

Understanding Autologous Transplants

A guide for patients and
families



Leukaemia
Foundation

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The 2010 revisions were provided by Rosita van Kuilenberg and Diana Moore. The Leukaemia Foundation values feedback from patients, their families, carers and health care professionals working with people with blood disorders. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact the National Manager, Support Services at info@leukaemia.org.au.

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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 understandable. 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. These are highlighted in *italics*. Their meaning is explained 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 particular circumstances at all times with your doctor and treatment team.

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

THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders. Since 1975, the Foundation has been committed to improving survival for patients and providing much needed support. It does not receive direct ongoing government funding, relying instead on the continued and generous support of individuals and corporations to develop and expand its services.

The Foundation provides a range of **free** support services to patients and their carers, family and friends. This support may be offered over the telephone, face to face at home, hospital or at the Foundation's accommodation centres, depending on the location and individual needs. The Foundation provides practical and emotional assistance to patients and carers, including access to information, education and peer support through a variety of programs.

The Leukaemia Foundation funds leading research into better treatments and cures for leukaemias, lymphomas, myeloma and related blood disorders. Through its National Research Program, the Foundation has established the PwC Foundation Leukaemia and Lymphoma Tissue Bank and the Leukaemia Foundation Research Unit at the Queensland Institute for Medical Research. In addition, the Foundation funds research grants, scholarships and fellowships for talented researchers and rural health professionals.

Support Services



"Foundation staff provide patients and their families with information and support across Australia"

The Leukaemia Foundation has a team of highly trained and caring Support Services staff with qualifications and/or experience in nursing or allied health that work across the country. They can offer individual support and care to you and your family when it is needed.

Support Services may include:

Information

The Leukaemia Foundation has a range of booklets, fact sheets and resources such as this one that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from the website. Translated versions (in languages other than English) of some booklets and fact sheets are also available from our website.

Education & support programs

The Leukaemia Foundation offers you and your family disease-specific and general education and support programs throughout Australia. These programs are designed to empower you with information about various aspects of diagnosis and treatment and how to support your general health and well being.

Emotional support

A diagnosis of a blood cancer/disorder can have a dramatic impact on a person's life. At times it can be difficult to cope with the emotional stress involved. The Leukaemia Foundation's Support Services staff can provide you and your family with much needed support during this time. They may refer you or a loved one to a specialist if professional counselling services are required.

Online discussion forum

The Foundation has established an on-line information and support network for people living with leukaemia, lymphoma, myeloma, or a related blood disorder. Registration is free and participants can remain anonymous, see www.talkbloodcancer.com

Telephone Discussion Forums

This support service enables anyone throughout Australia who has or has had a bone marrow transplant to share their experiences, provide tips, education and support others in a relaxed forum. Each discussion is facilitated by a member of the Leukaemia Foundation Support Services Team who has a background in haematology nursing.

Accommodation

Some patients and carers need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation staff can help you to find suitable accommodation close to your hospital or treatment centre. In many areas, the Foundation's fully furnished self-contained units and houses can provide a 'home away from home' for you and your family.

Transport

The Foundation also assists with transporting patients and carers to and from hospital for treatment. Courtesy cars and other services are available in many areas throughout the country.

Practical Assistance

The urgency and lengthy duration of medical treatment can affect you and your family's normal way of life and there may be practical things the Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for patients who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

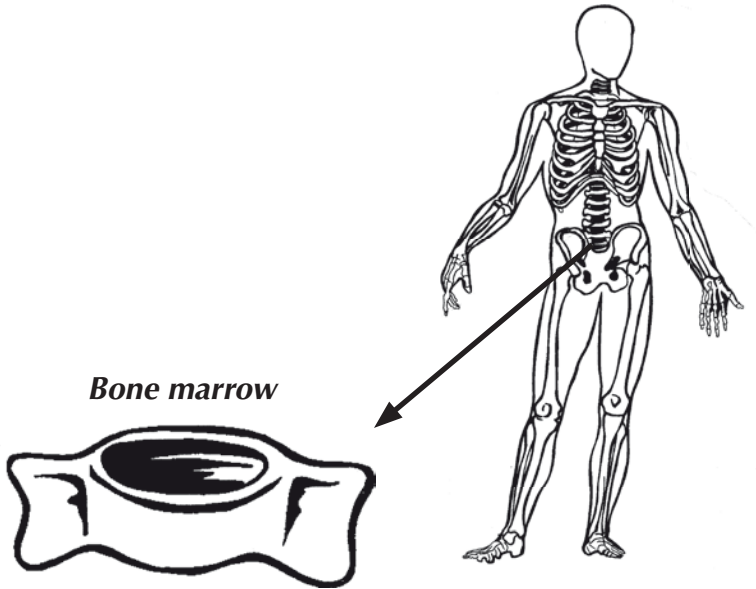
Young Adults

A website for young adults has been developed called "Revive". This site has information specifically designed for young adults and contains a discussion forum to allow patient to patient interaction and support. The site is www.teamrevive.com

Contacting us

The Leukaemia Foundation provides services and support in every Australian state and territory. Every person's experience of living with these blood cancers and disorders is different. Living with leukaemias, lymphomas or myeloma is not easy, but you don't have to do it alone. Please call **1800 620 420** (Freecall) to speak to a local support service staff member or to find out more about the services offered by the Foundation. Alternatively, contact us via email by sending a message to info@leukaemia.org.au or visit www.leukaemia.org.au

BONE MARROW, STEM CELLS AND BLOOD CELL FORMATION



Bone marrow

Bone marrow is the spongy tissue that fills the cavities inside your bones. Most of your blood cells are made in your bone marrow. The process by which blood cells are made is called *haemopoiesis*.

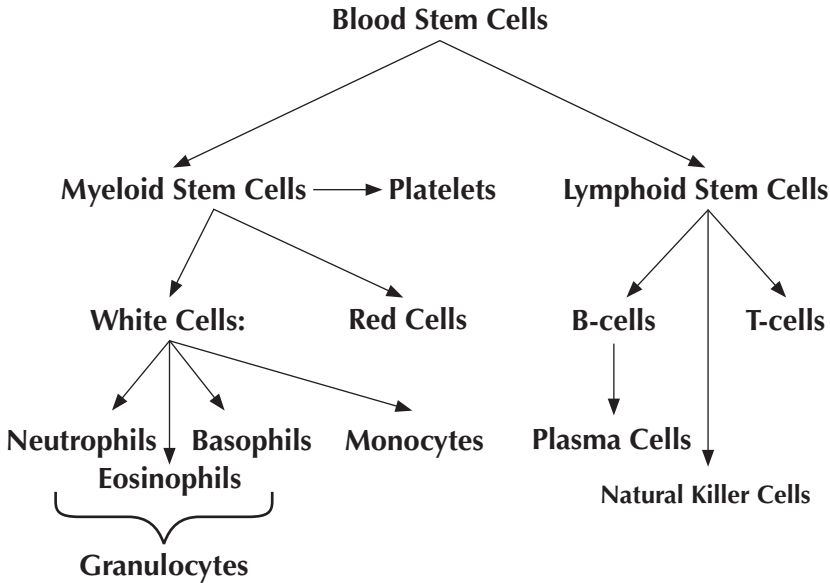
As an infant, haemopoiesis takes place at the centre of all bones. In later life, it is limited to the hips, ribs, spine, skull, breastbone (*sternum*) and the ends of your long bones. Some of you may have had a *bone marrow biopsy* taken from the bone at the back of your hip (the *iliac crest*) or the 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 cells, white cells and platelets. All blood cells need to be replaced because they have limited life spans.

There are two main families of stem cells, which develop into various types of blood cells.

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

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



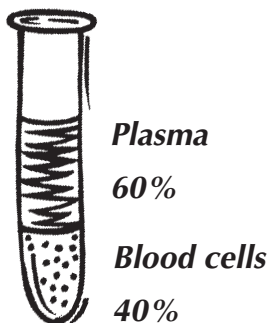
Growth factors and cytokines

All normal blood cells have a limited survival in circulation and need to be replaced on a continual basis. This means that the bone marrow remains a very active tissue throughout your life. Natural chemicals in your blood called *growth factors* or *cytokines* control the process of blood cell formation. Different growth factors stimulate the blood stem cells in the bone marrow to produce different types of blood cells.

These days some growth factors can be made in the laboratory (synthesised) and are available for use in people with blood disorders. For example, *granulocyte-colony stimulating factor* (G-CSF) stimulates the production of white cells called *neutrophils* while *erythropoietin* (EPO) stimulates the production of red cells. Unfortunately, drugs to stimulate platelet production have been less successful but research is continuing in this area.

Blood

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



Red cells and haemoglobin

Red cells contain haemoglobin (Hb), which gives the blood its red colour and transports oxygen from the lungs to all parts of the body. The body uses this oxygen to create energy.

*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*

Red cells are by far the most numerous blood cell and the proportion of the blood that is occupied by blood cells is called the *haematocrit*. A low haematocrit suggests that the number of red cells in the blood is lower than normal.

*The normal haematocrit range for a man is
approximately 40 - 52%
The normal haematocrit range for a woman is
approximately 36 - 46%*

Anaemia

Anaemia is a reduction in the number of red cells, or low haemoglobin. Measuring either the haematocrit or the haemoglobin will provide information regarding the degree of anaemia.

If you are anaemic you will 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. In this situation a red cell transfusion may be given to restore the red cell numbers and therefore the haemoglobin to more normal levels.

White cells

White cells, also known as leukocytes, fight infection. There are different types of white cells that fight infection together and in different ways.

<i>Neutrophils</i>	<i>kill bacteria and fungi.</i>
<i>Eosinophils</i>	<i>kill parasites.</i>
<i>Basophils</i>	<i>work with neutrophils to fight infection.</i>
<i>Monocytes</i>	<i>work with neutrophils and lymphocytes to fight infection; they also help with antibody production and act as scavengers to remove dead tissue. These cells are known as monocytes when they are found in the blood and macrophages when they migrate into body tissues to help fight infection.</i>
<i>T-cells</i>	<i>kill viruses, parasites and cancer cells; produce cytokines</i>
<i>B-cells</i>	<i>make antibodies which target microorganisms</i>

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

The normal adult total white cell count varies between 3.7 and 11 x 10⁹/L

Neutropenia

Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1 ($1 \times 10^9/L$) you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections.

*The normal adult neutrophil count varies between
2.0 and $7.5 \times 10^9/L$*

Platelets

Platelets are disc-shaped cellular 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 injury, stick together and form a plug to help stop the bleeding.

*The normal adult platelet count varies between
150 and $400 \times 10^9/L$*

Thrombocytopenia

Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops below 20 ($20 \times 10^9/L$) you are at risk of bleeding and are likely to bruise easily. Platelet transfusions are sometimes given to bring the platelet count back to a safe level.

The normal blood counts provided here may differ slightly from the ones used at your transplant centre. You can ask for a copy of your blood results, which should include the normal values for each blood type. In children, some normal blood cell counts vary with age (see table below).

Normal range of blood values for children						
	1 month	1 year	3 years	5 years	9 years	16 years
Haemoglobin g/L	102-130	104-132	107-136	110-139	113-143	115-165 F 130-180 M
White cell count x 10 ⁹ /L	6.4-12.1	5.4-13.6	4.9-12.8	4.7-12.3	4.7-12.2	3.5-11
Platelets x 10 ⁹ /L	270-645	205-553	214-483	205-457	187-415	150-450
Neutrophils x 10 ⁹ /L	0.8-4.9	1.1-6.0	1.7-6.7	1.8-7.7	1.8-7.6	1.7-7.0

If your child is having a 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 and marrow stem cell transplantation (commonly known as BMT or *Stem Cell Transplantation*) is used to treat a range of diseases. These include haematological (blood) diseases as well as some non-haematological diseases. The following list gives you some examples of conditions which are treated with stem cell transplantation:

- leukaemias
- lymphomas
- myeloma
- amyloidosis
- some solid tumours (such as relapsed testicular cancer and relapsed Ewing's sarcoma.)
- aplastic anaemia
- some immune system disorders (for example sclerodema)

How does it work?

All 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.

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 blood cells, white blood cells or platelets*.

High-dose cancer treatment aims to destroy disease and consequently destroys the precious population of blood



stem cells, which then need to be replaced. In some cases, these stem cells are defective because of disease and need to be replaced with healthy stem cells. In short, a stem cell transplant is necessary to ensure that the bone marrow is repopulated with healthy stem cells following high-dose treatment. The new stem cells will rebuild your body's blood and immune systems. The recovery of these systems is vital for your survival.

The word '*transplant*' can be a little misleading as it conjures up inaccurate images of a surgical procedure. In reality, on the day of the 'transplant', stem cells are simply given intravenously (through a vein into the blood stream) almost like a blood transfusion. From here they travel to the bone marrow, set up home (that is they *engraft*) 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 bone marrow stem cells which have been collected from the peripheral blood stream while a *bone marrow transplant (BMT)* uses stem cells collected directly from the bone marrow. Another source of stem cells is from the umbilical cord blood.

You will find that many people will use 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-a-ic). This booklet mainly describes autologous stem cell transplants.

In 2008, a total of 1,126 stem cell transplants were carried out in Australia. Of these:

- 744 were autologous transplants
- 382 were allogeneic transplants

Autologous

In autologous stem cell transplants. The patient's own peripheral blood stem cells are collected in advance (when their disease is stable, or in remission), stored and then returned to their blood stream at a later date after they receive high-dose treatment (chemotherapy with or without radiotherapy).

Most people have a single autologous transplant. Others depending on the type of cancer may need to 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 minimise the chances of the cancer coming back (relapsing).

Allogeneic

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

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 bone 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 specialist consultant doctor (haematologist or medical oncologist) will discuss with you the best option for your particular situation.

**There is a separate Leukaemia Foundation booklet called 'Understanding Allogeneic Transplants - A guide for patients and families'.*

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, especially high risk treatments, can be very stressful. Some

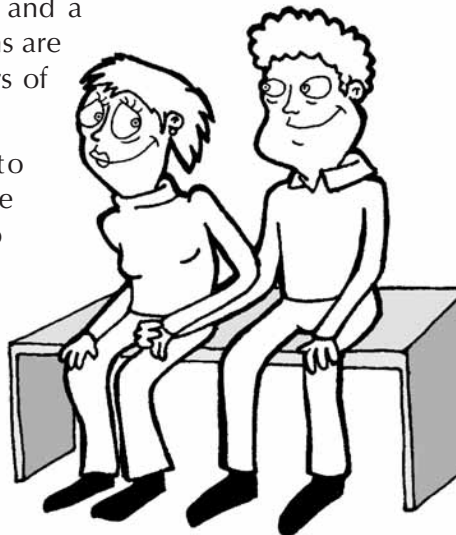
people do not feel that they have enough information to make such decisions while others

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 specialist doctor, make a list of the questions you want to ask. It is handy to keep a notebook or some paper and a pen handy 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 stem cell transplant may not be considered the best way to treat their disease. Other approaches, such as those using chemotherapy alone, may offer some people just as good or an even better chance of survival, free of disease. For others, a transplant may be the only option which offers a prospect of cure, or long term 'control' of their disease.

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

Your treating specialist doctor will spend time discussing with you and your family what they feel 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.

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 re-test previous treatments given in new ways to see if they work better (more effective). 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 the government.**

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.*

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 (this is known as 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.

** You can also refer to the information sheets about clinical trials on our website www.leukaemia.org.au. There is also a list of questions you can ask your doctor.*

SOURCES OF AUTOLOGOUS STEM CELLS

Stem cells are usually collected when the patient's disease is in remission or their disease is in a more stable state.

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

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

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) using a special needle that is passed through the skin and into the centre of the hip 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.

If you are having a bone marrow harvest you may be asked to give (donate) one or two bags of blood in the weeks leading up to the procedure. This blood is then given back to you as a blood transfusion during or after the bone marrow harvest. This is to replace the red blood cells which have been collected in the bone marrow fluid.

Following the procedure, your bone marrow is processed in the Stem Cell Laboratory to remove fragments of bone, red cells, fat and other unwanted tissue. It is then frozen (cryopreserved) and stored in special tanks until the day of your stem cell transplant. Blood stem cells can remain frozen for many months or years until they are needed.

Due to improvements in peripheral blood stem cell harvest procedures, bone marrow harvest are now rarely performed for autologous stem cell transplants.

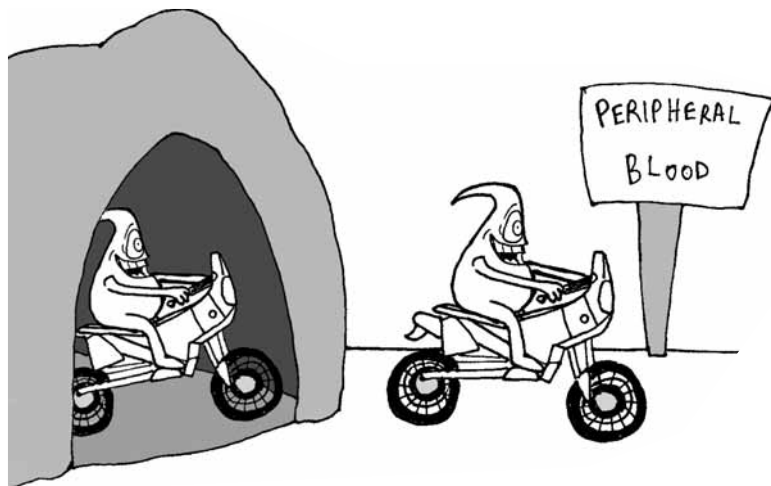
Peripheral blood stem cell harvest

Stem cell mobilisation

It is more common these days to collect bone marrow stem cells from the blood stream (called the peripheral blood). Stem cells normally live in the bone marrow. They can however 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 mobilisation* and usually involves the use of chemotherapy in combination with colony stimulating growth factor injections - usually G-CSF. G-CSF promotes the production of stem cells in the bone marrow which then leak out into your normal blood circulation in your veins.

You may need to be admitted to hospital overnight for your mobilising chemotherapy or it may be given in the outpatients' 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. A few days after your chemotherapy has been given your blood cell counts will decrease (particularly your white blood cell count). Your blood cell count will increase as your bone marrow stem cells begin to 'recover' from the effects of the chemotherapy, as they begin to multiply, increasing in numbers in an attempt to replace vital blood cells damaged as result of the chemotherapy.



Growth factor injections are usually given for several days, usually starting 24 hours after the completion of your chemotherapy. Your nurse will teach you, or a family member or a friend on how to inject the G-CSF. Regular blood tests will be taken over the following week to 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 (known as cell count recovery).

It is important to keep taking your injections of growth factors 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 some analgesia to relieve any discomfort you may be feeling. **DO NOT TAKE ASPIRIN-BASED MEDICATIONS.**

Stem cell collection

Stem cells are collected from your blood stream by passing all your blood through a special machine called a *cell separator (or apheresis machine)*. This procedure is usually performed in the Apheresis Unit by specially trained nurses. A peripheral blood stem cell collection usually takes three (3) to four (4) hours and may take a couple of days to collect the number of stem cells required for your stem cell transplant.

When your stem cells have been collected they are then frozen (cryopreserved) in the dedicated stem cell laboratory and stored in tanks until the day of your stem cell transplant. Blood stem cells can remain frozen for many months or years until they are needed. Various laboratories have different rules about how long these cells may be stored. Ask your doctor about the rules of your treatment facility.

Before commencing the stem cell collection process your doctor or apheresis nurse will assess the veins in your arms to see if they are suitable for this procedure. Blood is to be drawn from a *cannula* (plastic needle) placed in a large vein in one arm and returned to a cannula in a large vein in the other arm. If your veins are not suitable, a special tube called a central venous catheter (also called central line or central venous access device) may need to be inserted before the collection of your stem cells. This central venous catheter is inserted into a vein just above your clavicle

(collar) bone allowing access into your blood stream via one of the bigger veins in your body.

The apheresis machine draws blood from the body, spins the blood very quickly, collects the part that contains the blood stem cells, and returns the rest of the blood back to the body. This is a continuous process.

As the procedure is very long, you might like to bring along a book, a video, some music or a friend for company. Sometimes you cannot move your arms very much if the cannulas have been inserted in them. If you do become uncomfortable during the procedure, let the nurses know and they will assist you to feel as comfortable as possible.

STAGES OF A STEM CELL TRANSPLANT

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

It might be useful to think about your stem cell 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, dieticians, pharmacists, physiotherapists, 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 other times during the process. This is normal and your family and friends can play an important role in supporting you in many ways throughout your journey.

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 stem cell transplant
2. Pre-stem cell transplant 'work-up'
3. Conditioning therapy
 - Chemotherapy
 - Total body irradiation
 - Common side-effects
4. Stem cell transplant (stem cell re-infusion) also known as 'Day 0'
5. Pre-engraftment
 - the early days
 - waiting for engraftment
6. Potential stem cell transplant complications
7. Leaving hospital
8. Potential late side-effects
9. Recovery

1. PLANNING FOR YOUR TRANSPLANT

This section of the booklet deals with the things you need to plan before you start your stem cell transplant.

The issues covered here are:

- timing
- things to consider
- fertility

Timing

While it is not usually possible to give an exact date, you will be given some indication of when your stem cell 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. However, for some patients, the timing of the stem cell transplant may be critical and these events may have to be put on hold until you have recovered from your stem cell transplant.



Things to consider

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

In general it takes between three and six months to recover from an autologous stem cell transplant.

It is important to feel that you are prepared as much as possible for your 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 Centrelink 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 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
- delegating a principal point of contact in your family or close circle, so that you and your main carer can let them provide updates to the extended family, your circle of friends and contacts

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

The health care team (usually a social worker) can help you with organising affordable and comfortable accommodation for your family or close friends while you are in hospital, especially if they live far away. They may also be able to help with travel costs. You may also require accommodation for some time after your transplant. This is because you may need to stay close to the hospital for a few weeks so that the doctors can keep a close eye on you and monitor your recovery.

The **Leukaemia Foundation** may be able to provide assistance with accommodation and travel to and from the hospital. For further information contact the Leukaemia Foundation in your capital city or phone 1800 620 420 (Freecall).

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 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. In men sperm production can be impaired. The effects of treatment on your fertility can be permanent or reversible. This 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 foetus. Therefore it is important to avoid becoming pregnant and to use a suitable form of contraception for some time after your transplant.

For your information we have included below a brief description 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, men may have sperm of low quantity and quality at the time of diagnosis.

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 time. 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 is still a fairly new approach to protecting your fertility. 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.

It is important to understand that the methods are still at early stages of development and use 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.

Speaking with the fertility experts, in consultation with your haematologist, is critical (if time allows) before treatment commences.

2. PRE-TRANSPLANT 'WORK UP'

This section of the booklet deals with the preparation that's needed before you start your stem cell transplant. This is commonly called the 'pre-stem cell transplant workup' and addresses your:

- pre-stem cell transplant tests
- dental check
- blood tests
- central venous catheter

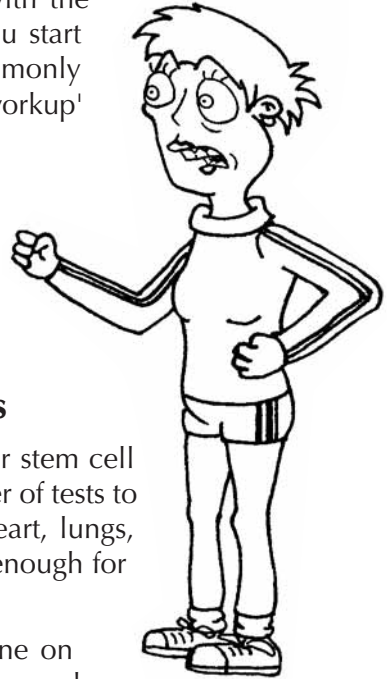
Pre-stem cell transplant tests

During the weeks leading up to your stem cell transplant you will undergo a number of tests to make sure that your vital organs (heart, lungs, liver and kidneys) are physically fit enough for the high dose chemotherapy.

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 that you may need to have:

- chest x-ray
- heart function tests (for example a gated heart pool scan, ECG or an electrocardiogram (ECHO))
- CT scans
- respiratory (lung) function tests
- eye tests
- bone density scan



- 24-hour urine collection
- bone marrow examination
- lumbar puncture
- pregnancy test

Dental check

A dental check-up is advised to ensure that any potential dental problems are cleared up before starting the high dose chemotherapy +/- radiation treatment for the stem cell transplant. It is important to maintain good dental and oral hygiene during and after your transplant to prevent any problems and your nurse will teach you how to properly care for your mouth and teeth.

Blood tests

The following is a list of blood tests commonly carried out before the transplant. Some of which will be repeated frequently throughout the transplant in monitoring and accessing your progress.

- full blood count
- blood grouping
- kidney (renal) function
- liver function
- thyroid function
- clotting screen
- iron levels
- blood glucose
- screening for viral and bacterial infections - such as human immunodeficiency virus (HIV), hepatitis, cytomegalovirus (CMV), syphilis.

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, your central venous catheter will be inserted before the transplant (see below) and blood tests can be taken directly from this special line without causing you discomfort from frequent needle pricks.

Central venous catheter (CVC)

During the stem cell transplant process you will need to have a number of intravenous (into the vein) therapies. These include fluids, chemotherapy, antibiotics, drugs and blood transfusions including red cells and platelets. You will also need to have blood taken, often every day, to check on your progress. Blood tests can be painful when taken from the veins in your arms and it is for these reasons that a central venous catheter or central line is inserted prior to your high dose chemotherapy and stem cell transplant.

A central venous catheter is a special type of catheter (or tube) inserted into a large vein in your neck or upper chest. The catheter tip will lie at the top of your heart providing direct access to your blood circulation to allow the safe delivery of the various drugs and therapies during your stem cell transplant.

There are several different types of central lines used. The ones most commonly used for transplant patients have one, two or three lumens or tubes. 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 your own stem cells are transplanted (re-infused) into you, you will have a few days of what is known as *conditioning therapy*. Conditioning therapy is used to help destroy any left over cancer cells in your body and to make or create a space in your bone marrow for the new stem cells to grow. It is more common to be admitted to hospital for this part of the transplant process but some patients can 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 it involves high-dose chemotherapy (and in some cases with radiation therapy). Single chemotherapy drugs or a combination of two or more chemotherapy drugs may be used over a number of days. There are many different combinations of chemotherapy drugs used. Commonly used combinations in autologous stem cell transplantation include:

- *Carmustine* (BCNU), *Etoposide* (VP-16), *Cytarabine* and *Melphalan* (BEAM) with or without Intrathecal Methotrexate (lumbar puncture)
- Melphalan (Mel)
- Cyclophosphamide, Etoposide and Carmustine (BCNU) (CVB)

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

The conditioning therapy chosen for you will depend on several factors which include your type of disease, your age and general health and the type of transplant.

Conditioning (transplant) protocols

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

The conditioning therapy is usually given within the week preceding your stem cell 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 the stem cells. 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 lines (or lumens) of your central venous catheter, or in tablet form.

Some chemotherapy drugs require you to have up to six 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 body, 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 intravenous fluid, it is important to monitor the amount of fluid going in and coming out of your body. This can be measured through your urine output and your weight. The nurses may ask you to pass all your urine into a bottle or a pan, so that it can be measured and tested, in addition to checking your weight on a daily basis.

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.

Radiation therapy

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.

Some people may require localised radiation therapy to specific sites if they have bulky-disease. This particularly may be the case with non-Hodgkin lymphomas.

Common side-effects of conditioning therapies

Now let's look at some of the common side-effects of the conditioning therapies some of which may last for a short time, some can last longer.

Nausea and vomiting

Nausea and vomiting is often associated with high-dose chemotherapy and total body irradiation but 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.

Do not be too concerned if you are unable to eat or drink much at this time, but report any changes to your treating team. The doctors and nurses will closely monitor your condition every day. They may decide to give you some additional fluid through a vein (intravenously) to stop you becoming dehydrated if the nausea and/or vomiting become severe.

Low blood cell counts

Your white 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 too.

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

Mucositis

Mucositis is the inflammation of the cells lining your mouth and throat causing mouth ulcers. Your gut may also become inflamed causing diarrhoea. *Mucositis* is a common side-effect of both chemotherapy and radiotherapy. It usually appears about three (3) to four (4) days after your conditioning therapy has been completed. *Mucositis* begins to get better, as soon as your new stem cells re-grow (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 your doctor or nurse when your mouth or throat is starting to feel dry, sore, or when your saliva is getting thick or if you are having difficulty swallowing. It is also important to tell your doctor and nurse when you have diarrhoea. All these changes can be signs of '*mucositis*'.

Mouth ulcers 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 in your central line.

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 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.

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 or anal area 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.

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 when you are trying to move your bowels. You may need a gentle laxative to help soften your stool.

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 savoury 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.

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 you are not eating what you 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.

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.

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. Try to eat small meals as frequently as you feel like it.

You might like to ask your family to bring your favourite 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.

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 or scarf 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.

Infertility

As we mentioned previously, treatment can damage your fertility. See page 27 for more details.

Tiredness, tension and stress

You may feel more tired than usual during the days, weeks (and even months) 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 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 re-infusion) is carried out on day 0 (zero) of the transplant process. Some protocols may have two day zeros. This happens when the volume of stem cells is too large to be re-infused in one day.

The transplant itself is a relatively straight forward process. The stem cells are infused through your central venous catheter, rather like a pink-coloured blood transfusion. This can take between thirty 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, sweet corn or asparagus) during and for up to twenty four 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 or infused. 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 - the early days

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 ten and twenty eight days.

The transplant team will take a 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 keep an eye on 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 deals with 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
- hepatic veno-occlusive disease (VOD) or sinusoidal obstruction syndrome (SOS)
- haemorrhagic cystitis

Many of the complications which occur in the first few weeks after a 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 usually 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 may 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 line, chest, gut and in your bladder. Causes of infections include bacteria, viruses and fungi. You may be prescribed routine preventive antibiotics, anti-viral and anti-fungal medication during the transplant and for some 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 line 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, faeces 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 you 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 consequence of low white cell counts during 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 us take a look at some of them now.

Hand washing

Hand washing is the single most effective way of reducing the spread of microorganisms that cause infection. Antibacterial soaps and/or lotions are 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 with this soap 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, help you sleep better 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 close contact with anyone with colds, flu, chicken pox, measles or any other infectious or 'catching' illness or anyone who has had a live vaccine such as polio. **No visitors are allowed if they are sick.**

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 microorganisms 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. Thin-skinned fruits need to be washed thoroughly. You should avoid salads, yogurts and soft cheese, which can all harbour bacteria. Your dietician may advise you on some exceptions to this. 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 or low bacterial diets* for when your white cell count is low.

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 cell transfusions are often needed in the weeks following the transplant. If your platelet count is low you will be

given a platelet transfusion to reduce your risk of bleeding. Red 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 twenty four hours).

Transfusions these days are safe and usually don't cause any complications. You will be carefully monitored throughout the transfusion. Remember to call someone, however, if you are feeling hot, cold, 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 and sometimes filtered 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.

Hepatic veno-occlusive disease (VOD) or sinusoidal obstruction syndrome (SOS)

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.

Haemorrhagic cystitis

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

Remember to tell your doctor or nurse if you are experiencing any of the symptoms of cystitis such as pain on passing urine, passing urine frequently and 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 to keep you close to the hospital where you have had your transplant, 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 your family. The health care team (usually the social worker) and the Leukaemia Foundation may help you with these arrangements.

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 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 will 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 twenty-four hour emergency numbers written on it as well as 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 travelling a long distance from your doctor and hospital. If you are travelling interstate, ask your doctor for the contact details of key hospitals you could go to if you need help.

If you have any concerns or questions do not hesitate to contact your doctor or the nurses at the transplant unit or clinic. They are more than happy to talk to you over the phone.

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. 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 (even if it returns to normal) and/or an episode of uncontrolled shivering (a rigor)
- **bleeding** or **bruising**, for example blood in your urine or 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
- if you notice **pain, swelling, redness** or **pus** around your central line
- if you think you might have had contact with someone with a 'catching' or infectious illness, for example **chicken pox, measles, shingles** or someone who has had a **live vaccine**

Do not 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.

Relapse

Unfortunately, an autologous transplant is not always successful and some 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 often 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.

8. 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. As 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. Simple physical activity, including weight-bearing exercise (walking) helps to prevent osteoporosis.

9. RECOVERY - Take good care of yourself!

Prevention of infection

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

- regular hand washing
- daily shower
- regular mouth care
- avoiding close contact with people with suspected colds, flu and other viruses
- avoiding people who have been in contact with children who have chicken pox, measles or other viruses, or children who have had a live vaccine such as polio
- avoiding garden soil and potting mix
- washing your hands after handling animals - patting the dog or cat is okay 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, as well as organising its removal when treatment is finished.

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. 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 dietitian 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 and months 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

**The Leukaemia Foundation has developed a booklet: 'Eating well: A practical guide for people living with leukaemias, lymphomas and myeloma'. Contact us for a copy.*

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 or physical activity 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 of course 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. Avoid using soap when you are bathing as this causes further dryness. 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, particularly if you have had total body irradiation. Your skin is particularly sensitive and can burn easily. Whether you are hanging out the washing or travelling 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 pants as well as applying sunscreen to any exposed areas. You can go out in the early morning and late evening but 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.

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. Finally, 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 and men that runs programs on how to manage the appearance-related side-effects of cancer treatments. You might like to visit their website at www.lgfb.org.au or Freecall them on 1800 650 960.

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 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.

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 crossroad 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 fulfil 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 a psychological or psychiatric condition, please inform your doctor and don't hesitate to request additional support from a mental health professional.

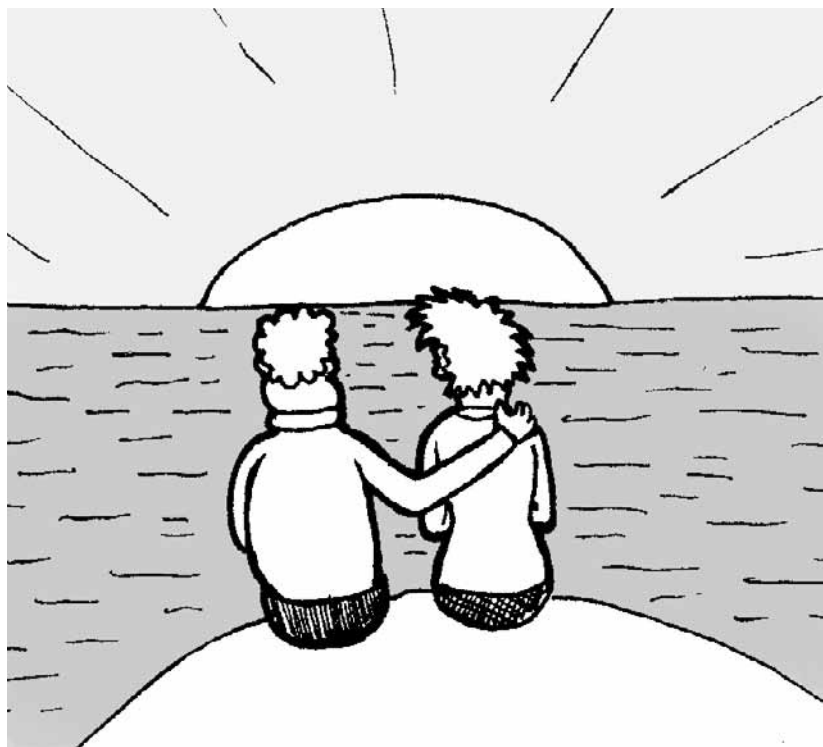
Most people benefit greatly by the support and love of their family and friends and the care provided by the members of the transplant team. Many centres have psychologists, social workers and pastoral care workers who can assist you and your family in coping better with any psychological, emotional or financial difficulties you may be experiencing. They can also identify strategies that will help you and your family to cope during and after the transplant. The Leukaemia Foundation's support service coordinators also are at hand to help and are just a phone call away (Freecall 1800 620 420).

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 is 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.



USEFUL INTERNET ADDRESSES

- Leukaemia Foundation
www.leukaemia.org.au
- American Cancer Society
www.cancer.org
- Australian Organisation for Young People Living with Cancer
www.canteen.org.au
- Bone Marrow Transplant Network NSW
www.bmtsw.com.au
- MacMillan Cancer Support (A UK cancer information site)
www.macmillan.org.uk
- Cancer Council of Australia
www.cancercouncil.com.au
- Leukaemia Foundation's Online Forum
www.talkbloodcancer.com
- Leukaemia Foundation's Network for Young Adults
www.teamrevive.com
- Leukemia & Lymphoma Society of America
www.leukemia-lymphoma.org
- Leukaemia Research Fund (UK)
www.leukaemia-research.org.uk
- Look Good... Feel Better program
www.lgfb.org.au
- National Cancer Institute (USA)
www.cancer.gov/cancerinfo

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 level in the blood. Haemoglobin normally carries oxygen to all the body's tissues. Anaemia causes tiredness, paleness and sometimes shortness of breath.

Antibiotic

A drug used to treat bacterial infections.

Anti-emetic

A drug which prevents or reduces feelings of sickness.

Anti-fungal

A drug used to treat fungal infections.

Antigens

Proteins found on the surface of all cells. Antigens are like flags identifying different types of cells.

Anti-viral

A drug used to treat viral infections.

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 they have received high doses of chemotherapy to destroy their disease.

Blood count

Also called a full blood count (FBC). A routine blood test that measures the number and type of cells circulating in the blood.

Blood stem cells

Primitive cells found in the bone marrow, capable of producing our blood cells.

The tissue found at the centre of our bones. Active or red bone marrow contains stem cells from which all blood cells are made and in the adult this is found mainly in the bones making up the

axial skeleton - hips, ribs, spine, skull and breastbone (sternum). The other bones contain inactive or (yellow) fatty marrow, which, as its name suggests, consists mostly of fat cells.

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 malignant disease characterised by uncontrolled growth, division, accumulation and invasion into other tissues of abnormal cells from the original site where the cancer started. Cancer cells can grow and multiply to the extent that they eventually form a lump or swelling. This is a mass of cancer cells known as a tumour. Not all tumours are due to cancer; in which case they are referred to as non-malignant or benign tumours.

Cannula

A plastic tube usually inserted into a vein via a sharp needle. The needle is then removed leaving the patient with a cannula through which fluids and drugs can be infused.

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.

Cerebrospinal fluid (CSF)

The fluid that surrounds and protects the brain and spinal cord. Samples of this fluid can be collected for examination using a procedure known as a 'lumbar puncture'. Chemotherapy is sometimes given into the cerebrospinal fluid to prevent or treat cancer in the central nervous system (CNS).

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.

Computerised axial tomography (CAT or CT scan)

A specialised x-ray or imaging technique that produces a series of detailed three dimensional (3D) images of cross sections of the body.

Cord blood

The blood contained in the umbilical cord and placenta at birth. This blood contains a rich supply of blood stem cells. These stem cells have the capacity to repopulate the bone marrow spaces and produce blood cells. Cord blood can be collected through a cord blood banking program. The collection of cord blood does not harm the baby in any way.

Cord blood transplant

The use of donated *cord blood* as part of an allogeneic transplant.

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.

Cytomegalovirus (CMV)

An opportunistic virus which is harmless to healthy people but can cause serious infection in those with a poorly functioning immune system.

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 stem cell transplantation.

Haemopoiesis

The processes involved in 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 / or residual (left over) cancer cells that have survived standard-dose therapy.

Iliac crest

The back of the hip bone. A common site for a bone marrow biopsy.

Immune system

The body's main defence system against infection and disease.

Immunocompromised

When someone has decreased immune function.

Immunosuppression

The use of drugs designed to reduce the function of an individual's immune system.

Leukaemia

A cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal blood cells. These cells take over the bone marrow often causing a fall in blood counts. If they spill out into the bloodstream however they can cause very high abnormal white cell counts.

Lumbar puncture

A procedure used to remove fluid from around the brain and spinal cord (cerebrospinal fluid or CSF) for examination in the laboratory. A lumbar puncture may also be used to administer chemotherapy into this fluid to prevent or treat disease in the central nervous system (CNS).

Lymphoma

Cancer that arises in the lymphatic system.

Menopause

The stopping of menstruation (periods). Also called 'the change of life'.

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.

Oncologist

A doctor who specialises in treating cancer.

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.

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 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.

Sibling

A brother or sister.

Stage

The extent of the disease in the body.

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 (haemopoietic 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.

Sternum

The breastbone, a site sometimes used for a bone marrow biopsy.

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.

Tumour

An abnormal mass of cells. May be non-malignant (benign) or malignant (cancerous).

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.



Leukaemia
Foundation
—
VISION TO CURE
MISSION TO CARE

A bequest

Your planned gift to the Leukaemia Foundation

A wonderful way to make a significant gift is through a bequest in your will. After making due allowance for loved ones, a bequest of a specific amount or a proportion of the residue of your estate, is a way of leaving a real and lasting legacy to the future.

Your bequest to the Leukaemia Foundation will be used to support our mission to care for patients, carers and families and help us achieve our vision to find a cure for leukaemias, lymphomas, myeloma and related blood disorders.

Wording your bequest to the Leukaemia Foundation

You may choose to make a general bequest and allow the Leukaemia Foundation to decide how your bequest will be used, or you may prefer to make that decision yourself e.g. direct your bequest to patient support or research. Your legal adviser can provide further information on the different types of bequests, and on the appropriate wording for a bequest.

As a guide, the following wording may be useful:

'I give and bequeath free of all duties (here state the amount/percentage or share/residue or assets to be gifted) to the Leukaemia Foundation of (here insert the address) absolutely -

- for the general charitable purposes of the said Foundation (this is the Leukaemia Foundation's preferred option); or
- for the purpose of patient and family support; or
- for the purpose of research into the cause, cure or treatment of leukaemia, lymphoma, myeloma and related blood disorders

and I direct that a receipt of the proper officer for the time being of the Leukaemia Foundation shall be a good and sufficient discharge to my trustee/s'.

Please see the next page for the response form.



Response Form

- I have already made a bequest to the Leukaemia Foundation in my will
- I am considering/it is my intention to make (please circle) a bequest to the Leukaemia Foundation
- I would like more information about making a bequest and/or where to direct my bequest
- I would like to speak to the Planned Giving Manager about appropriate recognition for my bequest
- I would like to receive invitations to functions

Dr/Mr/Mrs/Ms/Miss:

Address:

..... Postcode.....

Telephone: (h).....

(w)

Email:

Please return this form to the:

Planned Giving Manager,
The Leukaemia Foundation,
GPO Box 9954,
in your Capital City
(marked Private & Confidential)

If you are interested in leaving a bequest to the Leukaemia Foundation in your will and you would like further information, without any obligation, in strictest confidence, please contact the Planned Giving Manager in your state on Freecall 1800 620 420.







Leukaemia
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VISION TO CURE
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Making a donation

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

You can help by making a donation. Please fill out the form below or visit www.leukaemia.org.au to make your gift online.

Dr/Mr/Mrs/Ms/Miss:

Address:

..... Postcode.....

Telephone: (h).....

(w)

Email:

Please accept my tax deductible donation for \$

My cheque, made payable to the Leukaemia Foundation, is enclosed, or please charge \$..... to my credit card:

Bankcard Visa Mastercard Amex Diners

_____/_____/_____/_____

Cardholder's name:

Cardholder's signature:

Expiry date:/.....

Please send to:

The Leukaemia Foundation
GPO Box 9954
in your capital city.



Please send me a copy of the following information booklets:

- Eating well: a practical guide for people living with leukaemias, lymphomas & myeloma
- Living with Leukaemias, Lymphomas, Myeloma & Related Disorders, Information and Support
- Understanding Leukaemias, Lymphomas, Myeloma & Related Disorders
- Understanding Acute Lymphoblastic Leukaemia in Adults
- Understanding Acute Lymphoblastic Leukaemia in Children
- Understanding Acute Myeloid Leukaemia
- Understanding Allogeneic Transplants
- Understanding Autologous Transplants
- Understanding Chronic Lymphocytic Leukaemia
- Understanding Chronic Myeloid Leukaemia
- Understanding Hodgkin Lymphoma
- Understanding non-Hodgkin Lymphoma
- Understanding Myelodysplastic Syndrome
- Understanding Myeloma
- Understanding Myeloproliferative Disorders
- Young Adults with a Blood Cancer

Or information about:

- The Leukaemia Foundation's Support Services
- Workplace giving
- Regular deduction scheme
- National Fundraising Campaigns
- Volunteering
- Receiving the Foundation's newsletters

Name:

Street or Postal Address:

Suburb.....

State/Postcode

Email: Tel: (.....).....

Please send to:

Leukaemia Foundation, GPO Box 9954, In Your Capital City

or Freecall 1800 620 420

or email: info@leukaemia.org.au

Further information is available on the Leukaemia Foundation's website

www.leukaemia.org.au



Leukaemia Foundation

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This information booklet is produced by the Leukaemia Foundation and is one in a series on blood cancers and related disorders.

Some booklets are also available in other languages. Copies of this booklet and the other booklets can be obtained from the Leukaemia Foundation in your state by contacting us on

Freecall: 1800 620 420
Email: info@leukaemia.org.au
Website: www.leukaemia.org.au

The Leukaemia Foundation is a non-profit organisation that depends on donations and support from the community.

Please support our work by calling 1800 620 420
or by mailing your donation to:
The Leukaemia Foundation
GPO Box 9954
in your capital city

June 2010

