Autologous Stem Cell Transplants

A guide for patients, families & whānau

leukaemia & blood cancer new zealand

our mission is to care, our vision is to cure

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INTRODUCTION

This booklet has been written to help you and your family understand more about autologous bone marrow and peripheral blood stem cell transplantation.

You may be feeling anxious or a little overwhelmed if you, or someone you care for is having an autologous transplant. This is normal. Perhaps you have already started your transplant or you may be discussing the possibility of having a transplant with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet answers some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

In writing this booklet we have tried to follow as much as possible the usual sequence of events in an autologous transplant. Keep in mind however that things do not always go to plan and that not everything written here will necessarily apply to you and your experience of the transplant process.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

We have used some medical words and terms commonly used in transplantation, which you may not be familiar with. Their meaning is explained both in the booklet and in the glossary of terms at the back of the booklet.

Some of you may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, many of you will also receive written information from the doctors and nurses at your treating hospital.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your circumstances at all times with your doctor and treatment team.

Finally, we hope that you find this booklet useful and we would appreciate any feedback from you so that we can continue to serve you and your families better in the future.

Acknowledgements

Leukaemia & Blood Cancer New Zealand acknowledges the support of the Leukaemia Foundation of Australia for granting us permission for the use of much of the material within this booklet.

Leukaemia & Blood Cancer New Zealand gratefully acknowledges Dr Leanne Berkahn (Auckland City Hospital) and Dr Alwyn D'Souza (Wellington Hospital) for assisting us with the development of this booklet.

Leukaemia & Blood Cancer New Zealand

Leukaemia & Blood Cancer New Zealand (LBC) is a not-for-profit organisation dedicated exclusively to the care and cure of patients and families living with leukaemia, lymphoma, myeloma and related blood disorders. Since 1977, we have worked to improve the lives of patients and families living with these devastating diseases.

Our work is made possible through fundraising activity and the generous support we receive from individuals, companies, trusts and grants as well as support in kind. We receive no Government funding.

We are also responsible for managing the New Zealand Bone Marrow Donor Registry which matches people who need a bone marrow transplant to people who have volunteered to donate their bone marrow. As well as holding information on New Zealand donors, the registry has access to a worldwide database of over ten million donors.

VISION TO CURE - MISSION TO CARE

Within our vision to cure and mission to care Leukaemia & Blood Cancer New Zealand provides:

Patient Support

Leukaemia & Blood Cancer New Zealand have trained staff who provide personalised and practical programmes assessed on an individual needs basis. These include financial assistance, counselling, support groups, friendly advice and empathy when it is needed most.

Education and Information

Information for patients, families, health professionals and the community to aid understanding about these conditions.

Research

Supporting and funding investigation into these cancers. Research plays a critical role in bringing further understanding and better treatment to patients which in turn leads to improvement in survival rates.

Advocacy

Representing the needs of patients and their families to the government, related agencies and other relevant bodies.

Contacting us

Leukaemia & Blood Cancer New Zealand provides services and support throughout the country. Every person's experience of living with these cancers and disorders is different. Living with leukaemia, lymphoma, myeloma and a number of other blood diseases is not easy, but you don't have to do it alone.

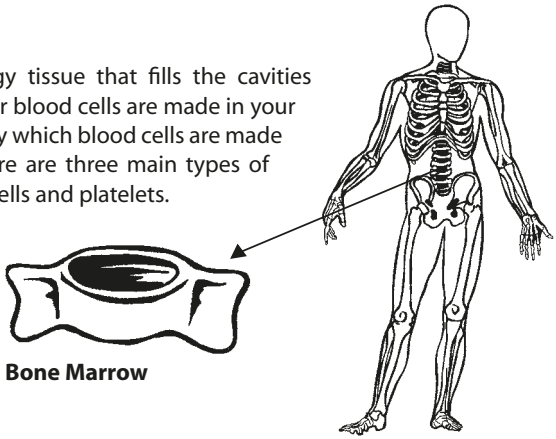
Please freephone **0800 15 10 15** to speak to a local support service staff member or to find out more about the services offered by Leukaemia & Blood Cancer New Zealand. Alternatively, contact us via email by sending a message to supportservices@leukaemia.org.nz or visit www.leukaemia.org.nz.

We are pleased to welcome personal visitors to our national office located at 6 Claude Rd, Epsom, Auckland.

BONE MARROW, STEM CELLS AND BLOOD CELL FORMATION

Bone marrow

Bone marrow is the spongy tissue that fills the cavities inside your bones. All of your blood cells are made in your bone marrow. The process by which blood cells are made is called haemopoiesis. There are three main types of blood cells: red cells, white cells and platelets.



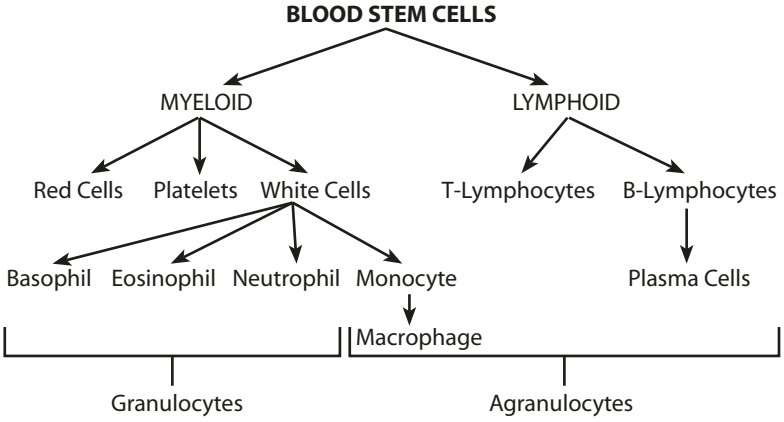
Bone Marrow

As an infant, haemopoiesis takes place at the centre of all bones. In later life, it is limited to the hips, ribs and breastbone (sternum). Some of you may have had a bone marrow biopsy taken from the bone at the back of your hip (the iliac crest) or the breastbone.

You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the blood stem cells. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of red blood cells, white cells and platelets. All blood cells need to be replaced because they have limited life spans. There are two main families of blood stem cells, which develop into the various types of blood cells.

The myeloid ('my-loid') stem cells develop into red cells, white cells (neutrophils, eosinophils, basophils and monocytes) and platelets.

The lymphoid ('lim-foid') stem cells develop into two other types of white blood cells called T-lymphocytes and B-lymphocytes.



Growth factors

The production of blood cells is controlled by natural chemicals in your blood called growth factors or cytokines. Different growth factors stimulate the blood stem cells in the bone marrow to produce different types of blood cells.

These days some of the growth factors can be made in the laboratory. You may be familiar with the drug G-CSF (granulocyte-colony stimulating factor). This is a synthetic (man-made) growth factor which stimulates the stem cells to produce more white cells.

Blood

Blood consists of blood cells and plasma. Plasma is the straw coloured fluid part of the blood, which blood cells use to travel around your body.

Blood cells

RED CELLS AND HAEMOGLOBIN

Red cells contain haemoglobin (Hb) which transports oxygen from the lungs to all parts of the body. Haemoglobin also carries carbon dioxide to the lungs where it can be breathed out.

The normal haemoglobin range for a man is approximately 130 - 170 g/L

The normal haemoglobin range for a woman is approximately 120 - 160 g/L

A reduction in the normal haemoglobin level is called anaemia. If you do not have enough haemoglobin in your blood you may feel run down and weak. You may be pale and short of breath or you may tire easily because your body is not getting enough oxygen. A red cell transfusion is sometimes used to increase the amount of haemoglobin in the blood.

The haematocrit is the percentage of red cells present in the blood. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

The normal range of the haematocrit for a man is between 40 - 52%

The normal range of the haematocrit for a woman is between 36 - 46%

WHITE CELLS

White cells fight infection. There are different types of white cells which fight infection together and in different ways.

Granulocytes:

Neutrophils	kill bacteria and remove damaged tissue
Eosinophils	kill parasites
Basophils	work with neutrophils to fight infection

Agranulocytes:

B-lymphocytes	make antibodies which target micro-organisms and some cancers
T-lymphocytes	kill viruses, parasites and some cancer cells (includes natural killer cells)
Monocytes	work with neutrophils and lymphocytes to fight infection, also needed for antibody production

The normal adult white cell count is between 4 - 11 x 10^9/L

If your white cell count drops below normal you are at risk of infection.

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1.0 (1.0 x 10^9/L), you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections.

The normal adult neutrophil count is between 2.0 – 7.5 x 10^9 /L

PLATELETS

Platelets are disc-shaped fragments that circulate in the blood and play an important role in clot formation. They help to prevent bleeding.

If a blood vessel is damaged (for example by a cut) the platelets gather at the site of the injury, stick together and form a plug to help stop the bleeding.

The normal adult platelet count is between 150 - 450 x 10^9/L

A reduction in the normal platelet count is called thrombocytopenia. If your platelet count drops below 20 (20 x 10^9/L), you are at risk of bleeding, and tend to bruise easily. Platelet transfusions are sometimes given to bring the platelet count back to an acceptable level.

The normal blood counts provided here may differ slightly from the ones used at your treatment center. You can ask for a copy of your blood results, which should include the normal values for each blood type.

Children

In children, some normal blood cell counts vary with age. If your child is having a stem cell transplant you can ask your doctor or nurse for a copy of their blood results, which should include the normal values for each blood type for a male or female child of the same age.

BONE MARROW AND BLOOD STEM CELL TRANSPLANTATION

Bone marrow and blood stem cell transplantation (commonly called stem cell transplantation) is used to treat a range of diseases. These include haematological (blood) diseases such as leukaemia, as well as non-haematological diseases. The following list gives you some examples of conditions which are treated with stem cell transplantation.

- acute and chronic leukaemia
- lymphoma
- myeloma
- myelodysplastic syndrome
- some solid tumours (for example testicular cancer)
- aplastic anaemia
- some immune system disorders (for example scleroderma)

How Does it Work?

All of our blood cells, including the cells of our immune system, develop from a small number of primitive bone marrow cells called bone marrow stem cells, or blood stem cells. These stem cells can be likened to 'baby' cells which have not yet decided which type of blood cell they want to be when they grow up. Under the right kind of stimulation blood stem cells develop and mature into red cells, white cells or platelets.

High-dose chemotherapy aims to destroy disease. As an unwanted effect, it may also destroy the precious population of blood stem cells, which then need to be replaced. In short, a stem cell transplant is necessary to ensure that the bone marrow is repopulated with healthy blood stem cells following high-dose treatment. The new blood stem cells will rebuild your body's blood and immune systems. The recovery of these systems is vital for your survival.

The word 'transplant' is a little misleading here and conjures up inaccurate images of a surgical procedure. In reality, on the day of the transplant, blood stem cells are simply given intravenously (through a vein) almost like a blood transfusion. From here they travel to the bone marrow, set up home and begin to rebuild your body's blood and immune systems.

Strictly speaking, a peripheral blood stem cell transplant (PBSCT) refers to the use of blood stem cells which have been collected from the blood stream (i.e. peripheral) while a bone marrow transplant (BMT) refers to the use of blood stem cells collected directly from the bone marrow.

You will find that many people just stick to using the terms bone marrow or stem cell transplant regardless of the source of the stem cells.

TYPES OF TRANSPLANTS

There are two main types of stem cell transplants - autologous (au-tol-o-gus) and allogeneic (al-o-gen-aic). This booklet mainly describes autologous stem cell transplants.

Autologous

In an autologous stem cell transplant, the patient is their own stem cell donor. The patient's blood stem cells are collected in advance (while they are in remission) and then returned to them after they receive high-doses of chemotherapy.

Most people have a single autologous transplant. Others have a tandem transplant where two (or more) autologous transplants are given over a period of a few months. This approach, also called staged autologous transplantation, is used to help reduce the chances of disease coming back (relapsing) in the future.

Allogeneic

In an allogeneic stem cell transplant the stem cells are donated by another person. Allogeneic transplants are more complex and carry more risks than autologous transplants.

There is a separate booklet called 'Allogeneic Stem Cell Transplants – A guide for patients and families' available from Leukaemia & Blood Cancer New Zealand.

In 2007 a total of 159 stem cell transplants were carried out in New Zealand.
Of these:

- 99 were autologous
- 60 were allogeneic

The type of transplant you will receive depends on a number of factors. These include the type of disease you have, your age, your general health, the condition of your marrow and whether you would benefit by receiving donated blood stem cells (allogeneic transplant), or whether your own stem cells can be used (autologous transplant). Your haematologist will discuss with you the best option for your particular situation.

MAKING TREATMENT DECISIONS

Many people feel overwhelmed at the prospect of having a stem cell transplant. Having to make decisions about proceeding with recommended treatments can be very stressful. Some people do not feel that they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given, or that they are being rushed into making a decision. It is important that you feel you have enough information about your illness and all of the treatment options available, including a stem cell transplant, so that you can make your own decisions about which treatment to have.

Before going to see your doctor make a list of the questions you want to ask. It is a good idea to keep a notebook or some paper and a pen handy at all times especially by your bed at night as many questions are thought of in the early hours of the morning.

Sometimes it is hard to remember everything the doctor has said. It helps to bring a family member or a friend along who can write down the answers to your questions, prompt you to ask others, be an extra set of ears or simply be there to support you.

The best option for you

It is important to remember that everyone is different. For some, a transplant is not considered the best way to treat their disease. Other approaches, such as using chemotherapy alone, may offer some people just as good or an even better chance of survival, free of disease. For others, a transplant is the only option which offers a prospect of cure, or long term survival.

Important advances have been made in stem cell transplantation in the past ten years. Despite this, some transplants cause serious, ongoing and possibly life threatening complications. Unfortunately, a small number of patients will not survive the transplant process.

Your treating doctor (haematologist) will spend time discussing with you and your family what he or she feels is the best option for you. Feel free to ask as many questions as you need to, at any stage of the transplant process. You are involved in making important decisions regarding your health and wellbeing. You should feel that you have enough information to do this and that the decisions made are in your best interests.

Remember, you can always request a second opinion if you feel this is necessary.

Informed consent

Giving an informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you are happy that you have adequate information to make such a decision.

Your informed consent is also required if you agree to take part in a clinical trial, or if information is being collected about you or some aspect of your care (data collection).

If you have any doubts or questions regarding any proposed procedure or treatment please do not hesitate to talk to the doctor or nurse again.

Standard therapy

Standard therapy refers to a type of treatment which is commonly used in particular types and stages of disease. It has been tried and tested (in clinical trials) and has been proven to be safe and effective in a given situation.

Clinical trials

Clinical trials (also called research studies) test new treatments or 'old' treatments given in new ways to see if they work better. Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side effects. Clinical trials often give people access to new therapies not yet funded by governments.

If you are considering taking part in a clinical trial make sure that you understand the reasons for the trial and what it involves for you. You also need to understand the benefits and risks of the trial before you can give your informed consent. Talk to your doctor who can guide you in making the best decision for you.

SOURCES OF BLOOD STEM CELLS

In autologous transplantation stem cells are collected (or 'harvested') from either the:

- bone marrow (*bone marrow harvest*)
- blood stream (*peripheral blood stem cell harvest*)
- or a combination of both.

These cells are collected while the patient is in remission.

Bone marrow harvest

Collecting stem cells directly from the bone marrow (bone marrow harvest) is a surgical procedure usually carried out in an operating theatre under a general anaesthetic. Stem cells are collected from the back of the hip (iliac crest).A special needle is passed through the skin and into the centre of the bone. The bone marrow fluid is then drawn into a syringe attached to the end of the needle. This is done repeatedly until enough bone marrow fluid has been collected. The whole procedure takes about one or two hours to complete.

You may be required to have stem cell growth factor (e.g. G-CSF) injections for a few days prior to the harvest (see below for administration of G-CSF).

Following the procedure, your bone marrow is processed to remove fragments of bone, red cells, fat and other unwanted tissue. It is then frozen (cryopreserved) and stored to be used at a later date.

Peripheral blood stem cell harvest

STEM CELL MOBILISATION

Stem cells normally live in the bone marrow. They can be encouraged to move out of the bone marrow and into the blood stream, from where they can be collected. This process is called stem cell mobilization and usually involves the use of stem cell growth factors (e.g. G-CSF) in combination with chemotherapy.

You may need to be admitted to hospital overnight for mobilizing chemotherapy or it may be given in the outpatient's department of the hospital. This generally depends on the dose of chemotherapy being used and the policy of your transplant centre.

The chemotherapy not only helps to treat your underlying disease, it also affects the function of your bone marrow. After an initial drop in your blood counts (particularly your white blood cell count) your stem cells begin to 'recover' from the effects of the chemotherapy. They begin to multiply, increasing in number in an attempt to replace vital blood cells damaged as result of the chemotherapy.

Growth factors, such as G-CSF, take advantage of this recovery period and further stimulate the stem cells to multiply eventually moving out of the bone marrow and into the blood stream.

Growth factors are usually given for several days, as an injection under the skin (subcutaneous) starting between twenty-four hours and five days after the

completion of your chemotherapy, the dose of G-CSF is dependant on your weight and you will receive either one or two injections per day. You or a family member (or friend) will be taught how to do this by the nurse. Regular blood tests are taken over the following week to help identify the best day to start collecting your stem cells. This is generally around the time that the number of stem cells in your blood starts to increase.

IT IS IMPORTANT TO KEEP TAKING YOUR INJECTIONS OF GROWTH FACTOR AT THE SAME TIME EVERY DAY UNTIL YOU ARE TOLD TO STOP.

Some people experience 'flu-like symptoms' including mild to severe bone pain, fevers, chills and headaches while using G-CSF. Your doctor may recommend that you take paracetamol to relieve any discomfort you may be feeling.

Remember to check your temperature before taking paracetamol if it over 38°c at anytime please call the hospital immediately for advice.

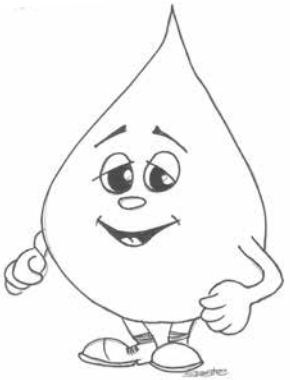
PERIPHERAL BLOOD STEM CELL COLLECTION

Stem cells are collected from the blood stream by passing all of your blood through a special machine called a cell separator or apheresis machine.

The blood is drawn from a cannula (plastic needle) placed in a vein in one arm. The machine spins the blood very quickly and removes the part that contains the blood stem cells. This is a continuous process. While the stem cells are being removed the rest of your blood is being returned to you via another cannula, placed in your other arm.

Before you start, the nurse will assess your veins to see if they are suitable for this procedure. If they are not suitable, a special line (central venous catheter) may need to be inserted into a vein in your neck. This line allows blood to be drawn from one of the bigger veins in your body.

A peripheral blood stem cell collection usually takes 3 - 4 hours. Sometimes you cannot move your arms much, especially if the cannulas have been inserted in the middle of your forearms. The nurses will make you feel as comfortable as possible but you might also like to bring along a book, a video, some music, or a friend for company. Some patients experience a tingling or cramping sensation around the lips or fingers. This is as a result of the anticoagulant drug (anti clotting) used during the procedure, depleting the blood of calcium. You may be given some calcium supplements to take.



A certain number of stem cells are needed for a blood stem cell transplant and they may not all be collected on the first day. It is sometimes necessary to go back a few times on the following days to repeat the procedure.

The stem cells will be frozen (cryopreserved) and stored until they are infused on the day of the transplant. Blood stem cells can remain frozen for many months or years before they are used.

STAGES OF A STEM CELL TRANSPLANT

While we tend to concentrate on the day that the stem cells are transplanted (day 0) as the most crucial day, it is important to realise that the processes involved in a stem cell transplant are often long and complex. In reality a transplant involves a lot of preparation and a lot of aftercare.

It might be useful to think about your transplant as a long train ride. Preparations need to be made before you embark on your trip. You will have many different experiences along the way and you may need to stop off at both expected and unexpected points along the way.

The transplant team is a specially trained group of professionals (doctors, nurses, social workers, dietitians, pastoral care workers and other allied health personnel) who are there to help you towards your recovery.

A stem cell transplant is a challenging experience. You may find that you need more support at some stages than at others during the transplant. This is normal. Your family and friends can play an important role in supporting you in many ways throughout your transplant and recovery.

Now let's look at the stages of a stem cell transplant in more detail. For convenience we have divided the process of a stem cell transplant into nine different stages. These are:

1. Planning for your transplant
2. Pre-transplant 'work-up'
3. Conditioning therapy
4. The transplant
5. Pre-engraftment
6. Potential post-transplant complications
7. Leaving hospital
8. Recovery
9. Potential late side effects

1. PLANNING FOR YOUR TRANSPLANT

This section of the booklet deals with the things you need to consider before you start your transplant. The issues covered here are:

- timing
- things to consider
- accommodation and travel
- fertility

Timing

While it is not usually possible to give an exact date, you will be given some indication of when your transplant might take place. You might like to think about the possibility of having a special family or social event (i.e. holidays, weddings) before your transplant begins. For some patients, however, the timing of the transplant may be critical and these events may have to be put on hold for several months.

Things to consider

The time you spend in hospital and/or visiting the outpatients' department will vary depending on the type of transplant you receive, any other treatment you require and any complications you experience. Most people find that the transplant has a significant impact on their lives. The time it takes to recover from the transplant varies between individuals.

As a general guide it takes between three and six months to recover from an autologous transplant.

It is important to feel that you are as prepared as possible for the transplant. The following is a list of things you should consider before you begin:

- organising your financial affairs
- making a will, organising a power of attorney
- sorting out employment issues such as sick leave entitlements, keeping in touch, plans for returning to work
- arranging leave from school, keeping in touch, postponing school or university study/exams
- organising health insurance and sickness benefits
- organising child care while you are in hospital
- organising help at home after your discharge
- collecting things to entertain yourself while you are in hospital including a radio, CDs, books, phone cards, photographs and videos/DVD's of your family, maps of the city if you or your family come from out of town
- setting your own personal targets and goals for the future

If you have not already done so you might consider learning some relaxation techniques such as meditation, yoga or breathing exercises that you can use while you are in hospital, and while you are recovering from your transplant.

Accommodation and travel

A social worker will see you as part of your transplant work up and preparation. He/she will discuss with you any help that is available in terms of accommodation and transport. If you live a distance from the transplant centre you and a family member or friend will probably be required to stay close to the transplant centre for a few weeks following your initial discharge from the transplant unit so that the doctors can keep a close eye on you and monitor your recovery.

Fertility

The use of high-dose chemotherapy with or without radiation therapy is likely to cause infertility. This means that if you receive these treatments you may not be able to have a baby or father a child in the future.

If you are considering having children in the future, it is very important that you discuss any questions or concerns you might have regarding your fertility with your doctor before you commence any treatment.

In women, some types of chemotherapy and radiation therapy can cause varying degrees of damage to the normal functioning of the ovaries, where the eggs are made. In some cases this leads to menopause (change of life) earlier than expected (see page 36). In men sperm production can be impaired for a while but the production of new sperm may become normal again in the future. The effects of treatment on your fertility depends on a number of factors such as your age, disease type and the kind of conditioning therapy (chemotherapy with or without radiation therapy) you receive prior to your transplant.

Although rare, successful pregnancies have been reported following the use of high-dose therapies. Unfortunately these therapies can cause damage to a developing fetus. Therefore it is important to avoid becoming pregnant and to use a suitable form of contraception for some time after your transplant.

We have included a brief description below of some of the current approaches to protecting your fertility. We realise that many of you may have considered the issue of fertility previously, before you received initial treatment for your disease.

PROTECTING YOUR FERTILITY - MEN

Sperm banking is a relatively simple procedure whereby the man donates semen, which is then stored at a very low temperature (cryopreserved), with the intention of using it to achieve a pregnancy in the future. You should discuss sperm banking with your doctor before starting any treatment that might impact on your fertility. In some cases however, people are not suitable for sperm banking when they are first diagnosed because they are too ill and therefore unable to produce the sperm in sufficient quantity or quality.

If possible, semen should be donated on more than one occasion. It is important to realise that there are many factors that can affect the quality and quantity of sperm

collected in a semen donation and its viability after it is thawed out. There is no guarantee that you and your partner will be able to achieve a pregnancy and healthy newborn in the future. You should raise any concerns you have with your doctor who can best advise you on your fertility options.

PROTECTING YOUR FERTILITY - WOMEN

There are several approaches that may be used to protect a woman's fertility. These are outlined below.

Embryo storage - this involves collecting your eggs, usually after having drugs to stimulate your ovaries to produce a number of eggs, so that more than one egg can be collected. This process takes some months. Once they are collected they are then fertilised with your partner's sperm and stored to be used at a later date. Your unfertilised eggs can also be collected and stored in a similar manner (egg storage).

Ovarian tissue storage - this technique has only recently been developed. It involves the removal and storage, at a very low temperature of some ovarian tissue (cryopreservation). It is hoped that at a later date the eggs contained in this tissue can be matured, fertilised and used to achieve a pregnancy.

To date, egg storage and ovarian tissue storage are techniques which remain under investigation. *They have not yet been proven to be successful in allowing women to bear children.*

The use of donor eggs might be another option for you and your partner. These eggs could be fertilised using your partner's sperm and used in an attempt to achieve a pregnancy in the future.

It is important to understand that the methods are still quite experimental and for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of them. In addition, some are time consuming and costly while others may simply not be acceptable to you or your partner.

2. PRE-TRANSPLANT 'WORK-UP'

This section of the booklet discusses the preparations that need to be made before you start your transplant. The issues covered here are:

- pre-transplant tests
- dental check
- blood tests
- central venous catheter (CVC) insertion

Pre-transplant tests

During the weeks leading up to your transplant you will undergo a number of tests to make sure that your vital organs (heart, lungs, liver, kidneys) are physically fit enough for the transplant process. While many of the tests can be done on the same day, some may require several visits to the hospital. Some take longer than others. You might like to bring a book or a friend for company. The nurse or the transplant coordinator will be able to advise you about any special preparations you need to make for the test (for example not eating beforehand), how long it will take, and whether or not you will have to wait around afterwards.

The following is a list of the tests which are likely to be carried out:

- chest x-ray
- heart function tests - e.g. a heart scan (ECHO) or an electrocardiogram (ECG)
- CT scans
- lung function tests
- bone density scan
- 24-hour urine collection
- bone marrow examination
- lumbar puncture

Dental check

A dental checkup is needed to ensure that any potential dental problems are cleared up before the transplant. The nurses will teach you how to properly care for your mouth and teeth during and after your transplant.

Blood tests

The following is a list of blood tests commonly carried out before the transplant. Some will be repeated frequently throughout the transplant, to assess your progress.

- full blood count
- blood group
- kidney function
- liver function
- thyroid function
- clotting screen

- iron
- blood glucose
- virus screening - to test for viruses such as: human immunodeficiency virus (HIV), hepatitis B and C , cytomegalovirus (CMV) and syphillis.

This may seem like a lot of tests and therefore a lot of needle pricks, but remember that several tests can often be done on one blood sample. In addition, a central venous catheter (CVC) will be inserted before the transplant (see below). Blood can be taken directly from this special line without causing you discomfort from frequent needle pricks.

Central venous catheter (CVC) insertion

During your transplant you will need to have a number of intravenous (into the vein) therapies. These may include fluids, chemotherapy, antibiotics, other drugs, and blood and platelet transfusions. You will also need to have blood taken, often every day, to check your progress. As well as being painful, the veins in your hands and arms could not cope with frequent needle pricks. In addition, some drugs cannot be given into the smaller veins in your hands and arms. It is for these reasons that a central venous catheter (CVC) or central line is inserted prior to your transplant.

A central venous catheter is a special line inserted through the skin, into a large vein in your neck or chest (this is usually done in a procedure room, the Radiology department or an operating theatre). From here it travels all the way down the vein and enters the top of the heart.

There are several different types of central lines used. The ones most commonly used for transplant patients have 1, 2 or 3 lumens. The lumens are the separate thin plastic tubes that hang on the outside, on top of your skin. The nurses will take blood and give various infusions through these lumens, and you won't feel a thing. During your transplant you may find that you sometimes have more than one infusion (for example fluids and antibiotics) going through your central line at the same time. This is perfectly safe. The nurses and doctors will examine your central line every day, paying particular attention to the surrounding skin. Remember to report any pain, redness or swelling around the central line as this might indicate that an infection has developed.

The nurses will flush the lumens of your central line regularly, to keep them open and flowing freely. They will also change the dressing which covers the site where the line enters your skin. You may be taught how to care for your own line, especially if you are going home with the line still in place.

Sometimes central lines need to be taken out, if for example they have become infected and the infection is not responding to antibiotics. Whether or not the central line is replaced will depend on where you are in your transplant process.

Like any invasive procedure carried out during your transplant, your written informed consent is required for the insertion of a central line.

3. CONDITIONING THERAPY

Before you receive your transplant you will have a few days of what is known as conditioning therapy. Conditioning therapy is used to help destroy any leftover cancer cells in your body and make space in your bone marrow for the new stem cells. It is more common to be admitted to hospital for this part of the transplant but some patients have their conditioning therapy as an outpatient, in the clinic.

There are many different types of conditioning therapies used in autologous stem cell transplantation but as a general rule they involve between one and eight days of high-dose chemotherapy. Single drugs, such as Melphalan, or a combination of two or more chemotherapy drugs may be used. There are many different combinations of chemotherapy drugs used. Commonly used combinations in autologous transplantation include:

- Bu/Cy: Busulphan and Cyclophosphamide
- BEAM: Carmustine (BCNU), Etoposide (VP-16), Cytarabine (Ara-C) and Melphalan
- CVB: Cyclophosphamide, Etoposide and Carmustine (BCNU)
- High dose Melphalan

Occasionally, chemotherapy is given with radiation therapy in the form of total body irradiation (TBI).

The kind of conditioning therapy chosen for you will depend on several factors including the type of disease you have, your age and general health and the type of transplant you are having.

Transplant protocols

Many patients are given a transplant protocol, a written summary of the schedule of treatment planned for the days leading up to and following the actual infusion of the stem cells.

The conditioning therapy is given in the week before your transplant. The days leading up to the transplant (pre-transplant) are called Day -6, Day -5 etc. with Day 0 (zero) being the day when you receive your stem cells back. You can then count forward; Day +1, +2 etc. (post-transplant).

Remember, the protocol is only a working plan. Sometimes adjustments may need to be made.

Chemotherapy

Chemotherapy may be given as an infusion through one of the lumens of your central line, or in tablet form.

Some chemotherapy drugs require you to have several litres of intravenous fluid a day, on the days that you are receiving the drug. This is to ensure that the chemotherapy is quickly flushed out of your system, once it has done its job. This helps to lessen any damage by the chemotherapy to your kidneys and bladder. In some cases, other drugs are also given to help reduce the toxic effects of chemotherapy on these important organs. With so much fluid going in, it is important to monitor the amount of fluid in your body and your urine output. The nurses may ask you to pass all of your urine into a bottle or a pan, so that it can be measured and tested.

It is important to ask your doctor and nurse about any special precautions which you or your family should be taking while you are having chemotherapy.

Total body irradiation (TBI)

Total body irradiation (TBI) involves exposing the whole body to high doses of ionizing radiation. TBI is sometimes used in combination with chemotherapy because it can penetrate and treat areas of your body less easily reached by chemotherapy (for example your brain and spinal cord). TBI is more commonly used in combination with high-dose chemotherapy as conditioning therapy for people undergoing an allogeneic transplant. It is occasionally used in people undergoing an autologous transplant.

Common side effects of conditioning therapies

Now let's look at some of the other side effects of the conditioning therapies. While most of these last for a short time, some can last longer.

LOW BLOOD COUNTS

Your white blood cell and platelet counts will drop dramatically in the week following the conditioning therapy. Your red cell count will eventually drop too. This is because the stem cells and other immature blood cells in your bone marrow have been damaged as a result of the conditioning therapy used. This is expected at this time. Your counts will rise when the new stem cells start to grow and produce new blood cells.

Your blood counts will be monitored on a daily basis and you may need to receive some blood or platelet transfusions until your transplanted stem cells re-establish the process of blood cell formation in your bone marrow. You might like to ask the nurse or doctor for a copy of your blood count each day so that you can keep an eye on your own progress.

At this stage you may be taking some medications to help prevent bacterial, viral and fungal infections while you white cell is low over the next couple of weeks. Infections and their management are discussed in more detail later in this booklet.

NAUSEA AND VOMITING

Nausea and vomiting are often associated with high-dose treatment. Thanks to improvements in anti-emetic (anti-sickness) drugs, sickness is generally well controlled these days. You will receive anti-emetics on a regular basis, before and for a few days after your conditioning therapy has finished.

Be sure to tell the nurses and doctors if you think that the anti-emetics are not working for you and you still feel sick. There are many different types of anti-emetics that can be tried. A mild sedative may also be used to help stop you feeling sick. This may also help you to relax and even make you a little sleepy.

Remember, you are not expected to simply 'put up with' nausea and vomiting or any other side effects of treatment, at any stage of the transplant, when help is available for you.

The doctors and nurses will closely monitor your condition every day. If you are unable to eat or drink sufficiently you may be given some additional fluid intravenously, via your central venous catheter, to stop you becoming dehydrated if the nausea and/or vomiting are severe.

MUCOSITIS

Mucositis is another name for inflammation of the lining of the mouth, the throat and the gut. Mucositis is a common side effect of high-dose treatment. It usually starts about three to four days after your conditioning therapy has finished. Mucositis resolves after the transplant, as soon as your new stem cells engraft and your white cell count starts to rise.

The doctors and nurses will examine your mouth and throat each day. Be sure to tell them if your mouth or throat is starting to feel dry or sore or if your saliva is getting thick or difficult to swallow. These can all be signs of mucositis. Mouth ulcers are common at this stage and they can be very painful. Soluble paracetamol and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe stronger drugs like morphine are often used.

It is important to keep your mouth as clean as possible, especially when it is sore, to help prevent infection. Different treatment centres recommend different mouth care products. Your nurse will advise and teach you how to best care for your mouth during this time.

You should avoid commercial mouthwashes, like the ones you can buy at the supermarket. These are often too strong, or they may contain alcohol which will hurt your mouth.

You may be offered ice to suck before, during and after some types of chemotherapy. This can help to reduce mucositis afterwards.

Some centres may offer you the use of a humidifier, this is a special machine that moistens the air that is delivered to you via nasal prongs (small plastic tubes that sit in the base of your nostrils). This will help to keep your mouth and throat moist and therefore keep you more comfortable as well as help in the healing process.

CHANGES IN TASTE AND SMELL

Both chemotherapy and radiation therapy can cause temporary changes to your sense of taste and smell. You might like to try adding a little more sugar to sweet foods and salt to savory foods during this time.

Most centres have a dietician who can help you plan as nutritious and tasty a diet as possible while you are in hospital.

EATING IN HOSPITAL

There are many reasons why you may not feel like eating much while you are in hospital. This is normal. Your appetite should start to improve once you go home, but it can take some time to return to normal. Normal taste sensation may also take several months to return to normal and contribute to a loss of appetite. Try to eat small meals as frequently as you feel like it. You might like to ask your family to bring your favorite food to hospital, something you really fancy. Remind them, however, not to be surprised or too disappointed if you change your mind when you see it.

Be sure to tell the doctor or nurse if you are unable to drink or eat much. You may need to have some intravenous fluids to make sure you don't become dehydrated.

WEIGHT LOSS/WEIGHT GAIN

You will be weighed every day while you are in hospital, and regularly afterwards. Most people lose some weight during their transplant. This may be due to the effects of the conditioning therapy and the fact that they are not eating what they normally would at home. The doctors and the dietician may encourage you to have special high energy and high protein drinks during the day. You don't need to drink a lot of these fluids because they are so nutritious.

You may require feeding via a naso gastric (NG) tube, this is a fine tube that is passed via your nose into your stomach which enables liquid food and some medications to be given.

Sometimes your body can hold onto too much fluid, particularly during the conditioning phase of your transplant when you may be receiving extra intravenous fluid. This will cause weight gain. This is easily treated with diuretics - drugs that make you pass more urine.

BOWEL CHANGES

High-dose treatment can cause damage to the lining of your bowel wall. This may lead to cramping, wind, bloating and/or diarrhoea. Be sure to tell the nurses and doctors if you experience any of these symptoms. If you develop diarrhoea, the nurse will ask you for a specimen which will be tested in the laboratory, to rule out an infection in your bowel. After this you will be given some medication to help stop the diarrhoea and relieve any discomfort you may be feeling.

Your bottom can become quite sore if you are having diarrhoea. 'Baby wipes' are a good idea for cleaning your bottom at this time because they are clean and soft and usually gentler and less abrasive than toilet paper. Some transplant units have bidets that you can use after going to the toilet to help keep your bottom clean. If the skin is getting sore and excoriated (broken) you will need to apply a barrier cream to the area. It is important to tell your nurse or doctor if this a problem as broken or cracked skin is a route through which bacteria can get in, causing infection.

It is also important to tell the nurse or doctor if you are constipated or if you are feeling any discomfort or tenderness around your bottom (anus) when you are trying to move your bowels. You may need a gentle laxative to help soften your stool.

HAIR LOSS

Hair loss or thinning is a common side effect of both chemotherapy and radiation therapy. The hair starts to fall out within a week or two of the conditioning therapy. It usually grows back three to six months later. Hair can be lost from any place including your head, eyebrows, eyelashes, arms and legs.

Many people with straight hair are surprised to find that their hair comes back curly. In some cases, the hair not only has a different texture but also a slightly different colour than before.

Some people notice that their scalp becomes quite itchy and tender when they start to lose their hair. You may find that patting your hair gently with a towel to dry it, avoiding the use of heat or chemicals and using a soft brush can help to make you feel more comfortable at this time.

You should avoid direct sunlight on your exposed head. You may wish to consider wearing a cap, wig, scarf or turban on your head, if this makes you feel more comfortable.

You might like to bring a beanie to hospital with you as your head can get very cold without hair, regardless of the season.

SKIN REACTIONS

Total body irradiation can cause a reddening of the skin which looks a lot like sunburn. This should disappear within a few days of finishing your treatment. Your nurse will advise you on how to care for your skin during this time. In general, you should only use non-perfumed soaps and simple moisturising creams, such as aqueous cream.

Some antibiotics and other drugs can also cause rashes. These usually subside when the drug is stopped.

PAROTITIS

Parotitis is an inflammation of the saliva-producing glands in the mouth. These include the parotid or submandibular glands situated at the top of the jaw line, in front of the ears. Parotitis is often associated with total body irradiation. It causes dryness of the mouth and jaw pain, which usually settles down within a few days, once the inflammation subsides.

INFERTILITY

As mentioned previously, treatment can damage your fertility. See page 16 for more details.

TIREDNESS, TENSION AND STRESS

You may feel more tired than usual during the days (and weeks) following treatment. 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 all very normal.

It is important to talk to someone about how you are feeling. Ask your doctor or nurse about seeing the social worker, psychologist, occupational therapist or pastoral care worker. These people can help you through this period and advise you on practical ways to help you cope better.

Some people find that relaxation and meditation techniques can be helpful in coping with tension and stress. The nurse or social worker may be able to provide you with audiotapes or other information on relaxation and meditation which might be useful at this time. Some transplant centres have a selection of videos/DVD's and talking books which can help to pass the time if you are feeling bored.

4. THE TRANSPLANT (Day 0)

Your transplant (or stem cell infusion) is carried out on day 0 (zero) of the transplant protocol. Some protocols have two day zeros. This happens when the volume of blood stem cells is large. Some cells are infused on one day and the remainder on the next.

The transplant itself is a relatively straightforward affair. The stem cells are infused through your central venous catheter, rather like a pink-coloured blood transfusion. This can take between 30 minutes and four hours, depending on the volume of cells being infused.

Your frozen (cryopreserved) stem cells are defrosted at the bedside before being infused. Reactions to stem cell infusions are rare, but you will be carefully monitored during the infusion, just in case. Occasionally people have a reaction to the preservative used in the original freezing process, so you may be given a drug to prevent this before the infusion starts. Generally, any reactions that do occur can be quickly managed and the infusion is completed as planned.

You and your visitors may notice an unusual smell resembling garlic or asparagus during and for up to 24 hours after the stem cell infusion. You may also have a strange taste in your mouth, which may be relieved by sucking mints. These effects are due to a preservative used in the original freezing process.

Some people are quite surprised at how easily the stem cells are transplanted. The whole process may even seem like a bit of an anticlimax. For others, the day of the transplant is a highly emotional one. For many, it signifies a new beginning.

5. PRE-ENGRAFTMENT

After they are infused, the stem cells travel through your blood stream and find their way to your bone marrow. Here they set up home and begin to repopulate the bone marrow with families of immature white cells, platelets and red cells. This process is known as engraftment and it usually takes anywhere between 10 and 21 days.

The transplant team will take great interest in your blood counts over the next few weeks. They are looking for evidence that engraftment is taking place. Evidence of an early engraftment is seen in a rise in the number of normal white cells in your blood.

Waiting for engraftment

You will be monitored very carefully in the early days following your transplant. This involves being examined by the doctor every day and having regular temperature, pulse and blood pressure measurements taken by the nurses. Each day, blood samples are taken from your central line to check your blood counts and to monitor your kidney and liver function.

It is not easy waiting for the stem cells to engraft. You may feel a mixture of emotions ranging from anxiety and frustration to boredom. Waiting for the results of blood tests, together with constant monitoring may make you feel a little vulnerable. In addition, you may be feeling quite miserable if your mouth is sore or if you have developed an infection. This is all to be expected during this time. Once the stem cells engraft, things start to improve quickly. Your mouth should start to feel more comfortable, your fevers should settle and you should be generally feeling much better, although still quite weak.

Remember to talk to your doctor and nurse about how you are feeling. You may need them to repeatedly explain what is going on, and why certain tests or procedures might be necessary. Many people find that they feel more relaxed and in control if they are kept well informed of what is happening.

6. POTENTIAL POST-TRANSPLANT COMPLICATIONS

This section of the booklet discusses some of the potential complications which may occur in the first few weeks after your transplant. The following issues are covered here:

- Infections
- Prevention of infection
- Blood transfusions
- Veno-occlusive disease (VOD)
- Haemorrhagic cystitis

Many of the complications which occur in the first couple of weeks after an autologous stem cell transplant occur at the same time. This is because many of the complications are related to one another and the pre-transplant conditioning therapy used.

Infections

Infections are common after a stem cell transplant. This is because conditioning therapies destroy the blood stem cells in your bone marrow, which normally produce infection-fighting white blood cells.

The absence of white cells, and in particular the absence of neutrophils, increases the risk of developing an infection. People who have a low neutrophil count are regarded as being neutropenic. In general, the lower your neutrophil count and the longer it remains low, the higher your chances are of developing an infection. If you develop a temperature while you are neutropenic you are regarded as being a febrile neutropenic patient.

Fevers

It is important that you tell the doctor or nurse immediately if you are feeling unusually hot or cold or shivery. A fever (a rise in your body temperature) is often the first sign that you have an infection. You should also tell them if you are feeling in any way unwell or if you have developed a cough, pain or soreness anywhere.

Infections can develop anywhere, but common sites of infection at this stage include your mouth, central venous catheter and chest. Causes of infections include bacteria, viruses and fungi. Because of this you may be prescribed routine preventive antibiotics, anti-viral and anti-fungal medication during the transplant and for a short time afterwards.

If an infection is suspected, the doctor will examine you thoroughly. Blood samples, called blood cultures, will be taken and sent to the laboratory, to try to find which organism is causing the infection. Other samples such as a gentle swab from the

skin around your central venous catheter site or your nose and throat may also be taken to determine if the organism has originated from any of these sites. In addition you may be asked to supply a urine, stool and sputum sample, and a chest x-ray may be done.

Infections in transplant patients are taken very seriously because they can become life threatening if they are not treated promptly. Most people who develop an infection can be treated effectively.

Antibiotics

Sometimes it is not possible to find the cause of your infection. If you develop a temperature while your white cell count is low you will be given intravenous antibiotics straightaway. This is to help prevent the spread of infection in the blood. You may also be offered paracetamol to help bring down your temperature.

If the source of the infection is found, the doctors might choose a different antibiotic, one that treats the infection more effectively. If your temperature has not returned to normal within a few days they might decide to use a different antibiotic again, or to add in an anti-fungal drug, in case your have developed a fungal infection.

You may be feeling quite miserable and unwell while you are neutropenic and febrile. Try to remember that the development of an infection is an unfortunate but expected side effect of the transplant process. All measures will be taken to limit the infection and to make you as comfortable as possible until it subsides.

Prevention of infection

Lots of precautions are taken to try to reduce your risk of developing an infection while you are neutropenic. Let's take a look at some of them now.

HAND WASHING

HAND WASHING IS THE SINGLE MOST EFFECTIVE WAY OF REDUCING THE SPREAD OF MICRO-ORGANISMS THAT CAUSE INFECTION. Antibacterial soap and/or alcohol gel is available in dispensers throughout the hospital unit so that anyone entering your room can wash their hands first. You will notice that the doctors and nurses always wash their hands before entering your room, and on leaving.

PROTECTIVE ENVIRONMENT

Many transplant patients are cared for in single rooms to reduce their risk of infection. If you have a single room you may be advised to try to spend most of your time inside it while you are neutropenic. This does not mean that you should stay in bed. Try some gentle exercises like stretching, walking around your room and walking to the toilet. The physiotherapist may be able to advise you on some other light exercise if you feel up to it. As well as making you feel better in yourself, keeping yourself mobile and doing some gentle exercises can help improve your muscle tone and prevent complications such as chest infections.

Some transplant centres have single rooms with special filtering systems to ensure that the air in your room is as clean as possible. In other centres the air in the entire ward is filtered and you are free to roam around more freely. Not all transplant patients have single rooms. Some patients share rooms with other patients or are treated in the outpatients' clinic. Regardless of the type of room you are in, every effort is made to ensure that your environment is clean and safe.

VISITORS

You can still have visitors while you are neutropenic. Just make sure that they **WASH THEIR HANDS** well before entering the room. During this time you should avoid crowds and avoid close contact with anyone with colds, flu, chicken pox, measles or any other 'catching' illness or anyone who has had a live vaccine such as polio.

You should only allow a small number of visitors (two or three people) in your room at any one time. Individual transplant units usually have policies about visitors. Ask your nurse or doctor if you have any questions.

PLANTS AND FLOWERS

Plants and flowers are potential sources of harmful micro-organisms and should not be kept in your room. Balloons are a good alternative. Your family can be creative in choosing one that is most suitable for you.

FOOD

Food, especially meat and fish, should be properly cooked before being eaten. Thick-skinned fruit (e.g. oranges and bananas) can be eaten once the peel is removed. Thin-skinned fruits need to be washed thoroughly. You should avoid salads, yogurts and soft cheese, which can all harbour bacteria. If food is brought to the hospital for you, it should be freshly cooked, and only reheated once. Some transplant centres have specially designed neutropenic diets for when your white cell count is low.

The dietitian will be able to give you more information and a list of suitable foods that you can eat. Many of the measures described above also apply when you are discharged home after your transplant. Your immune system will still be low for some time. In spite of all these precautions, infections are common and are usually caused by organisms that normally live on and inside your body, rather than an outside source.

Blood transfusions

Platelet and red blood cell transfusions are often needed in the weeks following the transplant. If your platelet count is low you will be given a transfusion of platelets (a platelet transfusion) to reduce your risk of bleeding. Red blood cell transfusions are given when your haemoglobin levels are too low. White cell transfusions are rarely given because these cells have a very short life span (less than 24 hours).

Transfusions these days are safe and rarely cause serious complications. You will be carefully monitored throughout the transfusion. It is important that you tell the nurses immediately if you are feeling hot, cold, and shivery or in any way unwell during the transfusion, as this might indicate that you are having a reaction to the blood product. Steps can be taken to reduce these effects.

All blood donors and donated blood are screened to ensure that harmful viruses are not passed on in a transfusion. In addition, the blood and platelets used for transplant patients are irradiated to prevent other potential complications. Careful checks are made both in the blood bank and at the bedside to ensure that the blood you are receiving is compatible with your blood type.

Veno-occlusive disease (VOD)

Veno-occlusive disease (VOD) of the liver is a relatively uncommon complication of autologous transplantation. In VOD high-dose treatment damages small blood vessels in the liver, which become gradually clogged up with debris and tiny blood clots. As a result the liver is unable to function properly. Veno-occlusive disease can occur at any time after treatment is given, but it usually occurs within the first three weeks of the transplant. It is seen more commonly after an allogeneic transplant.

VOD varies in severity. Sometimes it is very mild and resolves quickly. At other times it can be more serious and even life threatening. It usually presents as weight gain (due to fluid retention), abdominal swelling or pain and jaundice (yellowing of the skin and eyes). To help prevent this condition, some transplant centres use a drug which reduces clot formation during your hospital stay. In addition regular blood tests are done to check that your liver is functioning properly. If VOD develops you are likely to be treated with a drug called defibrotide that goes through your central venous catheter.

Haemorrhagic cystitis

Haemorrhagic cystitis is a condition characterised by painful bladder spasms and blood in the urine. It can be a side effect of chemotherapy drugs like high-dose cyclophosphamide that can injure the inside lining of your bladder. To reduce the risk of haemorrhagic cystitis, extra intravenous fluids and sometimes a preventive drug are given together with chemotherapy known to cause this condition. If it does occur, haemorrhagic cystitis can be effectively treated.

Remember to tell your doctor if you are experiencing any of the symptoms of cystitis i.e. pain on passing urine, passing urine frequently, bladder spasms or if you see any blood in your urine.

7. LEAVING HOSPITAL

Once your blood stem cells have engrafted and you are otherwise well enough, it is time to leave the transplant unit. Generally the doctors like you to stay close to the hospital where you have had your transplant for a short time, so that they can keep a close eye on you during the early weeks of your recovery. If your home is not within easy reach of the hospital, suitable accommodation will be arranged for you and a caregiver close to the hospital.

You may need to return to the hospital's outpatient department several times a week when you first leave the transplant unit. This is because you will still need to have your blood counts checked and the doctor will want to see you to check on your progress. You may also need some intravenous medications, fluids and blood transfusions during this time.

As time goes on and you continue to recover, you will visit the hospital less frequently.

After you leave hospital you may still need to take some medications for a few weeks or longer depending on the type of transplant you have had. It is very important that you notify your doctor or the hospital if for some reason you stop taking any of your medications.

Mixed feelings

It is quite normal to have mixed feelings about leaving hospital. It can be both an exciting and stressful time. It is normal to be a little worried about moving away from the protection of the transplant unit. It is also important to ask your doctor or nurse for any special instructions or advice you should follow after you leave the hospital.

Before you leave the unit, you may be given a special card or pamphlet with important hospital and 24 hour emergency numbers written on it, and simple instructions to follow if you have a temperature or if you feel unwell. Otherwise, ask one of the nurses to write these details down for you. Keep these details with you at all times, particularly later on when you might be traveling a long distance from your doctor and hospital. Always discuss plans to travel any distance (especially overseas) with your doctor first.

If you have any concerns or questions don't hesitate to contact your doctor or a member of the nursing team at the transplant unit or clinic. They are more than happy to talk to you over the phone, so do give them a call.

Readmission to hospital

It is not uncommon for people to be readmitted to hospital more than once after they have been discharged. Try not to let this get you down. It is important that you are given every chance to recover fully from the transplant, and this may mean a little more time in hospital.

Things to look out for

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

- a temperature of 38°C or more, feeling unwell and/or an episode of uncontrolled shivering
- bleeding or bruising, for example blood in your urine, bowel motions, coughing up blood, bleeding gums or a persistent nose bleed
- nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- diarrhoea, stomach cramps or constipation
- persistent coughing or shortness of breath
- the presence of a new rash, reddening of the skin, itching
- a persistent headache
- a new severe pain or persistent unexplained soreness anywhere
- if you cut or otherwise injure yourself
- notice pain, swelling, redness or pus around your central venous catheter
- if you think you might have had contact with someone with a 'catching' illness, for example chicken pox, measles, shingles or someone who has had a live vaccine like polio

Don't feel that you are bothering busy people at the hospital. It is in everyone's interests that you recover well from your transplant. It is also very important to deal with any problems that might arise as soon as possible. The sooner they are treated the sooner you will recover.

8. RECOVERY

Prevention of infection

Although your stem cells have engrafted, your immune system will take some time to recover to a normal level of functioning. During this time you need to take simple precautions to reduce your risk of infection. These include:

- regular hand washing
- daily showering
- regular mouth care
- avoiding close contact with people with suspected colds, flu and other viruses
- avoiding people who have been in contact with children with chicken pox or measles or other viruses, or children who have had a live vaccine such as polio
- avoiding garden soil, potting mix, compost and grass clippings
- avoiding building dust, do not plan any major DIY or home renovations
- washing your hands after handling animals - patting the dog or cat is OK but don't let them lick you

It is important that you use your common sense when it comes to the prevention of infection. Ask your doctor if you have any questions about this issue. For example, you may wish to go overseas or attend an event or gathering where you think you might be putting yourself at some risk. Your doctor will be able to advise you on the best ways of protecting yourself while living a relatively normal life during this time.

Central venous catheter care

When you leave hospital you may still have your central venous catheter in place, particularly if you continue to require regular blood and platelet transfusions. If so, the nurse will advise you and/or your partner on how to care for it when you are away from the hospital.

Mouth care

Mouth care is still important after you leave the hospital. Keeping your mouth clean, particularly after eating, will help to prevent the development of oral infections. You may be given some mouth care products to take home with you from the hospital. Remember to ask your nurse or doctor about the best way of cleaning your mouth and teeth as time goes by. It is important that you report any soreness in your mouth, bleeding gums or if an ulcer or a cold sore develops.

Appetite

Most people find that although their appetite improves once they leave hospital, it takes some time before they are able to eat as much as they used to. Many people find that food just doesn't taste or smell the same as it did before the transplant. It can take some time for your sense of taste and smell to return to normal. In the meantime, cleaning your mouth before eating and adding a little more sugar or salt can help to improve the taste of food. If you are having difficulty eating large amounts at mealtimes, try eating small amounts more frequently. It is always important to drink fluids so that you don't become dehydrated (about six to eight glasses a day). Nutritious drinks like milk shakes, smoothies and soups can make good substitutes for solid foods during this time.

A healthy and nutritious diet is important in helping your body to cope with treatment and recovery following a stem cell transplant. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a nutritionist or dietician who can advise you on planning a balanced and nutritious diet.

Reduced energy levels and exercise

Feelings of tiredness and even exhaustion can persist for several weeks after your transplant. This is normal. Your body needs time to recover from the transplant.

Feeling like you have no energy can be very frustrating, especially if you are used to leading an active and busy life. Try to get plenty of rest but also try to take a little light exercise each day. Getting out into the fresh air and doing some gentle exercise is important for your general feeling of wellbeing and it also may help to give you more energy. Some hospitals have exercise departments. Talk to the physiotherapist about an appropriate program of exercise for you.

Perhaps you are a member of a gym or sporting club. You might like to ask your doctor about gradually increasing the amount of exercise you do over time and when you might be able to return to your previous way of exercising.

Fatigue can also be a symptom of anaemia. Your blood count will be monitored regularly in the weeks and months following the transplant and you will be given a blood transfusion if you need one.

Skin care

If you find that your skin is dry and sensitive after the transplant you may need to use an appropriate moisturising cream or oil. Ask your doctor or nurse about a suitable product for you. In some cases you may be referred to the dermatology (skin) clinic at your local hospital for advice.

It is important to avoid direct sunlight on your skin as it can be particularly sensitive and burn easily. Whether you are hanging out the washing or traveling as a passenger in a car, you still need to protect your skin from the sun by wearing a hat, a long sleeved top and trousers and applying sunscreen to any exposed areas. You can go out in the early morning and late evening but do try to avoid the sunniest parts of the day.

Sexuality and sexual activity

It is likely that the experience of the transplant and all that it entails will have some impact on how you feel about yourself as a man or a woman and as a 'sexual being'. Hair loss, skin changes, and fatigue can all interfere with feeling attractive. You may experience a decrease in libido, which is your body's sexual urge or desire, sometimes without there being any obvious reason. It may take some time for things to return to 'normal'.

It is perfectly reasonable and safe to have sex as soon as you feel like it, but there are some precautions you need to take. It is usually recommended that you or your partner do not become pregnant, as some of the treatments given might harm the developing baby. As such you need to ensure that you or your partner uses a suitable form of contraception. Condoms (with a spermicidal gel) offer good contraceptive protection as well as protection against infection or irritation.

Partners are sometimes afraid that sex might in some way harm the patient. This is not likely as long as the partner is free from any infections and the sex is relatively gentle. If you are experiencing vaginal dryness a lubricant can be helpful. This will help prevent irritation.

If you have any questions or concerns regarding sexual activity and contraception don't hesitate to discuss these with your doctor or nurse, or ask for a referral to a doctor or health professional who specialises in sexuality.

Body image

Look Good…Feel Better is a free community service for women that runs programs on how to manage the appearance-related side effects of cancer treatments. Leukaemia & Blood Cancer New Zealand can provide you with further information and contact details for Look Good... Feel Better.

Remember that you will not always look like a patient in a hospital. Over time your physical appearance will improve. In the meantime it is important to do things that make you feel good about yourself. This might include enjoying the company of friends and having regular exercise and regular relaxation.

Getting back to work

The decision about when to return to work is a very personal one. It will depend on how well you are feeling, the type of work you do and your personal and financial circumstances. Many people take a few weeks or in some cases months off and then go back to work on a part-time basis, increasing their hours as they feel up to it. When to go back to work is another issue you should discuss with your doctor.

Complementary therapies

Complementary therapies are therapies which are not considered standard medical therapies. Many people however find that they are helpful in coping with their treatment and recovery from disease. There are many different types of complementary therapies. These include yoga, exercise, meditation, prayer, acupuncture and relaxation.

Complementary therapies should 'complement' or assist with recommended medical treatment, they should not be used instead as an alternative to medical treatment. If you are taking or considering taking any forms of herbal medications or supplements please discuss this with your doctor or pharmacist, as they may interfere with some of the medications you will be required to take during and after your transplant.

9. POTENTIAL LATE SIDE EFFECTS

While many of the side effects of a stem cell transplant last for a short time, some can last longer. Some side effects persist for months and occasionally years after the transplant.

Infection

After an autologous transplant, the immune system usually recovers within a few months. It is important to remember to take sensible precautions as you will be at risk of infection during this time.

Shingles is a common infection during this time. Shingles develops from the chicken pox virus. It can be quite painful and you may need to be admitted to hospital for treatment.

Early menopause

Some cancer treatments can affect the normal functioning of the ovaries. This can sometimes lead to infertility and an earlier than expected onset of menopause, even at a young age. The onset of menopause in these circumstances can be sudden and understandably, very distressing.

Hormone changes can lead to many of the classic symptoms of menopause including menstrual changes, hot flushes, sweating, dry skin, vaginal dryness and itchiness, headache and other aches and pains. Some women experience decreased sexual drive, anxiety and even depressive symptoms during this time. It is important that you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you, or refer you on to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

Osteoporosis

Oestrogen is a naturally occurring hormone that is necessary for healthy bones. Because the levels of oestrogen drop during menopause, osteoporosis may develop. The bones become weak and can break more easily.

Osteoporosis can also occur as a side effect of steroids which are sometimes used following transplantation. As such it can affect both men and women.

There are effective treatments to help prevent and treat osteoporosis.

Cataracts

A cataract is a cloudy film that develops over the pupil of the eye and makes it difficult to see properly. Cataracts are late complication of total body irradiation and usually occur within six months to five years after the transplant. Cataracts can be corrected with minor surgery.

Relapse

Unfortunately, an autologous transplant is not always successful and many people may be faced with their disease once again. Finding out that your disease has come back or relapsed can be devastating. If your disease does relapse there are sometimes ways of getting it back under control. These may include more chemotherapy and/or a second transplant or a drug to stimulate your immune system to fight the relapsed disease.

Your doctor will advise you on your chances of relapse following an autologous transplant. The success of your transplant will depend on a number of factors including the type and stage of disease you have, your general health and your age.

SOCIAL AND EMOTIONAL ISSUES

While we like to talk about things getting 'back to normal' after a transplant, for some people, things are never quite the same again. The journey you and your family have taken may have involved, at times, a whirlwind of emotions. Making the decision to undergo a transplant in the first place represents a major crossroads in a person's life. There is often a great deal of hope of achieving a cure or long term survival from the transplant, but this is often balanced by fear of the potentially serious complications of this process and the risk of the disease relapsing in the future.

While in hospital there are new challenges to face. Coping with the side effects of the transplant, feeling uncomfortable and isolated can all take their toll on your sense of wellbeing. Normal family routines are often disrupted and other members of the family may suddenly have to fulfill roles they are not familiar with, for example cooking, cleaning, and taking care of children. In some cases, families from rural areas relocate to accommodation near the hospital in the city where the transplant is taking place, so that they can be together. All of these things can be very disruptive, stressful and upsetting.

Patients and families find the experience of a transplant very challenging. Unfortunately relationships sometimes break down under the strain. It is important for your family to talk together about how you are all feeling and to seek help in dealing with issues you are facing.

If you have or have had a psychological or psychiatric condition (depression, alcohol or drug abuse) , please inform your doctor and don't hesitate to request additional support from a mental health professional.

Most people benefit greatly by the support and love of their family and friends and the care provided by the members of the transplant team. Many centres have psychologists, social workers and pastoral care workers who can assist you and your family in coping better with any psychological, emotional or financial difficulties you may be experiencing. They can also identify strategies that will help you and your family cope during and after the transplant. Leukaemia & Blood Cancer New Zealand's Support Services Coordinators are also available to help and are just a phone call away.

Some people benefit from talking to others who have gone through, or are going through a similar experience. As such, support groups can be invaluable.

Focusing on the things you can do to help yourself recover both physically and emotionally is important. Enjoying simple pleasures every day, looking to better times in the future, making plans and having hope are all important in maintaining a sense of control in a time of uncertainty.

Remember, recovery takes time. Sometimes your recovery seems slow. It may seem that you are taking one step forward and then two steps back. Look forward to things getting a little better each day and each week. Sometimes it's helpful to look back to see how far you have come in the past week or month and consider the improvements you have made.

While no one can go through the transplant for you, there are people who care for you and will also help you through the journey, by your side.

LATE EFFECTS

Late effects may develop several months or years after transplant. Some people may develop only mild problems while for others they maybe more serious. Even if you are feeling well it is important to have the regular follow up and tests recommended, it is often easier to treat problems when they are detected early and before you start having symptoms. You will need to have follow up and tests for the rest of your life.

Remember also to schedule routine check ups and screening with your GP i.e. cholesterol levels, colon, prostate, breast and cervical cancer screening.

Report any new lumps or sores, unexplained weight loss, coughs or changes in bowel habits promptly.

Maintain a healthy lifestyle by:

- Avoiding smoking
- Eating a healthy diet
- Taking regular exercise
- Taking alcohol in moderation
- Maintaining a healthy weight
- Wearing appropriate sun protection

Remember stem cell transplantation is a major undertaking and the experience you have will be unique to you, returning 'back to normal' may not be possible and a 'new normal' may need to be established.

USEFUL INTERNET ADDRESSES

The value of the internet is widely recognised, however, not all the information available may be accurate and up to date. For this reason, we have selected some of the key sites that you might find useful.

With the exception of our own website, Leukaemia & Blood Cancer New Zealand do not maintain these listed sites. We have only suggested sites we believe may offer credible and responsible information, but we cannot guarantee the information on them is correct, up to date or evidence based medical information.

Leukaemia & Blood Cancer New Zealand

www.leukaemia.org.nz

Cancer Society of New Zealand

www.cancernz.org.nz

Leukaemia Foundation of Australia

www.leukaemia.org.au

Leukaemia Research Fund (UK)

www.lrf.org.uk

Bone & Marrow Transplant Information Network

www.bmtinfonet.org

Bone Marrow Transplant Network NSW

www.bmtnsw.com.au

CancerBACKUP (A UK cancer information site)

www.cancerbackup.org.uk

The Seven Steps by Michelle Kenyon
A downloadable resource developed to assist patients through transplant and each stage of treatment. (UK)

www.lrf.org.uk/en/1/disbmthome.html

Leukaemia & Blood Cancer New Zealand has a range of books and resources that are available for loan.

For more information, including a list of resources available, please contact Leukaemia & Blood Cancer New Zealand using the contact details listed on the back of this booklet.

GLOSSARY OF TERMS

Allogeneic stem cell transplant
The transplant of blood stem cells from one person to another. The donor is usually a sister or brother or an unrelated volunteer donor.

Alopecia
Hair loss. This is a side effect of some kinds of chemotherapy and radiotherapy. It is usually temporary.

Anaemia
A reduction in haemoglobin in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia can manifest as tiredness, paleness and breathlessness.

Antibiotic
A drug used to treat bacterial infections.

Antiemetic
A drug which prevents or reduces feelings of sickness.

Autologous stem cell transplant
Where the patient's own blood stem cells are collected, stored for a period of time and returned to them after the patient has received high doses of chemotherapy, to destroy their disease.

Blood stem cells
Primitive cells found in the bone marrow capable of producing all of our blood cells.

Bone marrow
The tissue found at the centre of many flat or big bones of the body. The bone marrow contains blood stem cells from which all blood cells are made.

Bone marrow aspirate
The removal of a sample of bone marrow fluid, under local or general anaesthetic, from the bone marrow at the back of the hip or the breastbone. The sample is then examined in the laboratory.

Bone marrow biopsy
The removal of a sample of bone marrow tissue, under local or general anaesthetic, from the bone marrow at the back of the hip or the breastbone.

Bone marrow transplant
See stem cell transplant.

Cancer
A disease characterised by uncontrolled growth, accumulation, division and maturation of cells; often called malignant disease or neoplasm. Cancer cells grow and multiply, eventually causing a mass of cancer cells known as a tumour.

Central nervous system (CNS)
The brain and spinal cord.

Central venous catheter (CVC)
A line or tube passed through the large veins of the neck, chest or groin and into the central blood circulation. It can be used for taking samples of blood, giving intravenous fluids, blood, chemotherapy and other drugs without the need for repeated needles.

Chemotherapy
Treatment using anti-cancer drugs. Single drugs or combinations of drugs may be used to kill and prevent the growth and division of cancer cells. Although aimed at cancer cells, chemotherapy can also affect rapidly dividing normal cells and therefore causes some common side effects including hair loss, nausea and vomiting and mucositis. The side effects of chemotherapy are usually temporary and reversible.

Conditioning therapy
The treatment given prior to transplant to prepare the bone marrow for transplant. It can be either chemotherapy or radiotherapy or a combination of both.

Cryopreservation
The storage of blood stem cells at a very low temperature. The technique used does not harm the stem cells and ensures that they remain intact and functional when they are thawed out months and even years later.

Cure
This means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Cytokines
See growth factors.

Engraftment
When blood stem cells find their way to the bone marrow, grow and produce all types of blood cells.

Full blood count
A blood test that measures the number of white cells, red cells and platelets in your blood.

G-CSF (granulocyte-colony stimulating factor)
A naturally occurring and man-made growth factor which stimulates bone marrow's stem cells to produce more white cells, particularly neutrophils.

Growth factors
A complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy, or bone marrow or peripheral blood cell transplantation, e.g. G-CSF (granulocyte colony stimulating factor).

Haemopoiesis
Blood cell formation.

Haematologist
A doctor who specialises in the diagnosis and treatment of diseases of the blood, bone marrow and immune system.

Haemorrhagic cystitis
A potential side effect of conditioning therapy characterised by painful bladder spasms and blood in the urine.

High-dose therapy
The use of higher than normal doses of chemotherapy to kill off resistant and left over cancer cells.

Immune system
The body's main defense system against infection and disease.

Immunocompromised
When someone has decreased immune function.

Leukaemia
Cancer of the blood and bone marrow characterised by an overproduction of abnormal and often immature blood cells.

Lymphoma
Cancer that arises in the lymphatic system.

Mucositis
An inflammation of the lining of the mouth, throat or gut.

Myeloma
Cancer that arises in mature B-lymphocytes known as plasma cells, which have undergone a malignant change.

Neutropenia
A reduction in the number of circulating neutrophils, an important subset of the white blood cell family. Neutropenia is associated with an increased risk of infection.

Neutrophils
Neutrophils are the most common type of white cell. They are necessary to protect the body against bacteria.

Osteoporosis
A condition whereby the bones become weak and can break more easily.

Peripheral blood stem cell collection
The collection of stem cells from the circulating blood stream.
Plasma
The straw coloured fluid that makes up part of the blood

Platelets
Tiny disc-like fragments that circulate in the blood and play an important role in clot formation.

Prognosis
An estimate of the likely course of a disease.

Radiotherapy (radiation therapy)
The use of high energy x-rays to kill cancer cells and shrink tumours.

Red cells
Blood cells that circulate in the blood carrying haemoglobin. The haemoglobin binds with oxygen and carries it to all the tissues of the body. Red cells are also called erythrocytes.

Relapse
The return of the original disease.

Stem cell mobilisation
The use of chemotherapy and/or growth factors to move blood stem cells out of the bone marrow and into the blood stream.

Stem cell transplant (haemopoeitic or blood stem cell transplant)
General name given to bone marrow and peripheral blood stem cell transplants. These transplants are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of cancers including leukaemia, lymphoma, myeloma and other diseases.

Subcutaneous injection
An injection under the skin.

Thrombocytopenia
A reduction in the normal platelet count.

Total body irradiation (TBI)
The exposure of the whole body to high-doses of ionising radiation. TBI is usually used in combination with chemotherapy as conditioning therapy for people undergoing an allogeneic transplant.

Veno-occlusive disease (VOD)
A complication of stem cell transplantation whereby the blood vessels that pass through the liver become blocked. Blood flow in the liver is reduced leading to toxic changes in the liver and a reduction in normal liver function.

White cells
Specialised cells of the immune system that protect the body against infection. There are five main types of white cells: neutrophils, eosinophils, basophils, monocytes and lymphocytes.

Please refer to the Dictionary of Terms booklet for further definitions.

Please send me a copy of the following patient information booklets:

- ☐ Dictionary of Terms
- ☐ Haematology Patient Diary
- ☐ Clinical Trials
- ☐ Autologous Stem Cell Transplants
- ☐ Allogeneic Stem Cell Transplants
- ☐ Myeloproliferative Disorders
- ☐ Myelodysplastic Syndromes
- ☐ Myeloma
- ☐ Acute Lymphoblastic Leukaemia in Adults
- ☐ Acute Lymphoblastic Leukaemia in Children
- ☐ Acute Myeloid Leukaemia
- ☐ Chronic Lymphocytic Leukaemia
- ☐ Chronic Myeloid Leukaemia
- ☐ Hodgkin Lymphoma
- ☐ Non-Hodgkin Lymphoma
- ☐ My Guide to Blood Cancer - for adolescents and young adults

Or information on:

- ☐ Leukaemia & Blood Cancer New Zealand's Support Services
- ☐ How to make a bequest to Leukaemia & Blood Cancer New Zealand

Newsletters:

- ☐ LifeBlood
- ☐ Leukaemia Today
- ☐ Lymphoma Today
- ☐ Myeloma Today

Name: _____

Address: _____

Postcode: _____ Phone: _____

Email: _____

Send to: Leukaemia & Blood Cancer New Zealand
PO Box 99182, Newmarket, Auckland 1149
Phone: 09 638 3556 or 0800 15 10 15
Email: info@leukaemia.org.nz

Leukaemia & Blood Cancer New Zealand will record your details to facilitate services and keep you informed about leukaemia and related blood disorders. We value your privacy and take all the necessary steps to protect it. You can access, change or delete this information by contacting us at info@leukamia.org.nz

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Contact details of Haematology Centres throughout NZ

Centre	Address	Phone
Whangarei Hospital	Hospital Road Whangarei	(09) 430 4100
North Shore Hospital	Shakespeare Road Takapuna	(09) 486 1491
Auckland Hospital	Park Road Grafton	(09) 379 7440
Starship Hospital	Park Road Grafton	(09) 379 7440
Middlemore Hospital	Hospital Road Otahuhu	(09) 276 0000
Waikato Hospital	Pembroke Street Hamilton	(07) 839 8899
Thames Hospital	Mackay Street Thames	(07) 868 6550
Tauranga Hospital	Cameron Road Tauranga	(07) 579 8000
Hastings Hospital	Omahu Road Hastings	(06) 878 8109
Rotorua Hospital	Pukeroa Street Rotorua	(07) 348 1199
Whakatane Hospital	Stewart Street Whakatane	(07) 306 0999
Palmerston North Hospital	Ruahine Street Palmerston North	(06) 356 9169
Wellington Hospital	Riddiford Street Newtown	(04) 385 5999
Christchurch Hospital	Riccarton Avenue Christchurch	(03) 364 0640
Dunedin Hospital	Great King Street Dunedin	(03) 474 0999
Invercargill Hospital	Kew Road Invercargill	(03) 218 1949

leukaemia & blood cancer new zealand

our mission is to care, our vision is to cure

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09/2015 V2
Charities Commission no. CC24498