taking care of your own Hickman line at home, the nurse will provide you with a supply kit.

What to Bring with You

During your hospital stay, we want you to be as comfortable as possible. If a lengthy stay is anticipated, you may want to have some important and special items that comfort you nearby.

The following is a list of things you may wish to bring with you. These are only suggestions and may not reflect your wishes, neither are they required.

• Photographs of family, friends, pets, and favourite places at home (we ask that you help us to protect our paint by putting pictures or posters on non-painted surfaces only, such as the windows or white drawing board).
• Posters.
• Electric razor. Safety razors are not permitted.
• Soft toothbrush.
• A selection of new cosmetics (mild or fragrance-free).
• An egg-crate” style foam mattress (single bed size).
• A comforter or quilt.
• Your own pillow (mark with your name).
• Binoculars (for a more interesting view from your room).
• Books, magazines, bible or other religious material.
• Drawing materials, puzzles, sewing, crafts, needlework etc.
• Cassette tapes or CDs of favourite music, or “talking books”.
• DVDs, Video tapes or games.
• Personal computers are welcome, provided that they are the laptop variety.
• Sweat suit or other clothing you find comfortable.
• Pajamas or nightwear (hospital pajamas are available if you prefer these).
• Robe.
• Slippers or other comfortable footwear.
• Clothing for discharge.

For safety, all electrical appliances must be checked and approved by an electrician at the hospital. To prevent loss of personal clothing, we ask patients or family members to take responsibility for the laundering of their own items.
BASIC GUIDELINES FOR PREVENTING INFECTION AND FOR HEALTHY LIVING

Written October 2007

Vancouver General Hospital
Basic Guidelines for Preventing Infection and for Healthy Living

The following are guidelines vital to helping you prevent infection and to assist you to cope with daily living while your immune system recovers post transplant.

Temperature

Take your temperature with a Celsius thermometer when you get up in the morning, in the early evening (around 6-8 pm), and any time you feel warm or unwell.

- Do not take your temperature right after eating or drinking, as this may not give an accurate reading.
- When taking your temperature, place the thermometer in your mouth, under the tongue, preferably back by the molars. Keep your lips closed and breathe through your nose.
- Keep the thermometer clean by rinsing with warm soapy water and drying it, or follow the manufacturer’s instructions for cleaning.
- **Call the nurse or doctor if your temperature is higher than 38.0°C.**

Central Venous Line (Hickman) Care

It is very important that your central line is cared for properly and kept clean. Developing an infection can be very serious. If you are or your caregiver is caring for your Hickman line:

- Make sure that you or your caregiver is able to care for the central line properly.
- Always wash your hands before doing any central line care.
- Clean the skin around the line, change the dressing and flush the line as you were shown in the hospital.
- If using a cloth dressing, it must be changed at the least, every two days. If the dressing gets damp, it must be changed immediately.
- Do not go swimming or use hot tubs while you have a central line.

Mouth Care

It is very important that prior to treatment, you see your dentist to identify and take care of any outstanding dental issues you may be having. Good oral hygiene will be important to you before, during and after your transplant. The chemotherapy you receive affects
the cells lining the inside of your mouth and throat. As a result, you may develop sores. If your mouth is not kept clean, an infection can occur that can potentially spread to other parts of your body. You will be given medications to help prevent infections if the sores develop, but the most important part will be keeping your mouth clean.

- Inspect your mouth, teeth, and gums before and after your mouth care routines.
- Floss your teeth daily and brush your teeth after every meal and at bedtime.
- Use a soft toothbrush and fluoride-containing toothpaste.
- Keep your toothbrush clean by rinsing it well after brushing.

Brushing and flossing may become difficult and should be avoided if your mouth, gums or teeth are painful, have sores, or are bleeding. A special mouth rinse will be prescribed for you. Use this and rinse your mouth thoroughly at least four times a day. Avoid commercial mouthwashes since most of them contain alcohol that can dry or irritate your mouth.

Once your blood cell counts begin to recover, we encourage you to continue with diligent and thorough mouth care and personal hygiene routines. In addition we recommend for oral care:

- Change your toothbrush once a month for the first 6 months after you are discharged.
- Have a thorough dental exam every six months.
- Contact your BMT doctor before you have any dental work done, as you may need antibiotics. Your BMT doctor and dentist will advise you.

## Hygiene

One of the most important, simple and effective ways to prevent infection is to WASH YOUR HANDS. In our daily activities our hands come into contact with a lot of things, so remember to wash them often, especially before you eat or touch your face. Washing your hands thoroughly with soap and water (antibacterial soap is not required), involves fully lathering the hands for at least 30 seconds, making sure to rub all surfaces vigorously and rinse thoroughly under a stream of water. Use a clean towel at home and if possible, disposable paper towel in public washrooms (use the paper towel to turn off the faucets and open the door). Wash your hands before and after preparing food, after using the bathroom, patting your cat or dog, and touching any soiled object.

Note: Small bottles of hand sanitizers (can be purchased at most pharmacies) are handy things to have with you in a pinch, when washrooms are not available.
Keep the rest of yourself clean too. It is necessary for you to wash yourself every day with mild soap. If you shower and you have a Hickman, cover it with a plastic wrap and secure it with tape. This will decrease soaking and soiling the dressing. Use clean towels and face clothes every day if possible and do not share these with other family members. Put on clean clothes and underwear every day after your shower. If you feel the need to shave, use an electric razor until otherwise advised by your BMT doctor. Do not go barefoot about as you might scrape, cut or bump your foot.

**For women:** Avoid douching. After using the bathroom, make sure you wipe from front to back. Avoid using tampons.

**Smoking**

Please **DO NOT SMOKE!** If you smoke, you must quit immediately. To decrease the risk of a serious respiratory infection that could lead to a life-threatening pneumonia or fungal infection, do not smoke cigarettes, cigars, pipes, or marijuana (this also includes inhaling cocaine and chewing tobacco) after chemotherapy and BMT when your immune system is severely weakened.

- Smoking marijuana could lead to potentially **fatal** lung infections.
- No one should smoke inside your home and avoid second hand smoke in public.

If you need assistance with this process, please talk to your doctor or nurse.

**Medic-Alert Identification**

A Medic-Alert Identification bracelet or chain is strongly recommended after BMT. Every **blood product** you receive must be **irradiated**. Irradiation inactivates the lymphocytes (a type of white cell) that could lead to an increase in severe blood reactions. For patients taking steroids (Prednisone or Decadron), this information should be carried with you as well.

Obtain your application form for your Medic Alert Identification from your nurse. Outside of any allergies you may have, the bracelet should also say:

- “Bone Marrow Transplant Patient, Irradiate All Blood Products – Call MD (604) 875-4343".
Visitors, Crowds, and Activities outside the Home

You are encouraged to get out and do things you enjoy, however, try to stay away from crowded areas where you may come into contact with people who could give you an illness.

- Take daily walks in the fresh air and enjoy rides in the car.
- If you have a sufficient white cell count, it is OK to visit public places such as a church or movie theatre during off-hours when fewer people are there.
- If you suspect someone is sick, avoid visits until they are well.

Children, Toddlers and Infants

Kissing or close contact with ill infants, toddlers and children under 12 could pass an infection to a recovering BMT patient. Let common sense be your guide and minimize contact if you suspect an infection.

Avoid children who have had the oral polio vaccine for 8 weeks. (In Canada the injectable polio vaccine is most commonly used and does not present a risk to BMT patients). Please note that even if children have had the chickenpox vaccine, there is still a possibility of them getting the disease. It is very important to avoid children who you suspect have come into contact with the virus. After exposure to chickenpox, symptoms may appear in 11 to 20 days. The contagious period starts 1 to 2 days before the rash appears and lasts until all the spots have crusted over. Notify your doctor immediately if you suspect you have been exposed to chickenpox.

Flu and Other Vaccinations

Some physicians may recommend that you get a flu vaccine prior to undergoing treatment. Most transplant patients who are more than 3 to 6 months post transplant should receive the influenza vaccine on an annual basis.

Family members and close household contacts of patients should also be vaccinated annually against influenza. This is especially important for those patients who are less than 6 months post transplant or those who, for other reasons, have been advised not to receive the vaccine.

Patients undergoing high dose (myeloblative) chemotherapy and stem cell transplant may lose the immunity that they have previously acquired through vaccinations or natural infection. It is therefore necessary that at some point you will need to be re-vaccinated against certain diseases. Generally this will be arranged one year post-transplant. Ask your BMT doctor for further information.
A Word about Shingles

Shingles (also known as “zoster” or “herpes zoster”) can occur when the virus that causes chicken pox (called Varicella zoster) becomes active again. The virus remains dormant, never leaving the body and can be reactivated in patients whose immune systems are suppressed. These viruses are highly contagious and can be passed on to others. Contact with anyone who has been exposed or has an active infection should be avoided.

For these reasons you may be given preventative medications while your immune system is suppressed.

Shingles can appear anywhere on the body. The most common symptom is a burning pain and/or itching, which may occur several days before a skin rash/lesions appear. When the lesions appear they are usually in groups of raised, red blisters that may look like clear pimples. They are usually quite sore and itchy. These blisters may ooze fluid, break and then, in time, dry up. The fluid in the blisters contains the virus and is contagious to others. When the blisters are dried and form a scab they are no longer contagious.

If you suspect you have shingles, here is what to do:

- **Let your doctor or nurse know right away – Do not delay.** If you are being treated in the outpatient clinic, let the health care team know as soon as you arrive or preferably, by calling beforehand. To avoid the chance of infecting other patients, do not use the waiting room until you have been examined. You will need to be isolated from other patients, until you are no longer infectious.
- Try not to touch the spots or scratch them.
- Do not apply topical remedies (calamine, baking soda, etc) until the doctor has assessed you. Some of these may make the infection worse and none of them will make it better.
- Wash your hands often to decrease the risk of spreading the infection.
- Stay away from anyone who might be pregnant, as there is a risk to the fetus if the mother gets infected.
- Wear loose clothing over the affected area (cotton is best). If the infection is in your groin area, wear cotton underwear or boxer shorts. Do not wear nylons/synthetics.
- Wash your clothes, linens, and towels often using bleach if possible. Keep your laundry separate from others at home. Do not share towels, facecloths, and so on.
Nutrition

Nutrition plays a vital role in helping you achieve the best result from your medical treatment. Good nutrition will:

- help prevent infections.
- help maintain and rebuild muscles and damaged tissues.
- provide you with energy helping you to maintain a sense of well being.

It is often difficult to stay well nourished during your treatments. The dietician will help you to meet your nutrient requirements by suggesting foods you can tolerate or offering nutritional supplements if needed.

It is important to “build yourself up”, especially if you lost weight during treatment.

- Eat a balanced diet with a variety of foods, including fruits, vegetables, breads, pasta, meats and dairy products.
- Include foods high in protein at each meal such as meat, fish, eggs, and cheese.
- If you are a vegetarian, talk to the dietician for more protein options.

It is not necessary to prepare a separate meal from the rest of the family.

Food Safety

If you are eating out, choose a clean restaurant with a good reputation. Be careful with salad bars, particularly items with mayonnaise or creamy dressings. Make sure all items are fresh and ask to have your meat well cooked.

Consult with your dietician before you stop following any of these food safety recommendations:

- Meat, poultry and seafood should be well cooked (no rare or pink portions). Barbecuing and grilling should be done carefully.
- Do not eat raw or undercooked seafood, especially sushi, clams, shrimp, oysters, squid, octopus, and marinated fish. It is best to avoid all sushi, as these are often prepared on the same surface as the raw fish sushi.
- Meat and fish should be thawed in the refrigerator or in the microwave. Defrosted foods should be used immediately and not re-frozen.
- Keep cold foods at 4°C (40°F).
- Perishable foods (such as those containing egg or mayonnaise) should not be un-refrigerated for over 2 hours.
- Thoroughly wash fresh fruits and vegetables under running water before eating. Trim away any bruised areas.
- Note all dates on foods and be sure to use before the expiry or “best before” date.
• Use a separate cutting board for meat and seafood and wash very well with hot, soapy water between uses.
• All areas used for the preparation of raw meat, poultry, or seafood should be sanitized with diluted bleach (5mls bleach in 1 litre of water) or bleach containing cleaner.
• Make sure to wash cutlery/dishes between use with raw and cooked meats.
• Avoid yogurt and ice cream from “soft-serve” machines.
• Avoid unpasteurized cheeses.

Drink Enough Fluids

It is very important for you to drink plenty of fluid. Not drinking enough can lead to dehydration and other problems such as nausea, vomiting and kidney complications.

In general, you should aim to drink about 6-7 cups or 2-3 litres of fluid each day. Here are a few suggestions to help you drink enough fluid:

• Get a water bottle that holds 1000 ml. (Make sure it gets a thorough cleaning every day).
• Always carry your water bottle with you and sip on it often.
• Dilute juices and other drinks with water.
• Remember how often you’ve filled your bottle to estimate how much you are drinking.
• Avoid caffeinated drinks (strong teas, coffee, colas etc) as these are of little benefit and may dehydrate you more.

Water Safety

In general, you should not wade in, swim in, or drink river, lake, ocean, or pond water. These bodies of water can lead to serious infections such as cryptosporidium. Do not drink water from a well, especially a private well.

Municipal tap water is safe to drink. Local health departments will issue warnings about water safety if and when they arise. If such a warning is issued in your area, follow the instructions for boiling water. Bottled water may be safe, however, to be certain, use one of the following:

• Boil water for more than one minute.
• Filter with a 1 mm filter.
• Use a reverse osmosis filtration system.
A Word about Fatigue

“Fatigue” is a common medical condition for people with cancer. For most people fatigue is a temporary condition felt after doing some moderate to heavy activity. It usually goes away after you rest or take a quick nap. For cancer patients fatigue can be chronic (meaning it doesn’t go away), and can severely affect their health and quality of life.

We tend to underestimate fatigue and its effects. Weakness and exhaustion are obvious indicators of fatigue. However, there are some subtler signs to look for. “I just don’t feel like myself” is a common statement made by patients undergoing chemotherapy. Pain in your legs, difficulties climbing stairs or walking short distances, and being short of breath after only light activity (like taking a shower) are all symptoms of fatigue. Fatigue can affect the way you think and feel. It can cause you to have difficulty in concentrating, lose interest in your normal activities, and make you impatient.

In cancer patients, the most common cause of fatigue is the lowering of their red blood cell/hemoglobin. However, there are other things that can contribute to fatigue such as a disruption of eating and sleeping habits (often due to nausea, pain and/or routine changes).

Everyone feels and deals with fatigue differently. Let your health care team members know that you are experiencing fatigue. They can provide you with helpful information to improve fatigue, or prescribe treatments to lessen physical conditions that may be contributing to fatigue. Some helpful hints to assist you in dealing with fatigue are as follows:

- Take several short naps or breaks, rather than one, long rest period.
- Plan your day so that you have time to rest.
- Take short walks or do some light exercise if possible. Some people find this decreases their fatigue and helps them sleep better at night.
- Eat as well as you can, and drink plenty of fluids.
- Ask your family or friends to help you with tasks you find difficult or taxing.
- Keep a diary of how you feel each day. This will help you with planning your daily activities, and can help you and your medical team regulate any anti-fatigue medication you may be taking.
- Join a support group, or seek help from a BMT Social Worker. Sharing your feelings with others can ease the burden of fatigue, and you can often learn coping strategies from talking about your own situation.
- Cultivate interests that can be less strenuous, like listening to music or reading.
- Finally, remember that you don’t have to do everything. Save your energy for things you find most important.
Activity and Exercise

Regular exercise and physical activity are important.
- You will feel better mentally and physically.
- You will sleep better at night.
- It helps to maintain your strength and circulation.
- It helps to lessen the side effects of your treatments.
- It helps to keep your skin, muscles, heart and lungs in shape.

When you are feeling unwell, do what you can. Regular exercise can simply mean getting up and walking for at least 15-20 minutes several times a day. It is also important for you to stay out of bed during the day as much as possible. Here are some suggestions:
- Sit in a chair for all of your meals.
- Walk to the bathroom instead of using a urinal or commode chair.
- Sit in a chair to read or watch television instead of lying in bed.
- You may find it helps to go more slowly or rest before continuing.

Walking is probably the best activity to start with while you recover. Over time, your stamina and strength will improve. Your physiotherapist can help you plan a re-conditioning program that includes gradual increases in activity.

Remember that a low platelet count can put you at risk for bleeding (Normal count = 125 - 400). Certain exercises should be avoided until your count recovers. Here are a few guidelines:

- **When platelets are less than 15** – limit your activity. You may need to receive a platelet transfusion.
- **When platelets are 15 to 20** – exercise gently without resistance. You can do sitting or standing exercises, gentle stretching and walking.
- **When platelets are 20 to 40** – you may use some resistance, such as weights or elastic tubing or theraband. You can walk more briskly and practice step-ups or stairs.
- **When platelets are 40 to 60** – activities such as stationary cycling and golfing are acceptable
- **When platelets are over 60** – you may do more vigorous resisted exercise and aerobic exercise such as biking or jogging. However, wear appropriate gear and continue to avoid injuring yourself.

There are no restrictions on exercise once your blood counts return to normal; however ask your doctor before taking up sports and activities that put you at risk for injury such as contact sports and skiing.
Sexual Health and Intimacy

Most men and women experience a temporary decrease in libido (desire). This may be due to tiredness, weakness, a change in how they feel about their appearance, or a general feeling of illness. Remember, sex requires extra energy! It is an individual thing, but it can take several months or more for interest to return. Resuming relationships will take patience and time.

It is important for both partners to be patient and sensitive to each other’s needs. Remember there are many ways to express love and closeness. Initially you may just want to sit close together, hold hands, and hug each other. Touching and caressing takes much less energy than sexual intercourse and can be just as intimate and satisfying.

Men should know that chemotherapy agents are not known to directly affect desire, ejaculation or orgasm, although the aforementioned decrease in libido is common. Due to chemotherapy or radiation therapy, semen may occasionally appear brown or orange. This is temporary. Also, patients receiving chemotherapy should wear a condom during sexual intercourse for up to seven days after the last dose of chemotherapy, as some drug by-products may be present in the ejaculate.

Women may experience several changes such as decreased, irregular, or absent menstrual periods after treatment. Symptoms that result from early menopause may also occur. If your period does not stop, medication (such as Ovral or Provera) may be prescribed in order to stop menstruation while your platelet and hemoglobin counts are down. Once your counts have recovered enough that blood/platelet transfusions are no longer necessary, these medications can be discontinued. Also, note that due to your increased susceptibility to infection, if you do have a period, avoid the use of tampons.

For women, menopausal symptoms can occur due to a lack of ovarian hormone production after chemotherapy/BMT. Symptoms of menopause include hot flashes, vaginal dryness, inflammation of the vaginal wall, pain with intercourse, irritability, and decreased libido. Some women find that using lubricants, gels or other vaginal creams such as K-Y jelly (Vaseline is not recommended) may help to relieve some of the vaginal discomfort. Hormone replacement therapy may also be used to lessen these symptoms. It is important to discuss these issues with your gynecologist or BMT doctor.
For Men and Women: During your recovery/engraftment period, engaging in sexual intercourse can put you at risk for infection and bleeding. We recommend the following guidelines:

- Do not engage in sexual activity if you or your partner has an infection, such as a cold, upper respiratory infection, open sores or cuts, or herpes/cold sores.
- Do not engage in sexual activity if your platelet count is less than 50
- For men who have had a transplant and for partners of women who have had a transplant, use condoms and discard after each use. Avoid the use of condoms with spermicides as these may irritate the penis and/or vagina
- Avoid anal sex
- Do not use intrauterine devices (IUDs) or diaphragms
- Avoid multiple sex partners

Alcohol

Following BMT your liver may be sensitive and unable to fully function as chemotherapy and other medications can greatly stress the liver. All alcoholic beverages should be avoided during treatment and for at least 3 months following transplant (longer for some patients). Ask your doctor before having beer, wine and other alcoholic beverages.

Clothing and Laundry

- If you find your skin is sensitive, loose fitting clothes may be more comfortable.
- During the winter, bundle up and don’t forget a hat or cap. Avoid staying outside for long periods on a cold day.
- Put on clean underwear and clean clothes every day after your shower.
- Wash all new clothes before wearing them.
- If it is necessary to use a Laundromat, liquid bleach should be added to all wash loads.

Housecleaning and Home Maintenance

Prior to discharge, the home should be thoroughly cleaned in the same way as you would do a good “spring cleaning”.

- Any commercial cleaning soap or solution can be used. It does not need to be labeled “anti-bacterial”.
- Rugs and carpets should be thoroughly vacuumed
- Clean kitchen and bathroom sinks, tubs, shower area, and toilets with a cleaner that kills mildew.
- Pour 1 cup of liquid bleach down all drains.
- All kitchen appliances, including the inside of the refrigerator and counter tops, should be thoroughly cleaned with a commercial cleaning soap or solution.
- All filters (air conditioning, heaters, and humidifiers should be removed and cleaned, or replaced.

Until your counts have fully recovered, general housekeeping is best left for someone else to do. You may help in clearing the dishes from the table, washing dishes and making beds. Remember to wash your hands after doing these activities. Someone other than the BMT patient should do the following:
- Dust and vacuum the house once a week.
- Clean all bathrooms weekly (more frequently as needed) with a good general disinfectant.
- Change bed linens weekly or more often if needed.

Plants and Flowers

It is not necessary for you to get rid of all your houseplants. However, we do recommend that you do not handle water plants or re-pot plants or flowers. Also avoid raking leaves and mowing the lawn until your doctor informs you that it is safe to do so. Soil contains bacteria and fungi/molds. When you get the OK to go back to gardening, be sure to wear gloves for at least 6 months.

Pets and Animals

Dogs, cats, and fish do not pose a great risk of infection to you, if you follow the guidelines below. Birds, rodents, or reptiles are not recommended (it is best to let someone else care for them for a while). If you do not have a pet, now is not the time to adopt a young pet or a stray.
- It is best that your pet does not sleep in the same room as you.
- Be sure to wash your hands after patting/handling your pet.
- Avoid being scratched by your cat.
- Do not clean your pet's cage, litter box, pen or fish tank.
- Check with the MD before resuming these activities.

If you or a member of your household has an occupation involving the handling of animals, such as a vet, farmer, or pet store vender/employee, be sure to talk with your BMT doctor about specific safety guidelines.
Driving

You will likely feel weak and tired after clinic appointments and will probably not feel like driving. You might also be taking medications that could make you feel drowsy (i.e., Ativan, Benadryl, Gravol, Dilantin or pain medications). **We do not want you to drive yourself** to clinic appointments, as you may need a blood transfusion or other treatment that requires pre-medications that will sedate you. To be safe, please check with your BMT doctor before driving.

While your immune system is recovering, **Please avoid public transportation** systems such as the train or buses as these are very crowded and you could pick up an infection. If you need to use the ferries, avoid the more crowded areas. If you are very concerned about picking up an infection, then take along a mask.

If you need help with transportation to and from daycare, talk to the social worker or your nurse.

Travel

Please check with your doctor before making any travel plans, especially air travel and travel to other countries. It is important for your neutrophil and platelet count to be at a level that is safe for travel.

Work and School

You can return to school or work when it is medically safe for you to do so. Most post-BMT patients find that they need at least 6 to 12 months before they feel well enough to begin going back to work or school. You may wish to limit schoolwork or work-related activities at home while you are recovering before returning to such activities on a part-time basis. Discuss your plans with your BMT doctor before you return to work or school.

The Sun

Your skin will be more sensitive to the sun because of the effects of chemotherapy.

- Avoid direct and prolonged exposure to sunlight especially between the hours of 11 am to 3 pm.
- When outside, always wear a hat (wide-brimmed preferred), long sleeved shirt and pants.
- Use a good sunscreen with an SPF of at least 15.
On a hot sunny day, avoid becoming overheated, seek air conditioning or shade, and wear loose fitting clothing.

Be careful of areas that can reflect sun/UV rays such as the beach, water and swimming pools.

Eye Examinations and Contact Lenses

Do not wear contact lenses unless your BMT doctor says it is safe to start wearing them again. If used too early after transplant, contact lenses can cause injury to your eyes. When you resume wearing contact lenses, you will be at a higher risk of getting an eye infection. Remember the following:

- Always wash your hands before putting in or taking out your contact lenses.
- Clean your contact lenses very well before putting them in your eyes.
- Some people experience changes in their eyes or vision following BMT. These changes are often temporary and due to medications such as prednisone. Cataracts can also occur after BMT. Because of these possible changes we advise that you have your eyes examined by an ophthalmologist (eye doctor) periodically.
EMOTIONAL CONCERNS

Written October 2007

Vancouver General Hospital
Emotional Affects of Cancer

It is important to identify and acknowledge the stress that comes with being diagnosed with a life-threatening illness and the resulting treatment and hospitalization experience. It is also important to focus on the strengths that you and your family have. The health care team will help you recognize these and help you and your family/friends develop your physical, social, emotional and spiritual strengths. It is important to talk about your concerns and feelings with those close to you.

Although each family’s emotional response to the diagnosis and the transplant process is unique, many share similar reactions. You and your family may experience some of the following.

**Shock**

Feeling shocked is often the first reaction when cancer is diagnosed. You may feel numb and not believe what is happening, be unable to express any emotion, find you can only take in small amounts of information, or ask the same questions or need to be told the same thing over and over again. Needing to have information repeated is a common reaction to shock.

Some people may find their feelings of disbelief make talking about their illness with family and friends difficult. Others feel the urge to talk about it as a way of helping them to accept the news. If you would like to talk to someone outside your own friends and family, please talk to your nurse or the social worker.

**Stress**

The first few weeks at Vancouver General Hospital (VGH) can be difficult. On top of the stress your illness is causing you and your family (whether it be physical, emotional, spiritual and/or financial), you will be dealing with the stress of being in a new area, adjusting to the outpatient or inpatient hospital routine and, more importantly, establishing trust in the health care team.

In a short time our health care team will attempt to make you very well informed. You may feel overwhelmed with the sheer volume of information presented to you regarding your treatment. You may be required to learn more than you wished or anticipated. If you have any questions or don’t understand what has been said, please ask for clarification.
Depression

People who face a diagnosis of cancer will experience different levels of emotional upset. Fear of death, changes in body image and self-esteem, interruption of life plans, changes in the social role and lifestyle, and money and legal concerns are important issues in the life of any person with cancer. However, not everyone who is diagnosed with cancer will experience serious depression.

Throughout diagnosis, treatment, and survival most people will periodically experience reactions of sadness and grief. On learning they have cancer; they often have feelings of disbelief, denial, or despair. They may also experience difficulties with sleeping, loss of appetite, anxiety, and a preoccupation with worries about the future. These symptoms and fears will usually lessen as a person adjusts to the diagnosis. Signs that a person has adjusted to the diagnosis are evidenced by their ability to maintain an active involvement in daily life activities, and an ability to continue functioning in their daily roles. A person who cannot adjust to the diagnosis after a long period of time, and who loses interest in usual activities, may be depressed.

The signs and symptoms of major depression include:

- loss of pleasure and interest in most activities.
- having a depressed mood for most of the day and most days.
- changes in eating and sleeping habits.
- nervousness or sluggishness or tiredness.
- feelings of worthlessness or inappropriate guilt.
- poor concentration.
- constant thoughts of death or suicide.

Mild symptoms of depression can be distressing and may be helped with counseling. However, when symptoms are intense and long lasting, or when they keep coming back, more intensive treatment is important. It is very important to talk to the health care team if you have any symptoms of depression.

Fear

Fear is an overwhelming emotion that patients and families experience before, during, and even after hospitalization/treatment. These fears include fear for the well being of your family, fear of discomfort, fear of what your future holds and fear of dying. Although our units in the leukemia/BMT program are a
place of hope, it is important to realize that patients can die during the course of hospitalization. Family members and patients may not always talk about their fears of death as a way of trying to protect one another. These fears are very real and sharing them with family and the health care team usually helps.

**Anger**

Another common reaction to illness is anger. Some patients direct their anger at their family or the staff, while others may be angry with God. Relatives may be angry with the patient for getting sick and disrupting their lives. Anger is a very normal reaction to the stress a family feels during diagnosis, treatment and transplant. It is very important to find an outlet, such as talking to someone, in order to relieve the tension. It is important to realize that this is a time when both the patient and their families/support persons need mutual support.

**Guilt**

Many families talk about feeling guilty. Parents can feel guilty because their child has cancer, while adult patients may feel guilty for being a burden to their family. Children can also feel guilty that a parent is ill (especially when they do not fully understand what is happening). These feelings are a common human emotion and coping with them can be difficult. Again, it is important and can be helpful to share these feelings with someone.

All of these reactions are perfectly normal. You and your family should not hesitate to use the understanding, experience and support of the health care team to help you deal with these emotions.

**Talking to Children about Cancer**

Talking to your child about cancer is one of the hardest things a parent will ever do. It is very difficult to think about the time, energy and concentration that may be required to find the words to explain cancer to your child. It is very important to talk to your child about the illness and to keep them up to date on their ill parent. *Helping Parents Explain Serious Illness to Their Children* by Joan Hamilton is an excellent resource and is available from the social workers. CancerCare, a national nonprofit organization that provides free, professional support services for anyone affected by cancer also has very good advice regarding this issue. Call 1-800-813-HOPE or email info@cancercare.org
MISCELLANEOUS TOPICS

Written October 2007

Vancouver General Hospital
Miscellaneous Topics

Taking Care of Loose Ends

Taking care of loose ends and putting one’s affairs in order does not necessarily signify an anticipated negative outcome. Sometimes, by dealing with difficult issues that may come up in the event of one’s death beforehand, it is then possible to put these issues aside and focus on more positive things. If you need assistance please contact the Social Worker.

Fertility

People undergoing high-dose chemotherapy have a high risk of becoming infertile.

For some male patients, sperm banking may be an option. Sperm banking involves freezing and storing sperm in a substance called liquid nitrogen. This sperm may be used at a later time for artificial insemination or in vitro fertilization (IVF). Sperm can be stored in liquid nitrogen for up to ten years. This procedure depends on the sperm count and the quality of the sperm.

For some women patients, options include the cryopreservation of fertilized ova (eggs), called “zygotes” (which requires a consenting partner) or the use of donor eggs and IVF in the future.

The process of cryopreserving fertilized ova, however, requires some forethought and coordination. Time must be taken for consultation, hormonal therapy (in coordination with the woman’s menstrual cycle), and harvesting and fertilization of the eggs. Although technology exists for storing unfertilized ova, it is not yet developed enough and therefore no services as yet are available.

If this is something that you would like to find out more about, you are encouraged to raise this with your doctor as early as possible. It is important to discuss these options early because disease status and previous treatment could lead to infertility. There are sperm and ova banking facilities in several Canadian cities including Vancouver. Your doctor or social worker can help you contact a sperm bank in your area.

Although uncommon, a few men and women have had children following treatment. For this reason, it will be important for you to discuss contraception issues with your doctor prior to discharge.
SOURCES OF INFORMATION

Written October 2007

Vancouver General Hospital
Sources of Information

This Manual was written using information from some of the following sources. There are many more good sources of information “out there”. If you come across something that you would like to see listed below, feel free to let your BMT nurse or coordinator know.

- **Myeloma.** A booklet provided by: *The Leukemia & Lymphoma Society* or visit their website: [www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org) this pamphlet can be found on the BMT Daycare Unit depending on availability.

- **Multiple Myeloma. What you need to know:** a pamphlet provided by the *Canadian Cancer Society* or visit their website: [www.cancer.ca](http://www.cancer.ca) This pamphlet can be found on the BMT Daycare unit depending on availability.

- **The Leukemia/ BMT Program Website:** the official website of the L/BMT Program: [www.leukemiabmtprogram.com](http://www.leukemiabmtprogram.com)

- **BC Cancer Agency Library.** Located in the BC Cancer Research Centre at 675 West 10\(^{th}\). The library also has sources in Victoria, Surry, and Kelowna. Visit their website: [www.bccancer.bc.ca](http://www.bccancer.bc.ca) and click on the “library” link.

- **Autologous Bone Marrow Transplant: Here’s what you should know.** Booklets provided by the International Myeloma Foundation (IMF) or visit their website: [www.myloma.org](http://www.myloma.org) this website is dedicated to providing you with the most up to date and in depth information about multiple myeloma including research and treatment advances, as well as information about upcoming events and their research, education, support and advocacy programs. [www.myelomacanada.ca](http://www.myelomacanada.ca) is also great.

- **CancerCare** is a national nonprofit organization that provides free, professional support services for anyone affected by cancer. Call 1-800-813-HOPE or email [info@cancercare.org](mailto:info@cancercare.org)

- **[www.multiplelyeloma.org](http://www.multiplelyeloma.org)** Founded by sisters in 1998, the multiple myeloma research foundation’s website is a great resource for up to date information on MM and when new treatments and/or drugs are being made available.

This manual was prepared by Anette Reitlingshoefer, RN BScN October 2007. The bulk of the information within was gathered, revised and adapted from the VGH Leukemia/Bone Marrow Transplant program’s website and admission and discharge booklets (revised editions March 2004).

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APPENDIX A

MEDICATION INFORMATION SHEETS

Written October 2007

Vancouver General Hospital
Appendix A
Medication Information Sheets

The following medication sheets are provided here for your convenience. These are arranged by drug class order. Not all of the following medications will necessarily be prescribed to you:

Steroid (Corticosteroid)/Anti-inflammatory
- Dexamethasone (Decadron®)

Chemotherapy agent
- Cyclophosphamide (Cytoxan®)
- Melphalan (Alkeran®)

Antibiotic
- Ciprofloxacin (Cipro®)
- Co-trimaxazole (Septra®)

Antifungal
- Fluconazole
- Itraconazole (Sporonox®)

Antiviral
- Valcyclovir (Valtrex®)

Antinausea
- Metoclopramide (Maxeran®)
- Ondansetron (Zofran®)
- Prochlorperazine (Stemetil)

Miscellaneous
- Filgastrim® (G-CSF, Neupogen®): colony stimulating factor
- Furosemide (Lasix®): diuretic
- Pamidronate (Aredia®): bisphosphonate