A Patient’s Guide to
HAEMATOPOIETIC STEM CELL TRANSPLANTATION

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1. INTRODUCTION

“Haematopoietic Stem Cell Transplantation” – the name sure sounds complicated and hard to pronounce. What is it actually? Well, in fact, it can be quite simple. “Haemato” just means blood. So, Haematology means the study of blood and “Haematopoietic” means blood forming.

What are stem cells? Stem cells are basically cells which can continue to produce more cells exactly like themselves forever. They can even produce many other “daughter cells” which perform various other functions. Haematopoietic stem cells are therefore cells which can continue to produce more cells like themselves while producing cells which circulate in the blood forever. These cells which circulate in the blood include white blood cells (which help you fight infection), red blood cells (which bring oxygen round the body) and platelets (which help your blood to clot when you bleed).

Transplantation is the process of taking an organ or tissue from a person and putting it in another person. A true gift of life! So, Haematopoietic Stem Cell Transplantation (which we will call HSCT from here on) means the taking of blood forming stem cells from one individual and giving it to another. The process of HSCT is a truly wonderful one as it truly reflects how we can share life giving cells to save the life of another person.

HSCT is not new. Hundreds of thousands of people have received or donated blood stem cells since the first HSCT in the 1950s. The process has been refined over the decades and we have learned a lot about how to do it, who to do it for and when to do it. Yet, every year we continue to learn more and the process continues to improve while patient survivals get higher. Not everyone needs to undergo HSCT, but if one is needed, there are many decades of worldwide experience and innovation that guides the process.

The process of HSCT is a team effort that requires the combined efforts of the transplant physicians and other doctors as well as nurses, pharmacists, social workers, dietitians, physiotherapists and many other healthcare professionals. However, the most important members of this team are the patient and caregivers. Their education and participation are vital to the success of each transplant. Thus, we have come together to write this book to help guide patients and their families through the process of HSCT.

We hope you will benefit from it.

2. BASICS OF BLOOD AND BONE MARROW TRANSPLANTATION

THE BLOOD AND BONE MARROW

Blood cells are produced within your bone marrow. The bone marrow is found in the centre of your bones. Some areas, such as the back of your pelvis, contain a large amount of marrow and are the sites for taking samples for testing or for harvesting. All blood cells have a limited life span and your bone marrow needs to continually make blood cells to maintain your normal blood counts.

There are different types of blood cells, each with its own function. The common cells you will become familiar with are:

**White blood cells:** There are 5 different types of white blood cells but the 2 most important ones are:

- **Neutrophils** – These white cells are made in your bone marrow. They are the most important type of cells which help fight bacterial infections.
- **Lymphocytes** – This type of white cell may be divided into T-lymphocytes which control the immune system, destroy viruses, cancer cells and are responsible for graft-versus-host disease after transplantation and B-cells – which make antibodies, proteins which help protect you from certain infections.

**Red blood cells:** Made in your bone marrow, these contain haemoglobin which carries oxygen from your lungs to the different parts of your body. They are responsible for giving your blood the “red” colour.

**Platelets:** Made in your bone marrow, these are small fragments of cells which stop bleeding or bruising.

When the bone marrow slows down or stops producing normal cells, you become:

- **Neutropenic** – i.e. have a low neutrophil count—with a risk of severe infections and mouth ulcers. If you are neutropenic, you may be given medication in the form of antibiotics and antifungals, to reduce the risk of (prophylaxis) or to treat infections. You may also be given growth factors i.e. a drug called G-CSF which may stimulate your bone marrow and reduce the time that you are neutropenic.

- **Anaemic** – i.e. have a low haemoglobin level. You may experience tiredness, shortness of breath, and look pale. Red cell (blood) transfusions may be given for anaemia.

- **Thrombocytopenic** – i.e. have a low platelet count. You may experience easy bruising, petechiae (pen dot spots) and an increased risk of serious bleeding. Platelet transfusions may be given for thrombocytopenia.
Finding a Donor

Tissue typing
A sample of blood is required in order to determine your tissue type. This is also known as Human Leukocyte Antigen (HLA) typing. Based upon these results a donor search may be conducted. Generally, a match at what is known as HLA-A, HLA-B, HLA-C and HLA-Dr alleles (the genes that determine your tissue type) is looked for.

Sibling donor
A sibling is a brother or sister from the same biological parents (i.e. same mother and father). Each biological sibling that you have has a 25% chance of being fully compatible with you.

Volunteer Unrelated Donors
Are donors who are not related to you. Volunteer donors register themselves with their local bone marrow donor registry who will perform tissue typing and match them with recipients. There are currently about 13 million registered donors worldwide. Matches may be considered full if the donor and recipient match on 8 of 8 or 10 of 10 HLA alleles.

Unrelated--Cord Blood
Umbilical cord blood units are bone marrow stem cells collected from the placenta following birth. These are then frozen and stored in cord blood banks, ready to be used when required. Public cord blood banks provide donated units for unrelated cord blood transplants. These are usually matched on 6 HLA alleles.

Haplo-identical Donors
A haplo-identical donor is one who is a 50% HLA match with you. Examples of these include biological parents, some siblings and your children.

3. Preparing for Your Transplant

Timing
The timing of your transplant is dependent on many factors especially the status of your disease and the availability of your donor.

For your transplant admission, you should expect to be in hospital for approximately 6 to 8 weeks. Following discharge, you will need to attend the outpatients department at least twice a week, sometimes more frequently, for monitoring and treatment. This may last for several months following your transplant and re-admissions to hospital are frequent. It may take you 6 to 12 months to regain your energy levels and be able to resume your normal activities.

You should plan to be away from work for at least 6–12 months following your transplant. If you have any concerns about the timing of your transplant, you should speak with your transplant team.

Pre-transplant Conference
Before your transplant admission, you will be invited to bring your family, close relatives and friends to a pre-transplant meeting with your transplant doctor and nurses. During this visit your transplant doctor will discuss with you in detail the reasons for offering you the option of a transplant, the entire process of transplantation, the risks of transplantation, the short and long term effects of your transplant. You and your companions will have the opportunity to ask as many questions as you wish regarding your transplant, and when you are fully satisfied and you agree to proceed with your transplant, you will be asked to sign the consent form. Depending on availability, you may be orientated to the transplant unit and room after this by your nurse.

Pre-transplant Investigations and Procedures
You will need to undergo a series of tests to assess your medical status to determine if you can proceed with your transplant. If you have come this far, it is unlikely that any of these will be a major problem, but your transplant doctor may need to make adjustments to your conditioning regimen or perform more detailed tests depending upon these results. These tests must be done within 28 days of your transplant.

Bone marrow aspirate and trephine
You will have had at least one of these previously. A sample of bone marrow is collected from the back of your pelvis to confirm that you are in remission.
24-hour urine creatinine clearance or EDTA clearance
These are tests to determine how well your kidneys are working. The former involves collecting all your urine in a bottle for a 24 hour period. When you bring this sample in, a blood sample will also be collected. An EDTA clearance involves an injection of a small amount of a harmless radioactive isotope into your bloodstream. How well your kidneys excrete this can then be measured. Usually only one of these tests is required. However if your doctor feels that the results are inaccurate, a second test may be requested.

Lung function tests
Lung function testing measures the volume of your lungs, how good your airways are and how well oxygen passes into your blood. It involves breathing and blowing into a machine.

MUGA scan or Echocardiography
These measure how well your heart pumps blood. A MUGA scan uses a small amount of a harmless radioisotope injected into your bloodstream. An echocardiograph uses ultrasound to place a small amount of a jelly on your chest and a small probe is placed over the jelly. The sound waves are reflected off your heart and a computer creates a picture. A normal ejection fraction result should be more than 50%.

Electro-cardiogram (ECG)
An ECG measures the electrical activity of your heart. This test involves attaching a number of wires to your shoulders, chest and legs.

Blood tests
The routine blood tests will be performed, looking at the chemical levels in your blood, your kidney, liver and thyroid function.

Infectious disease screening
You will need to undergo blood testing for certain infections which may cause a problem during or after your transplant. These include Hepatitis B and C, Human Immunodeficiency Virus (HIV), Human T-Lymphotropic Virus (HTLV), Syphilis, Cytomegalovirus (CMV) and Varicella Zoster Virus (VZV).

Imaging
You will need to have a routine chest X-ray. However, depending on your disease and previous history, more detailed imaging tests may be required. These may include CT scans, MRI scans or PET–CT scans. Your doctor will explain these to you.

DENTAL APPOINTMENT
You will need to see a dentist a few weeks before your planned transplant admission. This is to check that your teeth and gums are healthy so that any potential source of infection can be treated before your transplant admission.

CENTRAL VENOUS CATHETER INSERTION
During your transplant, you will need to have a large number of infusions. These may include fluids, chemotherapy, antibiotics, other drugs and blood products. There will be daily blood taking to monitor your progress. Some drugs cannot be given through small veins. Apart from being painful, the veins in your hands and arms will not cope with the frequent punctures.

The Central Venous Catheter (CVC), also called a Hickman line, is inserted before your transplant to allow all the infusions and blood taking to be done, minimising needle punctures to your veins. This is a special thin flexible tubing inserted through the skin into a large vein in your neck or chest. The procedure is usually done at the radiology (x-ray) department under local anaesthesia. A needle is inserted and the catheter is threaded in. The needle will then be removed. The catheter will be stitched onto the skin to prevent it from slipping out. Several centimetres of the catheter will remain outside the body. A light dressing will be placed over the exit site of the catheter.

An X-ray of your chest will be taken to check the position of the catheter in the central vein before it can be used. The catheter extends all the way down the vein and stops near your heart where the central blood circulation is. The drugs administered through the catheter are safely diluted with large amounts of blood.

As in any invasive procedures, there will be some risks. These include bleeding, infection and collapse of the lung. Before the procedure, the doctor will explain the risks in greater detail to you, and you will need to sign a consent form. If you would like to see a catheter before you consent, you can ask the nurse to show you the model. The catheter may have 2 or 3 lumens.

CARE OF YOUR LINE
Your catheter needs to be looked after well to prevent it from becoming blocked or infected. During your stay in hospital, your nurses will inspect it daily. When you return home after the transplant, you and your caregiver will have to look after it. Therefore, you need to identify a caregiver who can help you with it after discharge. The catheter dressing will need to be changed at least once a week and whenever it is wet. Flushing of the catheter is done at least once a week with heparinised saline to prevent blockage.

Looking after your catheter is easy. During your stay in hospital, your nursing team will arrange for a one to one teaching session with your caregiver. This will be done with a model initially before the hands on session on your line. Your nurses will
supervise you and your caregiver until you and your caregiver are proficient. Reading material will be given. The complete catheter dressing kit can be ordered before home. You will also be taught how to look out for abnormalities such as redness, discharge, pain and loose stitches. You will need to call the Haematology Centre Clinic Nurse for an urgent appointment if you notice any of these. (See page 65)

The catheter will stay until your doctor decides that you no longer need it. It can remain safely in place for many months. Sometimes catheters may need to be removed earlier by doctors if there are signs of infection, blood clots or if the catheter becomes blocked. Removal is a simple procedure and is easily done in the ward. A new catheter may be reinserted depending on whether you need a replacement.

THINGS TO TAKE INTO HOSPITAL
When you are admitted into hospital for your transplant, you should take some personal belongings with you.

This is a list of things that transplant patients may usually bring:
• Personal toiletries (a small toothbrush with soft bristles)
• Comfort toys, pillow, bolster and blanket (your caregiver will need to bring them home for washing if dirty)
• Socks, mittens, head covers to keep warm
• Family photos, favourite pictures, cheer posters, cards from well wishers
• Books, magazines to read, crossword puzzles, religious books
• Enjoyable projects to work on (e.g. craft project, jigsaw puzzles)
• Hand-held games, gaming console etc
• Entertainment devices such as VCD, DVD, MP3 etc
• Musical instruments, with earphones
• Laptops. For fast and reliable internet access, the wireless mobile broadband is recommended.
• Notebook / diary to record your transplant journey

Please bear in mind that the rooms in transplant units are small. It should be kept clean and tidy at all times. Personal belongings left on the floor and lockers may hinder proper cleaning. Generally, you have less energy than usual. At times, it may even be difficult to concentrate on doing all your usual activities.

Things not permitted into your room:
• Potted Plants
• Fresh and dried flowers
• Pets
• Cooking utensils. Cooking strictly is not allowed. There must be no burning of incense/aromatherapy as this is a fire hazard. Smoking is strictly forbidden.

SELECTING A CAREGIVER
It is important to select a caregiver who you feel comfortable with and cares for you unconditionally. The responsibilities of your caregiver during and post-transplant may include:
• Providing emotional support
• Providing physical care during and post hospitalisation
• Caring for your central venous catheter
• Serving you oral medication and reminding you to take your medication
• Identifying changes in your condition and reporting these to the transplant team
• Keeping family members and friends up-to-date about your condition
• Monitoring number of visitors during and after transplantation
• Maintaining a clean home environment after hospitalisation
• Preparing home cooked meals for you on discharge
• Accompanying you for follow-up visits to the hospital

Care giving responsibilities may be shared among family members or close friends. This will help to relief tension and stress shouldered by only one caregiver. Caregivers can rest and returned to hospital more refreshed. If your main caregiver is feeling unwell, another caregiver should take over till your main caregiver is able to care for you.

NUTRITION
Patients undergoing chemotherapy and transplantation are at an increased risk of malnutrition. Malnutrition and accompanying weight loss can be caused by the disease and made worse by treatments such as chemotherapy and/or radiotherapy. These may be further exacerbated by an increased demand for nutrients by your body and it may lead to a depletion of energy stores and weight loss if you do not take in enough food.

Recommendations will usually include a high energy, high protein diet to prevent malnutrition. A high energy, high protein diet can also preserve your muscle mass while maintaining strength and energy. If you are not able to maintain an adequate oral intake to meet your requirements, you may benefit from other forms of nutritional support. Oral nutritional supplements can help to meet your nutritional requirements and may optimize your nutritional status prior to your transplant. If you are still not getting enough nutrition, other alternatives may include enteral feeding via a small thin feeding tube or via a parenteral route (intravenous nutrition).

When you become neutropenic, you will be more susceptible to infections. Care should be taken to reduce as many sources of infection as possible. You will be advised to adhere to a ‘Neutropenic Diet’ which aims to reduce your risks from food and/or water borne infections, especially by not eating raw and/or undercooked food items. During the pre–transplant workup process, a dietitian will assess your nutritional status and nutritional needs. Additionally, you will be advised on the aims and goals of the medical nutrition therapy through the different phases of the transplant. Your dietitian will continue to monitor and review your nutritional status whilst in the ward or may arrange an outpatient follow up appointment.
KEEPPING FIT PRE-TRANSPLANT

Your pre-transplant physical health is a factor that may affect transplant outcome. Although your blood condition may influence your overall physical activity, you should still do what you can to get your body into the best physical condition possible before transplant. Regular exercise has a positive effect on both physical and emotional well-being. Establish your own exercise routine – try doing something active every day! Turn something you enjoy into your daily source of exercise; for example, brisk walking up to 15 minutes, three times a week as tolerated, tai-chi or line dancing.

FERTILITY ISSUES

Your ability to conceive a child may be affected by high-dose chemotherapy. The risk depends upon your age and the type of chemotherapy and/or radiotherapy you receive. These risks are not absolute and you are strongly advised to use appropriate contraception during your treatment and following your transplant. If you are female, you are strongly advised not to become pregnant for at least 5 years after your transplant. Your doctor will discuss the options for preserving your fertility before starting your treatment. Preservation of male fertility by semen storage is relatively straightforward and widely available. Before starting any treatment, you may wish to consider storing semen for use later on.

However, bear in mind that your fertility may have already been damaged by your illness. Your local reproductive medicine unit will be able to provide testing and advice. Preservation of female fertility is much more difficult. There may be several options available and you should discuss these with your reproductive medicine unit.

These may include – Using your own fertilised eggs i.e. embryo storage. This usually requires that you are in a stable relationship with a partner with whom you are planning to have children. Before starting chemotherapy, you will need to be given treatment to stimulate your ovaries to produce eggs. These eggs are then collected and fertilised with your partner’s sperm. The resulting embryos are then frozen and can be implanted in your womb when you have fully recovered from your treatment.

Using donor eggs – Donated eggs are fertilised with your partner’s sperm and implanted in your womb, when you have fully recovered from your treatment. Using your own eggs following egg storage – this may suitable if you do not have a partner with whom you are planning to have children. After your ovaries have been stimulated, the eggs can be collected and frozen without fertilisation.

Ovarian tissue storage – this is a relatively new treatment which involves removal of part of your ovaries and freezing the ovarian tissue.

4. THE TRANSPLANT ADMISSION

You should expect to be in hospital for approximately 6 to 8 weeks for your transplant. You are advised to prepare yourself psychologically before your admission. You can set short term goals for your transplant such as recovery of your blood counts to make your transplant experience more manageable.

PROTECTIVE ISOLATION OR REVERSE BARRIER NURSING

During your transplant, your resistance to infections will be severely compromised. You will be cared for in a single room with a special air filtering system to ensure that the air in the room is as clean as possible. This is known as protective isolation, or reverse barrier nursing. You are advised to remain in your room during your entire transplant stay. This does not mean you should stay in bed.

Try performing gentle exercise daily like stretching, walking around your room and walking to the toilet. Your physiotherapist will teach you some of these light exercises. Studies had shown that performing these exercises improve your physical wellbeing, maintain and or improve your mobility and muscle tone, prevent complications such as chest infection, and improve sleep.

You may have visitors while you are in a single room. You are advised to have 2 nominated visitors to reduce your risk of getting an infection. You should register the names of your nominated visitors with your transplant nurse. You should only allow two visitors at any one time and your visitors should report to the nurse before entering your room. Your visitors MUST wash their hands well before entering your room. Visitors with colds, flu, chicken pox, measles or any other infectious or “catching” illness or anyone who has had a live vaccine such as polio should not visit. You may consult your transplant nurse if you need more information.

NUTRITION

During your transplant, it is recommended that you do not consume any cooked food from home. You are advised to consume the food served in the ward. Your dietitian will be able to advise you in detail regarding food safety and safer food options that are available.
**CONDITIONING THERAPY**

Conditioning therapy is an important part of the transplant process. It starts a few days before the stem cell infusion – the transplant. It usually involves giving chemotherapy drugs, sometimes in combination with whole body irradiation therapy.

The purpose of the conditioning therapy is to:
1. Destroy any remaining cancerous cells in your body
2. Weaken your immune system so that it does not destroy your donor’s stem cells
3. Destroy your own bone marrow in order to make room for the healthy stem cells to grow (or ‘engraft’)

**Drugs Used for Conditioning Therapy**

Commonly chemotherapy drugs used in conditioning therapy include cyclophosphamide, busulfan, fludarabine, and melphalan in various combinations. The regimen used is dependent on your condition.

- **Cyclophosphamide** – This is a chemotherapy drug widely used in conditioning therapy. It is an “alkylating agent” and acts by damaging the genetic material (DNA) in cells, making them unable to grow. Cyclophosphamide is given as an intravenous infusion, usually over 2 to 4 hours. Cyclophosphamide also has a strong suppressive effect on the immune system.

  Common side effects include nausea and vomiting; a metallic taste in the mouth during the infusion; damage to the cells lining your mouth (mucositis); and drop in your blood counts. Occasionally some patients may experience bladder irritation, painful urination, and blood in the urine. This condition can start days to weeks after the drug is given. To reduce the risk of this complication, large quantities of intravenous fluids and another drug called MESNA are usually given together with cyclophosphamide. You should also empty your bladder frequently during your treatment.

- **Busulfan** – Like cyclophosphamide, busulfan is an alkylating agent with strong anti-leukemic activity that acts by damaging the DNA of cells. Busulfan is given as an intravenous infusion, usually over 3 hours. Common side effects include nausea and vomiting, and damage to the cells lining your mouth (mucositis), stomach and intestines and drop in your blood count. It may also give rise to seizures during the days when the drug is being given. An anti–seizure drug, such as phenytoin, is given during this time to reduce the risk of this complication.

- **Melphalan** – Melphalan is also an alkylating agent, usually given as a 30 minute infusion during conditioning therapy. The most common side effects include nausea and vomiting and damage to the cells lining the mouth (oral mucositis), stomach and intestines. You will be asked to suck ice chips starting 15 minutes before the infusion, during, and for another 30 minutes after completion of the melphalan infusion to reduce oral mucositis.

- **Fludarabine** – Fludarabine belongs to a class of drugs called nucleoside analogues as they resemble the building blocks of DNA. Fludarabine is commonly used in conditioning therapy because its strong immune-suppressant properties help with the growth of the new stem cells in your bone marrow. You may experience mild nausea during your treatment.

**TBI or total body irradiation**

TBI involves exposing your body to precisely controlled doses of radiation. To prepare for this, you will be seen by a Radiation Oncologist who will explain the procedure and the side effects to you in detail. In general, these include headache, drowsiness, nausea, vomiting, diarrhoea, mucositis and “sunburn”. Sometimes there may be side effects on other organs e.g. radiation pneumonitis– affecting the lungs. You are advised not to apply any cream or lotion during the days you are scheduled for TBI as it may increase the chance of ‘burning’ your skin.

**Types of conditioning**

- **Autologous transplant** – Usually refers to the use of “myeloablative conditioning” followed by the infusion of your own frozen stem cells. This is only suitable for certain diseases.

- **Myeloablative transplant** – A “myeloablative” transplant uses very high doses of chemotherapy and radiotherapy in the conditioning regimen. In theory if no stem cells are given after this treatment, your blood counts will never recover – hence the term “ablative”. This type of conditioning gives the best immediate control of your disease, but has the most side effects. It is generally reserved for younger medically fit patients who are able to withstand the side effects of the treatment.

- **Non–myeloablative conditioned transplant** – A “non–myeloablative” conditioning transplant uses low doses of chemotherapy and/or radiotherapy. The effect of the conditioning treatment is to suppress your immune system so that you do not reject the donor cells. In theory, if you do not receive any donor cells after conditioning, your own bone marrow will eventually recover. The conditioning has little activity against your disease, so there is a higher risk of relapse after the transplant. The immediate side effects from this form of transplant are usually mild to moderate in severity and most patients who are medically fit enough will tolerate the treatment well. This form of conditioning may be suitable for patients as old as 70 years.

- **Reduced–intensity conditioned (mini) transplant** – A “reduced–intensity” conditioned transplant uses conditioning which is about midway in strength between a “myeloablative” and “non–myeloablative” transplant. The immediate side effects are again between those of a “myeloablative” and a “non–myeloablative” conditioned transplant. The risk of relapse following this type of transplant is higher than a “myeloablative” transplant, but studies have shown that the ultimate success rates in groups of patients is very similar to those who have had “myeloablative” transplants. This type of transplant conditioning may be used in patients up to about 70 years of age.
THE TRANSPLANT

Your stem cell transfusion usually takes place 48–72 hours after completion of conditioning. The day of transplantation is “Day 0” and subsequent days are called “Day +1,” “Day +2,” etc. The day of transplant is very special as it signifies a new beginning and is an important landmark as you have come a long way in your treatment. There is still a long way to go and the BMT team will continue to support you in the remaining part of your transplant journey.

Collection of donor cells

Depending on who your donor is and where they live, your donor stem cells will be collected the day before or on the day of your transplant. Donors generally have a choice of donating either bone marrow or peripheral blood stem cells (PBSCs).

If your donor chooses to donate bone marrow, he/she will have a general anaesthetic and have approximately one litre of bone marrow sucked out of his/her pelvis. The product may then be filtered and may undergo processing when it arrives before it is infused into you.

If your donor chooses to donate PBSCs, he/she will have 4 days of G-CSF injections before the blood stem cells are collected on the 5th and possibly 6th days. Collection in this case is via a process called “leukapheresis”. Blood is taken out of the body into a machine, the stem cells are collected, and then the blood is immediately returned. The blood flow and collection is a continuous process and the donor will spend 4 to 6 hours connected to the machine. When the stem cells are ready, they will be infused into you without any further processing.

Other stem cell sources include your own frozen stem cells or frozen umbilical cord blood units. Frozen umbilical cord blood units will arrive in your hospital before you commence conditioning and will be kept frozen until immediately before the infusion.

Before the infusion

Stem cells may be given to you fresh, or after they have been thawed from frozen. Frozen stem cell units contain DMSO–a preservative to minimise stem cell damage during the freezing process.

Before the frozen stem cell infusion, you will be given intravenous hydration; usually normal saline followed by diuretics intravenously e.g. frusemide, to increase your urine output. This is to flush your kidneys and make sure they are working well. You will also be given oral paracetamol and intravenous anti-histamines e.g. Benadryl to lessen the side–effects of the DMSO in the frozen stem cells. The intravenous anti–histamine helps to reduce any discomfort you may experience and usually makes you feel drowsy.

You do not usually need any pre–medication if you are receiving fresh stem cells but you will be monitored closely during the infusion and if necessary, intravenous anti–histamine will be given. Your temperature and other parameters will be taken as a baseline prior to the stem cells infusion.

The infusion

Your stem cells will be brought by stem cell lab technologist to your bedside, checked and then infused using an unfiltered intravenous set through your central catheter. The stem cell infusion is similar to blood transfusions. The infusion usually takes about half an hour to an hour. Your doctor will be present during the infusion. Your nurse will be monitoring your vital signs closely. You should inform the doctor or nurse immediately if you feel any discomfort during the infusion.

If you are receiving frozen stem cells, it will be thawed in warm sterile water by your bedside. A culture sample will be taken from one of the bags to check for any possible contamination. Your parameters will be taken every 5 minutes for the first 15 minutes and subsequently every 15 minutes until completion of the infusion.

After the infusion

The stem cell bags will be flushed with saline to remove any remaining stem cells from the bags and the infusion tubing. You will be monitored hourly for the next six hours and 4 hourly thereafter. Inform your nurse if you feel any discomfort at anytime after the infusion. If you have received frozen stem cells, your creatinine level will be checked 4 to 5 hours post transfusion to ensure your kidney function remains normal as the DMSO may be toxic to your kidneys.

Side effects

The stem cell infusion is usually a brief and uncomplicated procedure. However, it is important to note that there are side effects which you may experience during or after the infusion. These may include allergic reactions like rash or urticaria, chills, rigor, fever, hypotension, tachycardia and breathlessness. The other commonly reported side effects are nausea, flushing and abdominal pain.

During the infusion of frozen stems cell, you may experience a strange taste in your mouth and a “garlic like” odour due to the DMSO preservative. You may also have some cough. You will be advised by your nurse to suck some sweets during the frozen stem cell infusion. You may not be able to experience the odour but you will be excreting the preservative through your skin and body fluids for 1 to 2 days after the infusion and others entering your room will be able to smell it. You may pass slightly reddish urine for 2–3 days. This is due to the break down products of the frozen red cells being excreted through your kidneys.
**WAITING FOR ENGRAFTMENT**

**Duration of neutropenia**
Your neutrophil, platelet and red cell production will be low for a period of time. The period of time in neutropenia depends on your disease, previous treatment and intensity of conditioning. We generally expect that your neutrophil count will start to rise by about 14–21 days after the infusion of stem cells, and platelet counts a few days later. This will be variable depending on the source and dose of stem cells given to you. During the period of neutropenia, you will need to remain in hospital for close monitoring and treatment. You will also be experiencing a variety of side effects from the conditioning therapy.

**EXPECTED SIDE EFFECTS**

**Mucositis and mouth care**

*Oral mucositis* – mouth ulcers and inflammation of the lining of your mouth develop in most patients who undergo transplantation. This is caused by the conditioning chemotherapy/radiotherapy affecting the cells lining the mouth, the throat and the digestive tract.

Mucositis usually occurs 5 to 8 days after starting conditioning. The symptoms can last up to 7 to 14 days before healing begins. There are 4 stages of mucositis. You may not experience all 4 stages.

Stages 1 and 2 are mild and characterised by soreness and the formation of ulcers. At stage 3, patients with mucositis cannot tolerate solid food and can only take liquids. Eating is not possible at stage 4 so you may need further help getting enough nutrients. Mucositis increases your risk of infections.

At the onset of mucositis, your mouth will start to have white patches and your saliva becomes thicker. Be sure to tell your doctors or nurses when your mouth and throat are starting to feel dry or sore, if your saliva is getting thick or if you start having difficulty swallowing. If it is painful swallowing your saliva, you can spit it out. As your blood counts continue to drop, the surface of your mouth may become red, inflamed and painful ulcers can develop. The areas of your mouth that are usually affected include the inner cheeks, the sides, underside of your tongue and the back of your throat. Your throat may become very sore and it may be very painful swallowing. You may have difficulty opening your mouth. This is a crucial time where mouth care is very important. Your nurse will advise you on the appropriate mouth care regime.

You will also be monitored for mucositis affecting your oesophagus, digestive tract and bowel which can manifest as pain, discomfort, indigestion, and diarrhoea. Your mouth and throat will be examined everyday.

**Tips for the Prevention of Oral Mucositis**

- **Good mouth care helps to reduce**
  ~ Risk of infection
  ~ Severity and duration of oral pain and bleeding
  ~ Duration of intravenous feeding and hospitalisation

- **Basic oral care**
  Keeping your mouth healthy is important part of mucositis management. Your doctors and nurses will assess your mouth for pain and other problems regularly. Basic oral care includes:
  ~ Twice daily teeth brushing using a soft toothbrush that is replaced regularly, unless otherwise instructed by your doctor
  ~ Frequent rinsing after meals and before bedtime
  ~ Keeping your lips moist with a water-based moisturiser (white soft paraffin)

- **Frequent mouth rinsing**
  After brushing, rinse your mouth thoroughly using the ballooning and sucking motion of the cheeks for at least 30 seconds. This action helps to remove loose debris from the teeth.

Various commercially available mouthwashes may be used. However, avoid mouthwashes containing alcohol. Salt-water mouthwash (normal saline) may help with healing if you do develop a sore mouth. Frequent rinsing for at least 4 times a day after each meal and before bedtime is important.

- **Ice or cryotherapy**
  Treatment with ice can reduce mucositis if you receive certain types of chemotherapy, such as melphalan. You may be advised to hold ice or ice water in your mouth for 15 minutes before, during and after your chemotherapy infusion.

- **Dietary**
  Spicy, acidic (citrus fruits and tomatoes) or hard food (dry cereals) may irritate the mouth and damage the mouth linings or gums.

**Management of Oral Mucositis**

Management of mucositis is usually means controlling the symptoms and providing support for your oral intake. Your doctors will assess your pain score (using a scale of 1 to 10) and oral condition daily.

Medication will be initiated to help relieve the symptoms. You should continue to maintain basic oral hygiene and mouth rinsing during this period. Frequent mouth rinsing with saltwater (normal saline) may be necessary. Once symptoms resolve, your frequency of mouth rinsing may be reduced, and ultimately discontinued.
• Commercial mouthwashes
  ~ Caphosol® is a supersaturated aqueous salt solution resembling human saliva used as an oral rinse in mucositis
  1. Supplied in 2 solutions of 15 ml each; blue container (A) and clear container (B)
  2. Combine the contents of the containers in a glass, swirl and mix well
  3. Swish and gargle half the solution for 1 minute, and spit out
  4. Repeat with the other half of the solution

~ Biotene®, OralSeven® mouthwashes contain antibacterial enzymes that kill bacteria involved in inflammation of the mouth and gums.
  1. Supplied in a flip-top closure bottle
  2. Swish and gargle 15 ml for 1 minute then spit out

• Oral care protocol during HSCT
Mouth rinsing will be initiated on the first day of your chemotherapy. You can follow the recommended oral care protocol regime below.

Normal saline 30 ml 4 times a day (Breakfast, Lunch, Dinner, Bedtime)
Biotene® or OralSeven® 15 ml 4 times a day OR Caphosol® 30 ml 4 times a day
Swish the mouthwash for 30 seconds to 1 minute (using the ballooning and sucking motion) then spit it out. Repeat this step after each meal (breakfast, lunch, dinner) and at bedtime.

Avoid using different mouth rinses within 15 minutes of each other. Avoid eating and drinking for at least 15 minutes after use.

Inform your doctor if you experience any mouth sore or ulcers during treatment.

At the first symptoms of mucositis:
Increase normal saline mouthwash rinsing to every 2 hours (7AM, 9AM, 11AM, 1PM, 3PM, 5PM, 7PM, 9PM & 11PM).

Continue to use commercial mouthwash after each meal and at bedtime (7 AM, 1PM, 7PM, 11PM).

Mouth rinsing can be discontinued if there are no symptoms or signs of mucositis.

Dissolved paracetamol tablets, morphine mixture and topical drugs (which can be applied to the sore area) can help to reduce the pain. If the pain becomes more severe, stronger drugs like morphine can be given through your CVC or as a slow release skin patch which slowly releases pain relief medication through your skin.

Nausea and vomiting
Nausea and vomiting are common problems that you may experience during and after conditioning therapy. These result from direct irritation to the gastrointestinal tract, as well as from stimulation of an area of the brain that triggers vomiting. Nausea and vomiting may also result from other medicines especially some antibiotics or graft–versus host disease.

There are many medicines that can help control nausea and vomiting (anti-emetics) and they are generally well controlled. You will receive anti-emetics on a regular basis when your conditioning starts and for a few days after completion. This can be given as a tablet or as an injection through your CVC.

Granisetron and/or dexamethasone will be given approximately 30 minutes before chemotherapy and radiation therapy to prevent nausea and vomiting. If you experience nausea, please inform your nurses immediately so that additional anti-vomiting medicines can be prescribed for you, as it will be harder to control once you have started vomiting. Other medication that may be used to help prevent or control nausea include metoclopramide, diphenhydramine, and lorazepam.

Lorazepam is a mild sedative which helps you stop feeling sick. It may also help you relax and even make you a little sleepy. Your team will work out which ones are best for you to use.

Don’t be too concerned if you are unable to eat or drink much at this time. The doctors and nurses will closely monitor your condition every day. They may decide to give you some additional fluid through a vein to stop you becoming dehydrated if the nausea and vomiting become severe.

Intravenous nutrition therapy known as “Total Parental Nutrition” may be started if you develop severe mucositis or are unable to take food /drink due to nausea.

Tips on coping with nausea and vomiting:
• Take anti-emetics as prescribed
• Have smaller meals more frequently during the day, rather than fewer large ones
• Take oral nutritional supplements as suggested by your dietitian
• Avoid strong and offensive smells
• Don’t go for long periods without eating or drinking, as this may make your nausea worse
• Do gargle more frequently; make sure your mouth is clean and refreshed.
Altered bowel habit

- **Diarrhoea**
  
  Chemotherapy and radiotherapy can cause damage to the lining of your bowel wall. This may lead to cramping, wind, bloating and/or diarrhoea. Be sure to tell your nurses and doctors if you experience any of these symptoms.

  When you develop diarrhoea, your nurse will collect a specimen to be tested in the laboratory to look for infections in your bowel. You will be given anti-diarrheal medication to help to stop the diarrhoea and relieve any discomfort you may be feeling. You will be monitored closely as severe diarrhoea can cause dehydration. Intravenous fluids and electrolytes will be started to replace the lost fluids and to rehydrate you.

  Your perianal area can become quite sore if you are having diarrhoea. ‘Baby wipes’ are gentler and less abrasive than toilet paper for cleaning your bottom at this time. Alternatively, we recommend the use of the shower spray to clean your perianal area after opening your bowels. You may also benefit from applying a barrier cream to help to protect the skin around your anus. It is important to inform your nurses and doctors if you experience any pain over the anal area as this area is prone to infection. You will be given analgesic gels to relieve the pain and antibiotics if necessary.

**Tips on coping with diarrhoea:**

- Take anti-diarrhoeal medication only if prescribed
- Limit food that may cause diarrhoea or make it worse, for example foods high in fibre such as cereals, spicy food, peas, beans
- Drink plenty of liquids, such as water and oral nutritional supplements
- Try isotonic drinks and/or oral replacement salts to replace electrolytes

- **Constipation**

  Your medication (e.g. some chemotherapy and pain relief drugs), changes in food and liquid intake and lack of mobility for long periods can slow bowel function and cause constipation. Be sure to tell the BMT team if your bowels are not working as regularly as they normally would, if you are experiencing any discomfort or tenderness around your anus when you are trying to move your bowels or if you have had previous problems with haemorrhoids (piles).

  Increasing the amount of fibre and fluids in your diet and having some regular exercise (if your condition permits) can help prevent constipation. Sometimes a gentle oral laxative is required to help soften the bowel motion. You should not use suppositories.

  You can increase your fibre intake by adding some of the following foods to your diet:
  
  - Wholegrain food products such as oats, wholemeal bread and brown rice
  - Hard skinned fruits, vegetables, or pasteurised packet fruit juices

  Your doctor may prescribe fibre supplements and you should drink plenty of water.

Altered taste and smell

Both chemotherapy and radiation therapy may cause temporary changes to your sense of taste and smell. You may find that you cannot tolerate some foods or certain smells during your treatment. It can take some time for your sense of taste and smell to return to normal. In the meantime you could try to improve the taste and smell by trying some of the suggestions below.

- Keep your mouth clean and fresh (gargle after meals and before sleep)
- Enhance the taste of food by adding a little more sugar or salt
- Avoid smells you find unpleasant
- Use plastic utensils if some foods taste metallic
- Choose a different type of food if you develop a strong dislike for particular items. However you should try and keep your diet as balanced as possible. Your dietitian will be able to assist you to meet your daily dietary requirements.

Tiredness and lethargy

Conditioning therapy can cause tiredness and lethargy. You may wish to maintain your independence while in hospital but it is often difficult to be totally independent when you are feeling unwell. It is common to have moments, or even days, when you don’t feel like doing anything and would rather depend on your nurse or your carer to help you.

You may feel more tired than usual during the days (and weeks) following your transplant. Initially, you may find it difficult to concentrate on reading, watching television or even keeping up with a conversation. You may be also feeling mentally exhausted as a result of the huge emotional and physical build up to the transplant. This is very normal and it may take 6 months to a year before you feel relatively normal again.

It is important to listen to your body and make sure that you have enough rest during the day, for example, you may take short afternoon power naps. Apart from getting adequate rest there are some things you can do which may give you more energy and reduce your feeling of lethargy.

- Take some gentle exercise or physical activity regularly. As well as making you feel better and less lethargy, exercise can give you more energy and help you improve your muscles tone. Seek help or advice from your physiotherapist about some suitable exercise
- Eat small nutritious meals frequently
- Choose high protein, high energy food throughout the day.
- Drink plenty of fluids e.g. water, high energy/fortified drinks or oral nutritional supplements. Your dietitian will be able to recommend the appropriate choices depending on your requirements.

If you don’t feel like having visitors, please let your nurses know.

Exercise can help prevent or minimize muscle loss from bed rest and lack of mobility. It also helps to promote feeling of wellness and enhance physical comfort.
Fluid gain
During your treatment, especially when you are receiving large volumes of intravenous fluids, you may find that you put on weight. This is usually due to water retention and is easily treated with diuretics i.e. drugs that make you pass more urine. These drugs can be given through your CVC as an injection or as a tablet orally. They take about 30 minutes to an hour to start working and the effect usually wears off after about four to six hours.

Weight loss
During your transplant, weight loss may not be significant but you will find that your appetite decreases. Small frequent meals may be beneficial and you will be closely monitored by your dietitian who will ensure that you receive adequate nutrition. You will be advised on the appropriate oral nutrition supplements suitable for you. These will provide calories, protein and nutrients essential for your recovery. Your weight will be monitored closely. If you continue to lose weight either through loss of appetite or mucositis, total parental nutrition (TPN) may be started via your CVC. Each bag of TPN contains sufficient nutrients and calories that you need to maintain your nutritional status. If you are able to eat or drink while on TPN, you may do so. TPN, like everything else, is not without its own drawbacks and will be discontinued once you are able to eat, drink and maintain your nutritional status.

Pain
Mucositis can be very painful. It is not the kind of pain that will go away completely with painkillers but painkillers will make you more comfortable. There are different ways these drugs can be given to you:
- Orally- tablets or liquid
- Topical- slow release patch
- Intravenously

The mucositis and the pain are temporary and will improve once you engraft. However this may take several days. Mouth care is crucial during this period to help to reduce the risk of infection and to help your mouth heal faster.

Veno–occlusive disease (VOD)
VOD is a condition in which the small blood vessels within your liver become damaged and obstructed. This leads to a yellowing of your skin and eyes (jaundice), retention of water, distension of your abdomen, weight gain and pain or tenderness over your liver (the right side of your abdomen). You will be closely monitored for this complication. If you are at high risk for this complication, you may receive a preventive medication called ursodeoxycholic acid to reduce this risk. Sometime a drug called defibrotide maybe used if you are at very high risk. Defibrotide is also used for the treatment of VOD.

Kidney problems
Your kidneys filter your blood and removes waste products, drugs and excess water from your body. Many factors can affect the function of your kidneys, including your previous treatment, many of the medication used in transplantation, especially ciclosporin, and medical conditions like veno–occlusive disease (VOD) and rarely TTP (thrombotic thrombocytopenic purpura).

Unless your doctor advises you otherwise, you should drink plenty of water every day.

Graft versus Host Disease
Graft versus host disease (GvHD) is a potential complication of allogeneic HSCT. The conditioning chemotherapy suppresses your immune system to stop your body from rejecting the donor stem cells. Once the donor stem cells begin to engraft and function as your new immune system, the donor T–lymphocytes of your new immune system (graft) may see your own body (host) as foreign and try to destroy your tissues and organs. Acute GvHD, which usually starts within 100 days of transplant, commonly appears as a skin rash, diarrhoea (green stools), unexplained nausea & vomiting, mouth ulcers, dry mouth, dry red eyes, abnormal liver tests, shortness of breath etc. The symptoms can be very variable and you should let your transplant team know about any new problems.

Chronic GvHD starts after 100 days and may give rise to similar symptoms.

Mild acute or chronic GvHD may not require any treatment. Having some GvHD reduces significantly your risk of relapse. Drugs are given to reduce the risk of severe GvHD as described below. Steroids may be needed if you develop GvHD that requires treatment.

Immunosuppressants are effective in minimising and controlling GvHD. Drugs such as ciclosporin, tacrolimus, mycophenolate and methotrexate are given to reduce the ability of your donor T–cells to attack your tissues and organs.

Some of these drugs will be given from Day–3 of your transplant and continued for about three to nine months after your transplant. The combination, dosage and duration of medication will depend on the type of HSCT as well as the grade and stage of GvHD if present.

Anti–thymocyte globulin (ATG) (Thymoglobuline®)
ATG is a solution of antibodies. Antibodies are proteins made by immune system cells (B–lymphocytes and plasma cells) that attach to specific bacteria, viruses, cells etc. Each antibody can only attach to and destroy one specific target.

Thymoglobuline® is made by injecting human thymus cells (T–cells) into rabbits. It contains antibodies which attach to and destroy some of the cells of your immune
system. It may be given to you as part of your conditioning therapy to reduce the risk of GVHD and graft rejection.

Thymoglobuline® is given as an infusion through your CVC over at least 6 hours. Fever, chills, rigors and rashes are extremely common during its administration and occasionally more serious side effects may be experienced. You will receive premedication with steroids, paracetamol and Benadryl® before the infusion starts to reduce the risk of these side effects.

Occasionally you may experience “serum sickness”. This is an illness caused by antibodies against Thymoglobuline® resulting in rash, itching, joint pains, kidney problems and swollen lymph nodes. It typically develops within 6–21 days. It is usually mild and goes away without treatment or with a short course of steroids.

Ciclosporin (Neoral®)
Ciclosporin is an immunosuppressive drug that prevents GVHD by slowing down the growth and development of the donor T-cells. It is started a few days before the stem cell infusion and is usually continued until about day +60 when, if there is no evidence of GVHD, the dose will be decreased slowly so that it is stopped 6–9 months after your transplant.

Initially it may be given as an intravenous infusion twice daily over 2–6 hours. It will be changed to oral capsules or solution twice a day when you can eat and drink normally.

• Proper Use of This Medicine
Ciclosporin is available as 10 mg, 25 mg, 100 mg capsules and as an oral solution. You will usually need to take the medicine twice a day, preferably on an empty stomach. To help you to remember to take your medicine, try to get into the habit of taking it at the same time each day and in relation to your meals. This will also help ciclosporin work better by keeping a constant amount in the blood.

Do not stop taking this medicine, change the amount you take, or change the brand of ciclosporin without first checking with your doctor. Absorption of this medicine may be changed if you change your diet. This medicine should be taken consistently with respect to meals. You should not change the type or amount of food you eat unless you discuss it with your doctor. If this medicine upsets your stomach, your doctor may recommend that you take it with meals. Check with your doctor before you decide to do this on your own.

Some herbs, grapefruit (and grapefruit juice) and pomelo have been shown to increase the effects of ciclosporine by increasing the amount of this medicine in the body. In addition, pineapples and papayas (and their juices) may prevent ciclosporine from working effectively. You should avoid these fruits and their juices while you are taking this medicine. Check with your physician or pharmacist before starting on any herbs or supplements.

• Dosing
The dose of ciclosporin will be different for different patients. Blood ciclosporin levels will be performed regularly to enable your doctors to adjust your dose. Follow your doctor’s orders or the directions on the label. On the day when you are due for a ciclosporin level test on your blood, do not take ciclosporin before the blood is collected. You should bring the medicine to the hospital to take after the blood test.

• Missed dose
If you miss a dose of ciclosporin and remember it within 6 hours, take the missed dose as soon as you possible. However, if it is almost time for the next dose, skip the missed dose, go back to your regular dosing schedule, and check with your doctor. Do not double the dose.

• Precautions
Ciclosporin makes you more susceptible to infections. Avoid people with contagious diseases, such as flu and colds. If you think you are getting an infection (signs of infection include fever, sore throat, cough, pain during urination, muscle aches, mouth sores), check with your doctor. If you are exposed to chicken pox, measles, or tuberculosis (TB) while taking ciclosporin, inform your doctor immediately.

After your transplant, you may need to receive various vaccinations. It is important that you do not receive any other vaccinations without consulting your transplant doctor. This is because ciclosporin lowers your body’s resistance, and therefore there is a chance you may get the infection that the immunization is meant to prevent. In some patients (usually younger patients), tenderness, swelling, or bleeding of the gums may appear soon after treatment with ciclosporin is started. Maintaining good oral hygiene may help prevent this.

• Side Effects
This medicine may cause some unwanted effects. Your doctor will monitor you closely for the following possible side effects:

More common
~ High blood pressure
~ Kidney damage: it is important for you to maintain good fluid intake to minimise this risk
~ Decreased magnesium levels in the blood, requiring magnesium supplements
~ Increased facial hair growth

Less common
~ Liver problems
~ High blood sugar
~ High blood cholesterol
Tell your doctor if any of these symptoms are severe or do not go away:
~ Stomach discomfort
~ Diarrhoea
~ Vomiting
~ Loss of appetite
~ Tremors
~ Overgrowth of the gums
~ Increased facial hair growth
~ Decreased urination
~ Swelling (feet, ankles, lower legs, and hands)
~ Weight gain

If you experience any of the following symptoms, let your doctor know immediately:
~ Unusual bleeding or bruising
~ Yellowing of the skin or eyes
~ Seizures or confusion

Tacrolimus (Prograf®)
Tacrolimus belongs to the same family of immunosuppressive drugs as ciclosporin. It prevents acute GVHD by slowing down the growth and development of donor T-cells. It is usually used in place of ciclosporin, if you are not able to tolerate ciclosporin or develop graft–versus–host disease while on ciclosporin. As with ciclosporin, it may be continued until about day +60 when, if there is no evidence of GVHD, the dose may be decreased slowly so that it is stopped by about six to nine months after your transplant.

- Proper Use of This Medicine
  Tacrolimus is available as 0.5 mg, or 1 mg capsules. You will usually need to take the medicine 2 times a day, preferably on an empty stomach. To help you remember to take your medicine, try to get into the habit of taking it at the same time each day and in relation to your meals. This will also help tacrolimus work better by keeping a constant amount in the blood. Do not stop taking this medicine, change the amount you take or change the brand of this medication without first checking with your doctor.

  Absorption of this medicine may be changed if you change your diet. This medicine should be taken consistently with respect to meals. You should not change the type or amount of food you eat unless you discuss it with your health care professional. If this medicine upsets your stomach, your doctor may recommend that you take it with meals. However, check with your doctor before you decide to do this on your own.

  Some herbs, grapefruit (and grapefruit juice) and pomelo have been shown to increase the effects of tacrolimus by increasing the amount of this medicine in the body. You should not eat grapefruit, pomelo or drink grapefruit juice while you are taking this medicine. Check with your physician or pharmacist before starting on any herbs or supplements.

- Dosing
  The dose of tacrolimus will be different for different patients. Blood tacrolimus levels will be checked regularly to enable your doctors to adjust doses accordingly. Follow your doctor’s orders or the directions on the label. On the day when you are due for a check tacrolimus level, do not take tacrolimus before the blood is collected. You should bring the medicine to the hospital to take after the blood test.

- Missed dose
  If you miss a dose of tacrolimus and remember it within 6 hours, take the missed dose as soon as you remember. However, if it is almost time for the next dose, skip the missed dose, go back to your regular dosing schedule, and check with your doctor. Do not double the dose.

- Precautions While Using This Medicine
  Tacrolimus makes you more susceptible to infections. Avoid people with contagious diseases, such as flu and colds. If you think you are getting an infection (signs of infection include fever, sore throat, cough, pain during urination, muscle aches, mouth sores), check with your doctor. If you are exposed to chicken pox, measles, or tuberculosis (TB) while taking tacrolimus, inform your doctor immediately.

  After your transplant, you may need to receive various vaccinations as planned by your doctor. It is important that you do not receive any other vaccinations without consulting your doctor. This is because tacrolimus lowers your body’s resistance, thus there is a chance you might get the infection that the immunization is meant to prevent.

  Tacrolimus may cause your skin to be more sensitive to sunlight. Avoid excessive exposure to sunlight and ultraviolet (UV) light. Wear protective clothing and sunscreen with a high protection factor.

- Side Effects
  Tacrolimus may cause the following side effects that your doctor will watch for:
  More common
  ~ High blood pressure
  ~ Kidney damage: it is important for you to maintain good fluid intake to minimise the risk
  ~ Decreased magnesium levels in the blood, requiring magnesium supplements

  Less common
  ~ Liver problems
  ~ High blood sugar
  ~ High blood cholesterol
Tell your doctor if any of these symptoms are severe or do not go away:
~ Stomach discomfort
~ Vomiting
~ Diarrhoea
~ Loss of appetite
~ Tremors
~ Decreased urination
~ Swelling (feet, ankles, lower legs, and hands)
~ Unusual weight gain

If you experience any of the following symptoms, let your doctor know immediately:
~ Unusual bleeding or bruising
~ Yellowing of the skin or eyes
~ Seizures or confusion

Mycophenolate (Cellcept® or Myfortic®)
Mycophenolate is a drug which inhibits the formation of B and T lymphocytes. This reduces the risk of GvHD. It is usually given by mouth or as an intravenous infusion if you are not able to swallow. You may be required to take this medicine until about day +40 when, if there is no evidence of GvHD, the dose will be decreased slowly so that it is stopped by about 80 days after your transplant.

• Proper Use of This Medicine
You may be given Mycophenolate either in the form of Cellcept® or Myfortic®. Cellcept® is available as 250mg capsule or 500mg tablets and will usually have to be taken 2 to 3 times a day. Myfortic® is available as 180mg or 360mg tablets and will usually have to be taken 2 times a day.

This medicine should be taken on an empty stomach. To help you remember to take your medicine, try to get into the habit of taking it at the same time each day. Do not stop taking this medicine or change the amount that you take daily without first checking with your doctor.

• Dosing
The dose of mycophenolate will be different for different patients. Follow your doctor’s orders or the directions on the label.

• Missed dose
If you miss a dose of mycophenolate and remember it within 12 hours, take the missed dose as soon as you remember. However, if it is almost time for the next dose, skip the missed dose, go back to your regular dosing schedule, and check with your doctor. Do not double the dose.

• Precautions While Using This Medicine
The capsules or tablets of mycophenolate should be swallowed whole. The tablets should not be crushed and the capsules should not be opened because it is important that other people not be exposed to mycophenolate powder.

If you are taking any magnesium supplements or antacids containing magnesium and/or aluminium, you should space them out from mycophenolate by at least 2 hours.

Mycophenolate may cause your skin to be more sensitive to sunlight. Avoid excessive exposure to sunlight and ultraviolet (UV) light. Wear protective clothing and sunscreen with a high protection factor.

• Side Effects of This Medicine
Although side effects from mycophenolate are not common, they can occur. Tell your doctor if any of these symptoms are severe or do not go away:
~ Diarrhoea
~ Vomiting
~ Stomach pain
~ Headache
~ Insomnia
~ Dizziness

If you experience any of the following symptoms, inform your doctor immediately:
~ Blood in your vomit, diarrhoea or black, tarry stools
~ Fever
~ Unusual bruising or bleeding
~ White patches in mouth or throat

Methotrexate (MTX)
Methotrexate impairs the ability of the transplanted T-cells to attack your organs and tissues. It is usually given as an intravenous injection on days +1, 3, 6 and 11.

Common side effects include:
• Bone marrow suppression
• Mouth and/or throat ulcers – doses may be withheld if your mouth is too sore
• Sensitivity to sunlight – a rash may develop
• Impaired liver function

Less common side effects include:
• Acne, itchiness and skin rash
• General tiredness
**Fever**

Fever will be common during your transplant admission. These are most commonly due to neutropenic infections or certain medication such as Anti-thymocyte globulin (ATG).

Infections are the most common life-threatening complication of HSCT. It is very important that you take precautions to reduce the risk of infection and remain alert to early signs of infection. Treatment can then be started as early as possible. This is especially important for patients who are neutropenic.

**Signs and symptoms of an infection include:**
- fever – body temperature of more than 38°C
- sore throat
- persistent cough or shortness of breath
- runny and/or blocked nose
- frequent urination and/or a burning sensation during urination
- shaking chills
- redness, swelling, or warmth at the catheter insertion site or any site
- diarrhea

When you develop a fever, you will have blood and urine taken for testing. An intravenous antibiotic will be given to you immediately after blood has been taken as neutropenic infections can quickly become life threatening. You may also require x-rays or CT scans.

- **Bacterial Infections**
  
  Bacteria are microscopic organisms that can cause infection anywhere in the body. They are responsible for the majority of infections in people undergoing HSCT, especially during the period of neutropenia.

  Bacterial infections are most common in the first 2–4 weeks after HSCT. These infections most often affect the bloodstream, the lungs (pneumonia), the gastrointestinal tract (gut) and the skin (especially around a central line). Most are caused by bacteria which are already living in your gut or skin.

  Bacteria can cause life threatening infections. Antibiotics to reduce the risk of bacterial infections will be given. While in the hospital, you will be monitored closely for fever and appropriate intravenous antibiotics will be started once you develop any symptoms or signs of an infection. After discharge, it is important to seek immediate medical attention if you develop a fever.

- **Viral Infections**
  
  Most viral infections in people with very low white blood cell counts are caused by herpes simplex virus (HSV, the virus that causes cold sores and genital herpes), varicella–zoster virus (VZV, the virus that causes chickenpox) and cytomegalovirus (CMV).

  a. Herpes simplex virus (HSV) causes mild infections in people with a healthy immune system. However it can remain inactive in nerve cells and become reactivated in patients with weakened immune system, causing mouth ulcers and cold sores.

  b. Varicella–zoster virus (VZV) is the virus that causes chickenpox and shingles. It can cause serious infections in people undergoing HSCT. Like HSV, VZV infection is never completely eradicated after an episode of chickenpox. Some of the virus remains inactive in the nerve cells. If the person’s immune system is weakened years later, the virus can be reactivated causing a condition known as shingles. People with this condition have painful blisters along their nerves on the skin. The virus may also affect other organs. The virus present in the blisters may infect another person and cause chickenpox.

  c. Cytomegalovirus (CMV) infection in healthy people is usually not serious and are usually “silent” – meaning most people who are infected with CMV have no signs or symptoms. However, the virus then goes to sleep within the body. When the immune system is weakened, e.g. after a transplant, the CMV virus can start dividing (reactivation) and may cause serious infection, blindness and death if untreated.

  You will need regular blood tests to check for any evidence of CMV reactivation or infection. If this is found, you will need treatment. This is a common cause of hospital re-admission after your transplant. The drugs commonly used to treat CMV include foscarnet and ganciclovir.

  d. BK virus (BKV) is a virus that may be present in the urinary tract. In healthy people it is usually suppressed by the immune system. In immunocompromised patients who have undergone chemotherapy or transplantation, the virus multiplies rapidly and may cause tissue damage in the urinary tract and blood in the urine. In some cases, the virus may affect the kidneys.

- **Pneumocystis infections**
  
  These organisms don’t usually cause problems for people with a normal immune system. In patients with a weakened immune system, they may invade the lungs causing difficult-to-treat life-threatening infections. You will be on medication to reduce the risk of this infection.

- **Fungal infections**
  
  In humans, fungi live in balance with other microbes in the body without causing symptoms or tissue damage. However, a fungal infection can occur when there is damage to the skin or mucous membranes, or during prolonged periods of neutropenia or weakened immune system. Fungal infections can be serious and even fatal and you will be on medication to reduce the risk of these infections.
Growth factors
You will usually receive a drug called G-CSF (Neupogen®) from D+3 or D+7. G-CSF is Granulocyte-Colony Stimulating Factor. It encourages your bone marrow to produce neutrophils and can reduce the period of neutropenia by a few days. G-CSF is usually given as an injection beneath the skin (subcutaneous) daily until your neutrophil count is well above 1x10⁹/L. It is then stopped. Often after a transplant, your neutrophil count may fall after stopping G-CSF. In this case you may need further doses intermittently.

Some recipients may experience significant bony aches and pains, especially around the thighs, pelvis, lower back, breastbone and shoulders after G-CSF. A dose of paracetamol usually helps with this, but if severe, stronger pain killers or stopping G-CSF may be necessary.

Graft rejection/failure
Sometimes the transplanted cells fail to grow. The risk of this varies from 5–15% depending on the conditioning treatment, the source and dose of stem cells. If there are no signs of neutrophil recovery after 21–28 days a bone marrow biopsy will usually be performed. Tests will be done to look at the proportion of donor cells present. If necessary, further stem cells may be given. Your transplant doctor will discuss this with you in detail should it occur.

Graft versus tumour effect– Graft versus Leukaemia/Lymphoma (GvL)
The graft-versus-tumour effect refers to the ability of the donor’s immune system cells to recognise and destroy any remaining disease cells. This reduces the risk of relapse significantly. GvL may be associated with GvHD, but one may exist without the other. GvL is desirable, but is suppressed by the immunosuppressive drugs and cannot fully develop until all immunosuppressive medication has been stopped.

INFECTION PROPHYLAXIS
As your immune system will be heavily suppressed, you will be prescribed antibiotics, antivirals and antifungals to reduce your risk of infection. You should work these into your routine as you will need to continue on some of these for many months post-transplant. If you are unable to swallow them, your doctor may use an alternative.

Ciprofloxacin and levofloxacin – antibiotics
Ciprofloxacin and levofloxacin belong to a class of antibiotics called fluoroquinolones. They are used to treat infections caused by certain bacteria. For HSCT patients, they are also used to prevent bacterial infections especially during the period of neutropenia. In addition, ciprofloxacin is useful against a virus called BK virus which may cause serious problems such as blood in the urine and kidney injury.

You will be required to take this medicine for up to 56 days after undergoing a HSCT. You may be able to stop this medicine earlier if BK virus is not detected in your body. The usual dose is 1 tablet (500 mg per tablet) 2 times daily, with or without food. However, the dose may be adjusted according to your condition. It is important that you follow the instructions on the label.

Precautions While Using This Medicine
If you are taking antacids containing aluminum hydroxide or magnesium hydroxide; calcium, iron or zinc supplements; or multivitamins with minerals, you need to separate ciprofloxacin from these medicines by at least 2 hour as they may reduce the effectiveness of ciprofloxacin.

What Side Effects Can This Medication Cause?
Although side effects from ciprofloxacin are not common, they can occur. Tell your doctor if any of these symptoms are severe or do not go away:
• Nausea
• Vomiting
• Stomach pain
• Heartburn
• Diarrhea
• Headache

If you experience any of the following symptoms, call your doctor immediately:
• Pain, swelling, tenderness, stiffness, or difficulty in moving a muscle
• Rapid, irregular, or pounding heartbeat
• Skin rash
• Breathlessness, chest tightness, swelling of face, lips, tongue, or throat.
• Severe diarrhea (watery or bloody stools)

Important
• To reduce the risk of bacterial infections and serious BK virus infections, it is very important that you keep taking this medicine for as long as your doctor instructs you to.
• If you miss a dose of this medicine, take it as soon as possible. This will help keep a constant amount of medicine in the blood. However, if it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double the dose.

Aciclovir – anti-viral
Aciclovir belongs to a family of medicines called anti-virals, which are used to treat infections caused by viruses such as chickenpox and herpes. You will be receiving aciclovir in order to reduce the risk of infections caused by:
1) Herpes simplex virus reactivation (cold sores and genital herpes)
2) Varicella–zoster virus reactivation causing shingles (clusters of tiny, painful blisters along the path of nerves on the skin)

Aciclovir is available in both 200 mg and 400 mg tablets. You may be required to take this medication for up to 12 months after an autologous or an allogeneic HSCT. The usual dose is 2 tablets (400 mg per tablet) 2 times daily. However, the dose may be adjusted according to your condition. It is important that you follow the instructions on the label.
What Side Effects Can This Medication Cause?
Although side effects from aciclovir are not common, they can occur. Tell your doctor if any of these symptoms are severe or do not go away:

- Headache
- Stomach discomfort. Taking aciclovir with food may help reduce discomfort.
- Vomiting
- Diarrhea or loose stools

If you experience any of the following symptoms, call your doctor immediately:

- Severe rash
- Severe itching
- Fever
- Confusion
- Yellowness of the skin or eyes
- Blood in the urine
- Stomach pain

Important
- To reduce the risk of these viral infections, it is very important that you keep taking this medicine for as long as your doctor instructs you to.
- If you miss a dose of this medicine, take it as soon as possible. This will help keep a constant amount of medicine in the blood. However, if it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double the dose.
- If you notice any unusual sores on your mouth, skin or genitals, please check with your doctor.

Co-trimoxazole (sulfamethoxazole and trimethoprim) – anti-pneumocystis Co-trimoxazole (Sulfamethoxazole and Trimethoprim) commonly known as Bactrim® is used for the prevention of pneumocystis carinii pneumonia (PCP) which may occur in patients who have undergone HSCT.

You may be required to take this medication for up to 6 months after undergoing a HSCT. The usual dose is 2 tablets (480 mg per tablet) 2 times daily on weekends (Saturdays and Sundays), starting after you have engrafted. However, the dose may be adjusted according to your condition. It is important that you follow the instructions on the label.

Precautions While Using this Medicine
The presence of other medical conditions may affect the use of sulfonamide and trimethoprim combinations. Make sure you tell your doctor if you have any other medical problems.

What Side Effects Can This Medication Cause?
Although side effects from co-trimoxazole are not common, they can occur. The commonest of these is a skin rash. You should stop taking co-trimoxazole immediately should this occur and inform your doctor.

Tell your doctor if any of these symptoms are severe or do not go away:

- Stomach discomfort. Taking co-trimoxazole with food may help reduce discomfort.
- Vomiting
- Loss of appetite

If you experience any of the following symptoms, call your doctor immediately:

- Skin rash or itching
- Fever or chills
- Unusual bruising or bleeding
- Yellowing of the skin or eyes
- Joint aches

Important
- To reduce the risk of contracting PCP, it is very important that you keep taking this medicine for as long as your doctor instructs you to.
- If you miss a dose of this medicine, take it as soon as possible. This will help keep a constant amount of medicine in the blood. However, if it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double the dose.

Dapsone – anti-pneumocystis
Dapsone is an antibiotic that can be used as an alternative to co-trimoxazole for the prevention of PCP. This is usually used in patients who are allergic to co-trimoxazole. You may be required to take this medication for up to 6 months after undergoing a HSCT. The usual dose is 1 tablet (100 mg per tablet) once daily, starting after you have engrafted. However, the dose may be adjusted according to your condition. It is important that you follow the instructions on the label.

Precautions While Using This Medicine
The presence of other medical conditions may affect the use of dapsone. Make sure you tell your doctor if you have any other medical problems.

What Side Effects Can This Medication Cause?
Although side effects from dapsone are not common, they can occur. Tell your doctor if any of these symptoms are severe or do not go away:

- Stomach discomfort. Taking dapsone with food may help reduce discomfort.
- Vomiting

If you experience any of the following symptoms, call your doctor immediately:

- Sore throat
- Fever
- Rash
- Yellowing of the skin or eyes
- Unusual bruising
Important

- To reduce the risk of PCP, it is very important that you keep taking this medicine for as long as your doctor instructs you to.
- If you miss a dose of this medicine, take it as soon as possible. This will help keep a constant amount of medicine in the blood. However, if it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double the dose.

Pentamidine inhalation – anti-pneumocystis

Pentamidine is an anti-infective agent that helps to prevent (when used as a nebulisation) or treat (when given intravenously) PCP.

Pentamidine is available as a solution to be inhaled using a nebuliser system known as Respigar®. Inhalation of pentamidine delivers the drug directly to your lungs. You will need to receive this inhalation before the transplant and once every month for up to about 6 months after undergoing a HSCT.

Precautions While Using this Medicine

Pentamidine inhalation may cause irritation to your airways and cause difficulty in breathing. An inhalation form of salbutamol (an airway dilator) will be given at least 5 to 10 minutes before pentamidine inhalation to reduce airway irritation.

A bitter or metallic taste may be experienced during and after the inhalation of this medicine. Sucking on a hard candy after each treatment can help reduce this problem.

What Side Effects Can This Medication Cause?

Although side effects from pentamidine are not common, they can occur.

Tell your doctor if any of these symptoms are severe or do not go away:
- Fatigue
- Metallic taste
- Cough
- Dizziness, lightheadedness or faintness
- Burning sensation in your throat
- Decreased appetite

If you experience any of the following symptoms, call your doctor immediately:
- Chest pain
- Shortness of breath or difficulty breathing
- Skin rash
- Confusion or slurred speech

Important

- To reduce the risk of PCP, it is very important that you keep using this medicine for as long as your doctors instructs you to. It will be helpful for you to remind your doctors to prescribe your pentamidine inhalation every month.

Itraconazole – anti-fungal

Itraconazole is an antifungal medication that may be taken by patients who have undergone HSCT to prevent fungal infections. These fungal infections may be superficial (e.g. oral thrush) or may affect deep tissues especially the lungs.

You will be required to take this medication until engraftment after an autologous HSCT or longer after undergoing an allogeneic HSCT.

Itraconazole is available as oral solution and oral capsules. The solution form is usually given because it is better absorbed by the body. You will need to take 20 ml (200 mg) of itraconazole solution twice daily, on an empty stomach. If you are not able to tolerate the oral solution, oral capsules may be given instead. You will need to take 2 capsules (100 mg per capsule) three times daily, immediately after food. The dose may be adjusted according to your condition. It is important that you follow the instructions on the label.

Itraconazole capsule may be taken with a cola drink to increase its absorption. If you are also taking antacids, famotidine, ranitidine, or omeprazole, space these medicines from itraconazole capsules by at least 2 hours.

What Side Effects Can This Medication Cause?

Although side effects from itraconazole are not common, they can occur.

Tell your doctor if any of these symptoms are severe or do not go away:
- Stomach discomfort
- Loss of appetite
- Nausea or vomiting
- Altered taste
- Diarrhea or loose stools

If you experience any of the following symptoms, call your doctor immediately:
- Rash
- Yellowing of the skin or eyes
- Dark urine
- Pale stools

Important

- To reduce the risk of life threatening fungal infections, it is very important that you keep taking this medicine for as long as your doctor instructs you to.
- If you miss a dose of this medicine, take it as soon as possible. This will help keep a constant amount of medicine in the blood. However, if it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double the dose.
- Itraconazole will affect the blood levels of most immunosuppressants such as ciclosporin. It is important to keep taking Itraconazole at the instructed dose daily. Inform your doctor or pharmacist of any changes to the dosing schedule or any missed doses.
Posaconazole – anti–fungal
Posaconazole is an antifungal medication that may be taken by patients who have undergone HSCT to prevent fungal infections. These fungal infections may be superficial (e.g. oral thrush) or may occur in deep tissues especially the lungs.

You will be required to take this medication for about a month after undergoing an allogeneic HSCT. Your doctor may switch you to itraconazole after engraftment. Posaconazole is only available as an oral suspension. You will need to take 5ml (200 mg) of it three times daily, after a full meal or liquid nutritional supplements. Shake the bottle well before each use to mix the medication evenly. Posaconazole should be taken at about the same time every day. The dose may be adjusted according to your condition. It is important that you follow the instructions on the label.

What Side Effects Can This Medication Cause?
Although side effects from posaconazole are not common, they can occur.

Tell your doctor if any of these symptoms are severe or do not go away:
• Stomach discomfort
• Nausea or vomiting
• Diarrhea or loose stools
• Headache
• Dizziness and weakness

If you experience any of the following symptoms, call your doctor immediately:
• Rash
• Yellowing of the skin or eyes
• Dark urine
• Pale stools
• Fast, pounding, or irregular heartbeat

Important
• To reduce the risk of life threatening fungal infections, it is very important that you keep taking this medicine for as long as your doctor instructs you to.
• If you miss a dose of this medicine, take it as soon as possible. This will help keep a constant amount of medicine in the blood. However, if it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do not double the dose.
• Posaconazole will affect the blood levels of most immunosuppressants such as ciclosporin, thus it is important to keep taking it at the instructed dose daily. Inform your doctor or pharmacist of any changes to the dosing schedule or any missed doses.

COPING WITH YOUR TRANSPLANT & ISOLATION
During your treatment it is normal to experience a wide range of different emotions. Stress, anxiety, anger and guilt are common experiences. Individuals cope with these emotions in different ways.

You should try to acknowledge your feelings. It is unrealistic to expect yourself to be positive all the time. Be honest about how you feel. Use your strengths and the positive coping skills that have worked for you in the past.

Most patients find the uncertainty of waiting for engraftment stressful. Feelings of isolation and boredom may set in while waiting for your blood counts to recover after transplantation. You are encouraged to be active in your own care. Keeping as active as possible and engaging in different activities may allow you to take your mind off treatment temporarily. During this time, you may want to focus on activities such as exercising, watching television, playing games, reading or writing. You may wish to decorate the wall in front of your bed with photos, posters or notes of encouragement from loved ones or friends to remind you that you are not isolated during your transplant.

Remember you are not alone in your transplant journey. Communicate with your BMT team nurses and doctors. Communicate with your loved ones and encourage them to visit you. Alternatively keeping in touch by phone or internet during your stay may help you cope with the isolation. Share your feelings, worries or problems you may have with your loved one or the transplant team even if they seem minor. This may help lessen your burden and you may find it easier to cope. If you are feeling overwhelmed, let your doctors and nurses know. Asking others to help may actually reduce a sense of helplessness. Let people know exactly what they can do to help you. Medical social workers can assist you with coping strategies and provide support.

Medication and other measures are also available to prevent or lessen the severity of the side effects that you will experience. The transplant team will do whatever is possible to help you feel better. Though coping at this time can be a challenge, be focused on the future and try to remain positive. Remember that laughter is powerful medicine and so is a positive attitude.
IMMOBILITY & THE IMPORTANCE OF EXERCISING DURING TRANSPLANT

During your transplant admission, your level of activity will inevitably be reduced due to many factors. These include isolation, fatigue from the conditioning, transplant and side effects of medication you are on. This would gradually lead to deconditioning, where your muscles become weaker and you have a lower endurance for physical activity. Therefore, establishing an exercise programme during transplant is important.

Types of Exercise
There are in general, 2 types of exercises that you could benefit from. They are:
• Cardiovascular exercises and
• Strengthening exercises.

Cardiovascular exercises are exercises that target your endurance. They help to make sure that you are able to work for a longer time before you feel tired. Please refer below for examples.

Strengthening exercises are exercises that work on your muscle strength. Muscle strength can be improved on in 2 ways – its power and its control. Please refer below for examples.

Tips on exercise level and intensity

<table>
<thead>
<tr>
<th>1–10 Borg rating of perceived exertion Scale</th>
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</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Rest</td>
</tr>
<tr>
<td>1</td>
<td>Really Easy</td>
</tr>
<tr>
<td>2</td>
<td>Easy</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
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<td>4</td>
<td>Sort of Hard</td>
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<tr>
<td>5</td>
<td>Hard</td>
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<tr>
<td>6</td>
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</tr>
<tr>
<td>7</td>
<td>Really Hard</td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Really, Really Hard</td>
</tr>
<tr>
<td>10</td>
<td>Maximal</td>
</tr>
</tbody>
</table>

Your exercise intensity should be between 3 – 4 on the Borg scale shown on the left. Alternatively, calculate your heart rate reserve.

Heart rate reserve (HRR) = (220 – age) – resting heart rate

You should be exercising at 60–80% of your heart rate reserve.

Gradually increase how hard you work and the amount of time you spend exercising.

Examples of Exercises
The following are examples of exercises that would benefit you during your stay in the hospital.

Bed exercises:

Shoulder Flexion
Bring both hands upwards and down again slowly. Keep thumbs pointing upwards.

Repeat 10 times. Perform exercise 3–5 times a day.

Straight Leg Raise
Tighten muscles on front of right thigh, then lift leg from surface, keeping knee locked. Hold for 5–10 counts.

Repeat 5–10 times per set. Do 2–3 sets per session. Perform exercise 3–5 times a day. Repeat exercise on left leg.

Inner Range Quadriceps
With right knee over bolster, straighten knee by tightening muscles on top of thigh. Keep bottom of knee on bolster. Hold for 5–10 counts.

Repeat 5–10 times per set. Do 2–3 sets per session. Perform exercise 3–5 times a day. Repeat exercise on left leg.

Bridging
With both knees bent, slowly raise buttocks from bed. Hold for 5–10 counts.

Repeat 5–10 times per set. Do 2–3 sets per session. Perform exercise 3–5 times a day.
**Exercise Precautions**
Changes in your blood counts during your transplant are expected. Caution should be taken when there is:

- **Decreased level of platelets – thrombocytopenia**
  When platelet levels are low, passive movements (i.e. someone moving your limbs for you) are not recommended due to possible damage to your muscle tissue.

  Exercising guidelines for low platelets:
  - Less than 20 x 10^9/l – Walk in your room with assistance. Active movements only.
  - 20–50 x 10^9/l – Walk in your room. Active exercises but no weight lifting. No stretching/passive exercises.
  - Above 50 x 10^9/l – Generally all programmes are safe.

- **Anaemia (decreased haemoglobin level)**
  When your haemoglobin level is low, dizziness, shortness of breath and increased heart rate may be experienced.

  Exercising guidelines for low haemoglobin
  - Less than 8 g/dl – Do not do your exercises. Daily activities are ok.
  - Between 8 and 12 g/dl – Walk short distances. Do your exercises as tolerated.
  - More than 12 g/dl – Generally all programmes are safe.

  Exercises should not be attempted on your own if you are not feeling well (for example, feeling dizzy, short of breath, having a fever etc.). If in doubt, please consult your doctor or physiotherapist.

  Exercises are not meant to induce pain although muscle aches are common after exercising. These muscle aches should be tolerable and should be resolved within 2–3 days. If you experience pain during your exercises, do consult your physiotherapist.

- **Exercise Log**
  This is an exercise log that could be used to chart your day to day physical activities and exercises.

  - **Date**
  - **Monday**
  - **Tuesday**
  - **Wednesday**
  - **Thursday**
  - **Friday**
  - **Saturday**
  - **Sunday**

  **BLOOD RESULTS**
  - **Hb**
  - **WBC**
  - **Platelets**

  **EXERCISES**
  - **Cardiovascular**
  - **Strengthening**

- **Continuation of exercises after discharge**
  It is very important to continue with your exercises after discharge as this will help to keep your legs strong and improve your endurance. You should try to resume your daily activities as soon as you are able. Exercising in public areas (i.e. gym) or swimming should not be undertaken if your white blood cell or platelet counts are low. If in doubt, consult your doctor.
5. GOING HOME AND RECOVERY

Following your discharge, you will be followed up closely in the Haematology Centre. You will need to be seen at least twice a week initially. This may last for several months following your transplant. You may also need to be re-admitted to the hospital for further treatment.

It may take you 6 to 12 months to regain your energy levels and be able to resume your normal activities. You should plan to be away from work for at least 6–12 months following your transplant.

GETTING READY TO GO HOME

Returning home following your bone marrow transplant will be a very special time for you and your family. You and your family may experience mixed feelings. While you may feel delighted to be escaping from the isolation of the hospital, you may also feel apprehensive and frightened about leaving the security of the transplant unit and the team. This is a natural feeling shared by most the transplant patients. You will be given the transplant unit’s telephone number to call if you need to clarify your concerns. A familiar voice is often reassuring.

Please be assured that your doctor will not be discharging you if you are not fit for discharge. You are ready for discharge when you have an adequate absolute neutrophil count (ANC), your nutritional needs are met, you have no infection or fever and have infrequent blood and platelet transfusions.

You and your primary caregivers will receive complete discharge teaching by your nursing team, dietitian and pharmacist. These include the care of the CVC, medication, diet and its preparation, housekeeping, special precautions as well as other issues about your care at home. You will not be discharged from the hospital until everyone is comfortable with your care at home. It is a good idea to prepare your home prior to your discharge. Get someone to clean your house before you return home.

THINGS TO LOOK OUT FOR

It is important that you contact your doctor or nursing team at the hospital for advice immediately (at any time of the day or night) if you are feeling unwell or if you experience any of the following:

- Fever – temperature of 38°C and above
  ~ chills and rigors even if your temperature is within the normal range
- New pain or persistent unexplained soreness anywhere
- Persistent nausea, vomiting or diarrhoea
- Rash of any type
- Signs of bleeding such as bleeding gums, nosebleeds, excessive or easy bruising, blood in the urine, blood in the stools, bloody vomiting, excessive menstrual bleeding and any other abnormal bleeding
- Signs of GvHD (allogeneic BMT recipients): skin rash, abdominal cramps, watery diarrhoea, severe vomiting and jaundice
- Problems with the central venous catheter:
  ~ catheter slipped out
  ~ stitches loose
  ~ difficulty flushing
  ~ redness or discharge at the exit site
  ~ swelling at the exit site or along the catheter
- Persistent cough or shortness of breath
- Persistent headache or dizziness
- Frequent urination or pain and burning during urination.
- Abnormal and/or prolonged symptoms which cause concern

RE-ADMISSION TO HOSPITAL

You may experience minor complications and may need to be readmitted for short periods to manage the problem if it cannot be treated as outpatient. It is common to be re-admitted to the hospital more than once after discharge. This can be discouraging but it is important for you to understand that this is part of the recovery process.

Common reasons for re-admission include:
- Infections – bacterial, viral or fungal
- Nausea and vomiting – especially if you are unable to drink or take your medication
- Severe diarrhoea
- Graft versus host disease

OUTPATIENT APPOINTMENTS

You will be given a follow up appointment before your discharge and the nurse will inform you where to go for the appointment.

As your new bone marrow is still immature, you will need to have frequent outpatient visits with your BMT team. Generally, allogeneic transplant patients will be seen at least twice weekly for the first 100 days post transplant and autologous transplant patients will be seen at least once weekly for a few weeks.

If you are a foreigner, you and your caregiver may have to find alternative living arrangements, before your discharge from the hospital.
Each outpatient visit involves a thorough assessment of laboratory results, your symptoms, physical examination and psychosocial status as well as a review of all your medication. Please remember to bring all your medication with you for each visit. You should arrive at the clinic at least 1 hour before your appointment time for blood samples to be collected, so that the results are available to the team during your consultation.

If you have been prescribed ciclosporin or tacrolimus, do not take the morning dose of these drugs on your outpatient appointment days unless instructed otherwise. Bring the ciclosporin or tacrolimus with you for the appointment. Come to the outpatient clinic at 9am in the morning to have your ciclosporin or tacrolimus blood levels taken. After the blood test, you should take your usual prescribed dose of ciclosporin or tacrolimus.

Bone marrow aspirations/biopsies may be performed as part of routine follow-up. Throughout this period it is important that you follow all the instructions carefully to improve your chances for a full recovery.

DRUGS TO TAKE AT HOME

When you are discharged from hospital, you will be given a supply of medication. Please remember to take them as directed and to bring the remaining medication with you when you come for your appointments. Please ensure that you have enough medication to last you till your next appointment.

You will usually be discharged on
- Your immunosuppressive drugs e.g. ciclosporin, tacrolimus, mycophenolate. The dose of this drug may vary from visit to visit, and you should pay careful attention to this.
- Drugs to reduce risk of infections – ciprofloxacin, posaconazole or itraconazole, cotrimoxazole and acyclovir.
- Other drugs as required – including magnesium and potassium supplements, antinausea medication etc.

You should not take any herbal remedies, traditional medicines, health supplements etc without first consulting your transplant doctor.

RISK OF INFECTION

Although your stem cells have engrafted, your immune system will take some time to recover to normal levels. It usually takes about 6 months (for autologous BMT) and 6 months to 1 year (for allogeneic BMT) before your new bone marrow is fully functional and is able to produce all blood cells you need. During this time you need to take extra precautions to reduce your risk of contracting an infection. These include:

- Maintain good personal and oral hygiene. Wash your hands frequently especially after using the toilet and before meals.
- Avoid close contact with anyone who has a cough, cold or other infections. You can have visitors, but limit them to small groups (2 to 4 at a time) of healthy people.
- Avoid contact with babies and children who have been vaccinated with the live-virus oral polio vaccine for at least 6 weeks. They shed the virus in their body secretions (sweat, stool) and may infect you.
- Do not receive any immunisations without your transplant doctors’ permission.
- Avoid swimming in public pools. You should not swim if your central catheter is still in place.
- Use a mask when out. Avoid crowded areas like shopping malls, fast food restaurants, cinemas, hawker centres, supermarkets and public transportation.
- Keep your house as clean as possible. Keep dust to a minimum. Try not to use a feather duster as its stirs up dust and disperses it in the air.
- Have someone look after your pets. Do not clean up after your pets and do not allow them to lick you.
- Limit the number of plants in your home. Remove all plants from your bedroom. The soil and water in your household plants can be a source of infection.
- Women should not use tampons.

BLEEDING

You will be at risk of easy bruising and bleeding until your platelet count returns to normal. Here are some suggestions to reduce this risk:
- Avoid strenuous activities that are likely to cause injury. Speak with your doctor before resuming any contact sports or strenuous activity.
- Do not use razor blades for shaving, use an electric razor instead.
- Use soft-bristled toothbrush to prevent injury to gums.
- Do not blow your nose forcefully or scratch inside of your nose as this can cause nosebleeds.
- Avoid cutting your finger or toe nails too deeply.
- Use caution to avoid falls.
- Avoid becoming constipated. If you have difficulty moving your bowels, inform your doctor. You may need a stool softener.

CENTRAL LINE

When you leave hospital you may still have your central line. Your nurse will advise you and your caregiver on how to care for it at home. Your doctor will decide on the removal of the line once the team thinks that it is no longer required.
FATIGUE AND TIREDNESS

Experiences of fatigue and tiredness are practically universal after a transplant. Relax and take it easy at home, have some gentle exercise and make sure you get plenty of rest.

Feelings of tiredness and fatigue can persist for several months after your transplant – often 6 to 12 months. This is normal as your body needs time to recover. Feeling of tiredness can be frustrating especially if you used to lead an active life before your transplant. Try to get plenty of rest. It is important to listen to your body. Getting out into the fresh air and doing some gentle exercise is important for your general wellbeing and may also help to give you more energy. Studies have shown that quality of life and fitness levels can improve with even a small increase in activity. Start slowly and increase your level of activity over time. Remember to consult your transplant doctor before beginning exercise.

Here are some suggestions for managing post-transplant fatigue:

- Get good quality rest– limit interruptions, say “no” if necessary, establish a regular sleep schedule and address any concerns that interfere with sleep e.g. pain.
- Keep active– adequate rest is critical, but too much rest can have a detrimental effect on energy production and increase fatigue.
- Recognise patterns of fatigue so that favourite or high-priority activities can be done when energy levels are highest.
- Plan ahead so that extra-demanding situations like visits to the doctor can be balanced.
- Use energy conservation techniques like sitting rather than standing, keeping frequently used items at close range, and clustering together all items needed for a task.
- Take time to relax with activities that are enjoyable or reviving, like music, walks or games.
- Report any increase in fatigue so that the cause may be determined and addressed.

EMOTIONAL CHANGES

Survivors often report that their quality of life post-transplant is similar to or better than before the transplant. Although patients are affected differently by the transplant, everyone, without exception is changed as a result of the transplant experience. They will be inevitably experience some losses and hopefully gain new strength and insights.

Many patients feel that their quality of life is better than before their illness and are often surprised that they notice and value things in life with renewed enthusiasm. Despite the intensity of the transplant experiences, most patients are happy with the results of their treatment and are very positive about their future and make effective adjustments in their life and maintain an optimistic outlook for the future.

Remember, it is important to return to your normal lifestyle as quickly as possible but your feelings of wellbeing are just as important as your return to physical health and also, that your recovery can take time.

GOING OUT

If you are feeling up to it, you should go out. You should take sensible precautions to reduce the risk of infections. Please see the section on infection (p48).

NUTRITION AT HOME

After discharge, you may still experience residual side effects from your treatment (even when you are fit for home) which may affect your nutritional status. Your appetite and sense of taste or smell should start to improve once you go home but it can take some time to return to normal.

You may find the following suggestions helpful if you are trying to gain weight or keep your weight stable:

- Eat small, nutritious meals frequently.
- Fortify your dietary intake with high protein, high energy food, snacks and/ or drinks.
- Supplement meals with high-protein/high-energy drinks as suggested by your dietitian.
- Even if you are not eating as much as usual make sure that you drink a lot – aim for six to eight glasses of fluid per day unless otherwise advised by your doctor.

Oral nutritional supplements are generally useful should you find difficulty maintaining weight or achieving your nutritional requirements from diet alone.

As you remain susceptible to infections, the adherence to the ‘neutropenic diet’ remains important for the next 3–6 months to reduce the risk of infections from dietary sources. The duration of this diet is usually determined by the type of transplant and whether you remain on any immunosuppressive drugs.

You should not eat any raw or undercooked meat (e.g. chicken/ pork/ beef/ lamb), seafood (e.g. oysters/ clams), eggs or foods that contain any of these. You should only consume well cooked food items. You should aim to avoid salads and fruit that cannot be peeled or washed thoroughly and choose only pasteurised fruit and/ or dairy products.

Post discharge follow up appointments will be arranged for you to see your dietitian where your nutritional status will be reassessed. This also allows you to raise any concerns or nutritional challenges you may face at home.

When you are medically stable post transplant, a healthy balanced diet is important to help prevent and/ or better manage other conditions such as diabetes, heart disease and hypertension. Your dietitian will advise and plan a diet for you according to your needs.
MOUTH CARE

Mouth care remains important even after your discharge from hospital. Your white cell count may still be lower than normal, so you need to protect your mouth from infections. Your mouth may also continue to be dry for some time. Keep your mouth clean particularly after eating to reduce the risk of infections.

- Brush your teeth 2 to 3 times daily using soft–bristled toothbrush.
- Rinse your mouth with the recommended mouthwashes after each meal. Avoid alcohol based mouthwashes.
- Apply a water based moisturizer to dry lips.
- If you wear dentures, clean them after each meal with a toothbrush. Remove your dentures at night.

If you notice any bleeding, ulcers or cold sores or problems with your dentures, let your doctor know. Do not visit a dentist without consulting your transplant doctor first.

SKIN CARE

After your transplant, your skin may be more sensitive and drier than normal. This may continue for several months. Certain anti–rejection drugs will also cause the skin to be more sensitive to sunlight. You should take the following precautions:

- Avoid excessive exposure to direct sunlight. Use sunglasses and a hat or scarf when necessary.
- Wear long pants and long sleeved dress/shirt when you are outdoors.
- Apply a good quality sunscreen of at least SPF 30 and above to all skin areas that are exposed to sunlight.
- If your skin is dry, you can apply baby lotion/oil or skin moisturizer. Avoid lotions containing alcohol, as it may increase dryness.

Check your skin daily for rashes or other changes. If you develop a rash, or your skin becomes red or itchy, you must inform your doctor immediately.

HAIR GROWTH

Hair usually grows back about six to ten weeks after your transplant. You may be able to see and feel the new growth of hair coming through. The new growing hair might be slightly different in colour and texture at first. The initial growth can tend to be slightly wavy or curly, thicker and darker. This often changes as your hair grows longer.

Until your hair grows back, it is important to look after your scalp. You should avoid direct sunlight on your exposed head and wear a cap, wig or scarf when you go out.

SEXUAL ACTIVITY

Transplantation can affect your sexuality in many ways. It can change hormone levels and sex drive. You may experience a decrease in libido, which is your body’s sexual urge or desire. Generally sexual activity is not recommended until your platelet count is greater than 50x10⁹/l and neutrophil count more than 2.0x10⁹/l.

Although you are likely to have reduced fertility after your treatment and transplant, it is strongly recommended that you always use a reliable method of contraception. If you are female, it is generally recommended that you do not become pregnant for at least 5 years after your transplant. Some treatments may harm the developing baby and becoming pregnant too soon increases the risk of relapse. Speak to your doctor if you have any concerns.

If you are male, it is recommended that you do not father a child for at least 3 months after completing your treatment. A barrier method of contraception, such as condoms (with a spermicide) is generally suggested as this also helps to reduce the risk of infection.

For most patients the effort of returning to normal health will overshadow their sexuality. Once normal health returns, it is likely that sexual interest will return. However, some of the changes you have experienced may interfere with your sexual lifestyle. Hair loss, skin changes, and fatigue can all interfere with feeling attractive. Other factors, such as changes in your body image or concerns about hygiene can also affect desire and sexual activity. Even small changes in energy levels can reduce one’s sexual drive. It may take some time for things to return to ‘normal’.

Many premenopausal women who go through this treatment will experience premature menopause. The reduced level of circulating oestrogen can cause a number of bodily changes. Some of these include hot flushes and sweats, vaginal dryness, mood swings and changes in sex drive. For men, neurovascular damage caused by chemotherapy or radiation may lead to erectile dysfunction.

It is important to communicate with your partner, particularly if your sexuality has changed or intercourse is no longer as comfortable as in the past. You may need to use a lubricating gel to reduce friction. Letting your partner know about these changes may help avoid feelings of rejection. Talking about your fears and concerns is the first step to finding ways to manage them. Open communication can lead to greater intimacy, regardless of whether sexual intercourse is possible or not. Sexual pleasure is not just about sexual intercourse. You and your partner can help each other reach satisfaction through touching and stroking. At times just cuddling can be pleasure enough.

If you have any concerns about sexuality, or other related matters, talk to your doctor or nurses. They can provide information and offer suggestions or refer you to a health professional who specializes in sexuality.
6. **LONG-TERM RECOVERY**

Conditioning chemotherapy and the stem cell infusion represent the first steps of your transplant journey. Recovery is a long process during which you will be seen regularly and supported by your transplant team. Even after you feel you have fully recovered and returned to a normal life, you will still need regular follow-up. These visits are important as monitoring for and detecting potential long-term complications early is vital for your continued well being.

**CHIMERISM**

A chimera is a single animal that is made up of two or more different populations of genetically distinct cells. If you have received a transplant from a donor, your blood cells will be genetically different from the other cells in your body. Sometimes populations of your own blood cells may start growing back after the transplant. These may co-exist with the donor blood cells. An increase in the proportion of your own cells may, in certain circumstances, indicate relapse or suggest an increased risk of relapse.

We are able to measure the proportions of donor cells circulating in your blood and bone marrow. This involves taking a sample of blood and/or marrow and looking at the genetic differences between these cells. This is known as a “chimerism” test. It will be performed regularly following your transplant.

**RELAPSE**

Relapse of your original disease is possible even after transplantation. Most occur within the first few years of transplant. As a general rule, the chance of relapse diminishes as time goes by. You would be usually be considered “cured” 5 years after your transplant. Relapse after that would be rare.

You will be monitored closely through regular blood tests, bone marrow tests and other investigations if necessary, to try and detect as early as possible, any evidence of relapse.

**DONOR LYMPHOCYTE INFUSIONS (DLI)**

Lymphocytes are cells which form part of the immune system of your body. They protect you from certain infections (especially viruses) and are capable of recognising foreign cells in your body. After a donor transplant, the vast majority of lymphocytes are usually from your donor. Some of these lymphocytes may cause graft-versus-host disease and others are responsible for the graft-versus-tumour effect. The group of lymphocytes responsible for these are broadly known as T-cells.

If there is any evidence of relapse after transplantation or if a fall in donor chimerism is detected, a donor lymphocyte infusion (DLI) may be given. This may be repeated with higher does of T-cells if necessary after an interval of a few weeks. These are usually given as an outpatient, with no preceding chemotherapy. You will usually be asked to stop all immune suppressing medication a few weeks before the infusion. There are usually no immediate side effects, but there is a risk of graft-versus-host disease (GVHD). You will need to report to your transplant team immediately if you experience any symptoms of GVHD (e.g. fever, nausea, vomiting, diarrhoea, skin rashes and jaundice).

**RECOVERY OF THE IMMUNE SYSTEM AND VACCINATIONS**

Your immune system may not recover for some years following your transplant. If you have chronic graft-versus-host disease, your immune system remains compromised. Common colds, flu etc may require treatment, especially within the first few months after your transplant.

When you have been able to stop all immunosuppressive drugs and have no GVHD, you will be asked to undergo a re-vaccination programme. The first set of vaccinations usually includes the “childhood” vaccines given to babies (diphtheria, tetanus etc). The second set about a year later usually includes measles, mumps, rubella, influenza and pneumococcal vaccination.

It is important that you avoid all live vaccines. Your transplant doctor will give you specific advice. Do not take any vaccinations before speaking with your transplant team.

You should avoid close contact with or handling the excrement of people who have received the live oral polio vaccine, as you may be able to catch this infection.

**CHRONIC GRAFT VERSUS HOST DISEASE**

Chronic graft-versus-host disease generally refers to a slow onset GVHD which starts more than 100 days after your transplant. It is still possible however to get acute GVHD after 100 days.

Chronic GVHD may be manifest in many ways and in some recipients may cause significant disability and death. Chronic GVHD may cause skin changes (e.g. thickening, contractures), affect your liver, bowel, mouth, lungs, eyes, muscle, heart etc. It can affect any part of your body. Early treatment is more effective at stopping the progression of chronic GVHD and you will be monitored on a regular basis.
SECOND MALIGNANCIES

Your risk of developing another form of cancer e.g. bowel, skin, blood, lung etc may be increased by your disease, the treatment you have received for your disease and by your transplant.

If you are female, you may be advised to perform self breast examination regularly. You may be advised to have regular mammograms. You may be advised to undergo screening for other forms of cancer starting a few years after your transplant. You should avoid habits which pre-dispose you to other forms of cancer– e.g. smoking, excessive sun exposure etc.

EARLY MENOPAUSE

If you are female, you may experience the symptoms of menopause soon after your transplant or some years after. This depends on your age, the type of treatment received before your transplant and your transplant conditioning. These symptoms may include the cessation of your monthly menses, vaginal dryness, hot flushes and mood changes. Hormone replacement therapy may be useful for some patients.

If you are male, a reduction of your testosterone levels may result in mood changes, tiredness and sexual problems. Hormone replacement therapy may be useful for some and you should speak with your transplant doctor.

OTHER LONG TERM ADVERSE EVENTS ASSOCIATED WITH TRANSPLANTATION

Your body may age at a more rapid rate following chemotherapy, radiotherapy and transplantation. Some of the conditions associated with aging may be experienced by posttransplant patients at an earlier age e.g. cataracts, vascular diseases– heart disease, peripheral vascular disease, arthritis, diabetes etc.

You should reduce your risk of these where possible by taking simple precautions and by adopting a healthy life-style and diet. As part of your post--transplant care, you may be screened for risk factors at regular intervals.

Some post transplant patients may develop an underactive thyroid and require life long thyroid replacement medication. Your doctor will monitor your thyroid function and advise you according. The thyroid gland is responsible for regulating your body temperature, growth and metabolism.

RETURNING TO WORK

It is common to feel that your life has been put on hold by your illness and transplant. The length of time it takes for you to fully recover is very individual and is dependent on the type of transplant that you have had and the treatment you received before your transplant.

Getting back to your previous routine may not be exactly what you want at this stage. You may need to make some adjustments, in your personal as well as your professional life. Preparing to re-enter work and balancing your family life can be difficult.

The decision about returning to work is very personal. It depends on how well you are feeling, the type of work you do and your personal and financial circumstances. Your transplant doctor will let you know when you can return to work, school, or your normal daily routine. Much of this decision will depend on your new bone marrow. Keep in mind that it may be 6–12 months before you are able to return to your normal routine. You should not plan to return to work for at least 6 to 12 months following your transplant, depending upon the nature of your work.

Increase your activity gradually. If possible you should start work on a part time basis before returning to full time work. Give yourself time to take care of yourself and fully recover. You deserve it!

Hiring, promotion and treatment in the workplace should depend entirely on ability and qualifications. Unfortunately, some employers may discriminate against you if they know you have had cancer. In discussions with your future employer, emphasize your strengths and capabilities. If you know that you will require modifications to your job, you will need to notify your employer of your disability and the need for reasonable accommodation.
7. PSYCHOLOGICAL ASPECTS

THE JOURNEY AHEAD - PATIENT

You are probably holding this booklet in your hand with a multitude of emotions, likely to be experiencing a mixture of feelings within you – a fusion of hope and dread. The adrenaline rush you feel and each deep breath you take symbolises anticipation and apprehension. On one hand, you feel a burst of joy knowing that there is finally a suitable match and a possible cure. On the other hand, you also feel a sense of long drawn fear and dreaded questions which you are afraid even to verbalise or admit to yourself. Thoughts like these keep appearing in your mind – “What if the transplant fails and I am left with another bout of suffering? What if... what if... I die?”

There are many “what ifs” in your mind right now and the greatest “what if” might be “what if you suffer a relapse after that?” You are filled with worry for your future and fear that your hope for a chance of cure might not turn out the way you want it to. You may be assured to know that these ambivalences are normal, and you are one of many who feel the same way.

PREPARING FOR YOUR HAEMATOPOIETIC STEM CELL TRANSPLANT

As the day of admission for transplant draws nearer, you may find your anxiety and ambivalence level heightening. You may be looking forward to it but subconsciously; part of you may be dragging your feet as the day approaches. Before your admission, you may have the urge to see all your family and friends in preparation for your “isolation” for the next one month or more. The transplant may mark a new beginning and the end of your long haul treatment.

Apart from being a patient, you also possess other roles in life. You may be a parent, the main breadwinner, or a student, and these significant roles come with great responsibilities which add on to your concerns when you are admitted.

As a parent, you worry that there is no one to look after your child and there is an overwhelming fear that this may be the last time you see your child. However, you hang on to the hope that after this ordeal, you will be well enough to give the best to your child once again.

As a main breadwinner, you are probably looking forward to completing the transplant and returning to work. You yearn to be able to resume your role as the main breadwinner for your family as this has given you profound meaning to your existence.

If you are still a student, you may be wondering what you are missing out when you are not in school. You look forward to resuming school and pursuing your future endeavours.

Reflecting upon this whole process of preparation, you may constantly be in a dilemma and asking yourself questions like “Am I making the right choice? Is this really worth the risks?” This journey has made you realise and appreciate the people you cherish most in your life. However, the helplessness and frustration you feel in the course of the journey may have caused you to vent your anger towards them after which, you feel a sense of guilt as your ventilation is unintentional. Such feelings are perfectly normal, and do be assured that we are here to journey with you through these uncertainties and to render available assistance.

DURING YOUR TRANSPLANT ADMISSION

At this point, you may feel a great sense of emotional isolation even amidst all the support given to you by family, friends and healthcare staff. It seems that no one truly understands what you are going through, and are thus unable to completely empathise with your fears and ambivalence. You seemingly have little control over the situation and may feel most vulnerable at this stage because you are most prone to infection.

Nevertheless, you try to stay positive by focusing on your blood counts each day. It becomes like your report card, whereby you monitor closely to make sure it gradually goes up. You believe that things will ultimately work out somehow. Looking at your “report card” may possibly give you a sense of control over situation as you try ways and means to spur yourself by focusing on every positive aspect. It may also be a period of reflection and meaning making process for you as you lay in bed, thinking of the journey you have gone through and trying to make sense of it. It makes you realise how resilient you actually are, and you should really give yourself a pat on the shoulder having gone this far.

As you continue to remain in the ward with each passing day, there may be times of exceptional boredom, or even overwhelming feelings of sudden meaninglessness in life. It may help to bring your personal belongings, such as stuffed toys, electronic devices for communication and entertainment, books and magazines, to provide some emotional comfort and brighten your mood. You could even decorate your room with your favourite things to make it feel more homely. Just remember that during this journey, there will be good days and bad, which makes patience and endurance important. Support and encouragement from loved ones can help to mitigate the bad and also provide additional strength to continue this journey. Each new day brings renewed hope.
DISCHARGE - GOING HOME AND MONITORING YOUR CONDITION

In your mind, you are probably excited at the thought of going home. There may be a million and one things that you wish to do after you are discharged. You probably also feel relieved that you are now a step closer to recovery.

Though you are excited at the thought of returning home, part of you may fear that you will not be able to cope with your daily activities at home. Your home will have to be kept spick and span, food has to be thoroughly cooked, and you wonder when your life will regain normalcy.

As you attend your weekly (or even more frequent) medical follow ups, you may find yourself gradually getting familiar with many types of expensive medication, which may make you feel like a pseudo-pharmacist / doctor at the end of the day. Some of the medication prescribed, being expensive, can be partially claimable from Medisave and/or Medishield. Alternatively, you could approach us to apply for Medifund assistance. (For more details, please refer to the last section on “Financing your HSCT”)

THE FUTURE - MOVING ON FROM TRANSPLANT

At this juncture, you may feel that life has changed to some extent. This is inevitable as you have undergone a major procedure and you may still be constantly fearful of suffering a relapse. When you look into the mirror, there may be physical changes to your appearance because of treatment side effects. It takes time to adapt to these changes and some of these side effects are usually only temporary. In time, the frequency of medical follow-ups would decrease and you could gradually resume some of the activities you had enjoyed.

For some, the journey could be longer than expected should unexpected complications occur. Some patients also experience treatment fatigue at some point along the trajectory. Nevertheless, you have come a long way since your diagnosis to reach this milestone. Look inside yourself and ask yourself what has given you the strength and motivation thus far? It has not been easy, but yet, you have managed to overcome your fears and obstacles.

THE CARE GIVING JOURNEY

As a caregiver, you would also have journeyed alongside the patient and have experienced a multitude of emotions, challenges and fulfilment. Feelings of fear and uncertainties regarding patient’s illness and future are part of the experience. It is understandable for you to feel illprepared as a caregiver because you might lack understanding of patient’s illness and treatment, unsure of the physical care required. You may also find yourself having to manage multiple responsibilities, e.g. shuttling to and from home, hospital and work. It may be stressful for you as you have to meet your work demands and care giving. However, finding meaning and having a sense of purpose in care giving will help you cope with the challenges faced.

There are various ways you can cope as a caregiver. You try to come to acceptance of patient’s condition and be positive. Practically, you prepare for care giving as you acquire information about services and resources. You help in managing patient’s care by providing physical care, emotional support and encouragement to patient.

It is also important that you develop ways to cope with care giving such as maintaining different family members’ involvement in caring for patient. Journaling may help as you pen down your thoughts as a caregiver. In the process of care giving, you discover unanticipated rewards such as appreciating what you have, valuing life, and an improved relationship with patient. This journey becomes an opportunity for all parties to show love, foster deeper bonds and treasure relationships. Care giving may be overwhelming at times and it may beneficial for you to take a break from care giving. Remember to rest or give yourself some time to relax. Talk to someone to share your burden!
8. FINANCING YOUR HAEMATOPOIETIC STEM CELL TRANSPLANT

The haematopoietic stem cell transplant can be extremely costly and you may have difficulties paying for the treatment.

Should you experience financial difficulties in paying for the treatment, you can apply for financial assistance with a Medical Social Worker (MSW) at the department of Medical Social Services (For eligible Singapore Citizens and permanent residents only). During the financial application process, you will be asked to submit financial documents to support your application for financial assistance. Your MSW will apply to the appropriate funding bodies for financial assistance upon completion of the application assessment.

9. APPENDICES

BONE MARROW DONATION AND HARVESTING

Your donor needs to have a tissue type which is compatible with you. This is determined by a simple blood test or a special swab of the lining of the mouth. He/she must be medically fit to undergo the harvesting procedure and must not carry any infections which may cause a problem. He/she will undergo a full medical examination, within 28 days of donation, including a chest x-ray and ECG. Blood tests will include a full blood count, kidney and liver function tests, G6PD screen, thyroid function, screens for Hepatitis B and C, Human Immunodeficiency Virus (HIV), Human T-Lymphotropic Virus (HTLV), Syphilis, Cytomegalovirus (CMV) and Varicella Zoster Virus (VZV).

Your donor may choose to donate either bone marrow stem cells or peripheral blood stem cells (PBSC). With certain conditions however, your doctor may request for either bone marrow or peripheral blood stem cells.

If bone marrow stem cells are selected, your donor will have a general anaesthetic and bone marrow will be extracted from his/her pelvis using hollow needles. About 1 litre of marrow is usually collected. This is filtered and may be processed in the stem cell lab before it is infused into you. The harvesting procedure usually takes about one hour. Your donor will be admitted to hospital the evening before the harvest and will usually be discharged the evening or morning after the harvest. There will be some bruising, pain and discomfort over the marrow collection sites for a few days to a week after the procedure. Other complications are rare, but damage to some of the nerves and bones of the lower back and lower back pain may occur.

If your donor is donating peripheral blood stem cells, he/she will receive injections of G-CSF. G-CSF is a hormone which stimulates the release of bone marrow stem cells from the bone marrow into the blood stream. G-CSF is given as an injection beneath the skin starting 4 days before the harvest. On the 4th day, your donor will need to attend the hospital for a check FBC in case the dose of G-CSF needs to be reduced. On the 5th day, he/she will be connected to a special machine known as an “apheresis” machine.

This machine takes blood from a vein, adds a harmless chemical to stop it from clotting, spins the blood, collects the stem cells and returns the remaining blood to the donor. In situations where the veins in your donors arm are not large enough, a small tube called a catheter, inserted into a large vein in the neck or groin may be required. This process is known as “leukapheresis”. The stem cells are usually given to you without further processing. If there are insufficient cells collected on the 5th day, a further collection is done on the 6th day. Each day’s leukapheresis usually takes between 4 to 6 hours.
Approximately 5% of healthy donors will fail to provide enough stem cells by this method. Should this be the case, he/she will be invited to undergo a bone marrow collection under general anaesthesia.

Donating peripheral blood stem cells is very safe, but not risk free. The common side effects include bruising or bleeding from the cannula sites and symptoms from a low blood calcium level. These symptoms include tingling around the mouth and extremities or muscle spasms. They are usually quickly relieved with a calcium drink.

G–CSF may cause side effects. The commonest of these are “flu” like symptoms—body aches. Occasionally bone pains may be severe enough to require treatment with paracetamol or stronger painkillers. Aspirin and other drugs known as non-steroidal antiinflammatory drugs (NSAIDs) should not be taken. Rarely, more serious side effects may be experienced which may need the drug to be stopped.

If your donor is a relative, the transplant doctor looking after you will be different to the doctor looking after your donor. This is to ensure that the doctor–donor confidentiality can be maintained and that you and your donor’s interests are protected. For this reason, your donor’s medical reports cannot be discussed with you unless your donor has explicitly permitted this.

### 10. CONTACT US

- **Main Switchboard**
  - 6222 3222

- **Admission Office**
  - 6321 4388

- **Business Office**
  - 6326 5477
  - 6326 6220
  - 6326 5747

- **Clinic K**
  - 6321 4345

- **Haematology Centre Reception**
  - (Office Hours)
    - 6321 4722

- **Haematology Centre**
  - (Office Hours)
    - 6321 3515

- **Medical Social Services**
  - 6321 4885

- **Transplant Coordinator**
  - 6321 4864

- **Transplant Ward**
  - (After Office Hours)
    - 6321 4720