



Understanding Allogeneic Transplants

A guide for patients and
families



Leukaemia
Foundation

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CONTENTS

	PAGE
Introduction	3
The Leukaemia Foundation	4
Bone marrow, stem cells and blood cell formation	8
Bone marrow and blood stem cell transplantation	13
Types of transplants	15
Making treatment decisions	17
Sources of blood stem cells	20
Allogeneic transplants and tissue typing	23
Stages of a stem cell transplant	26
1. Planning for your transplant	27
2. Pre-transplant 'work-up'	32
3. Conditioning therapy	35
4. The transplant	44
5. Pre-engraftment	45
6. Potential post-transplant complications	47
7. Leaving hospital	57
8. Potential late side-effects	61
9. Recovery	64
Useful internet addresses	71
Glossary of terms	72

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INTRODUCTION

This booklet has been written to help you and your family understand more about *allogeneic* (donor) *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 allogeneic transplant. This is normal. Perhaps you have already started your transplant or you may be discussing the possibility of having a transplant with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet answers some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

In writing this booklet, we have tried to follow as much as possible the usual sequence of events in allogeneic transplantation. 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 circumstances at all times with your doctor and treatment team.

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

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 geographical and individual needs. Support may include giving information, patient education seminars and programs that provide a forum for peer support and consumer representation, practical assistance, accommodation, transport and emotional support/counselling.

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 Laboratory at the Queensland Institute for Medical Research. In addition, the Foundation also 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/counselling

A diagnosis of a blood cancer/disorder can have a dramatic impact of 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 health professional eg psychologist if required.

Online discussion forum

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

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.

Telephone Discussion Forums

This support service enables anyone throughout Australia who has or has had a blood cancer or related disorder 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.

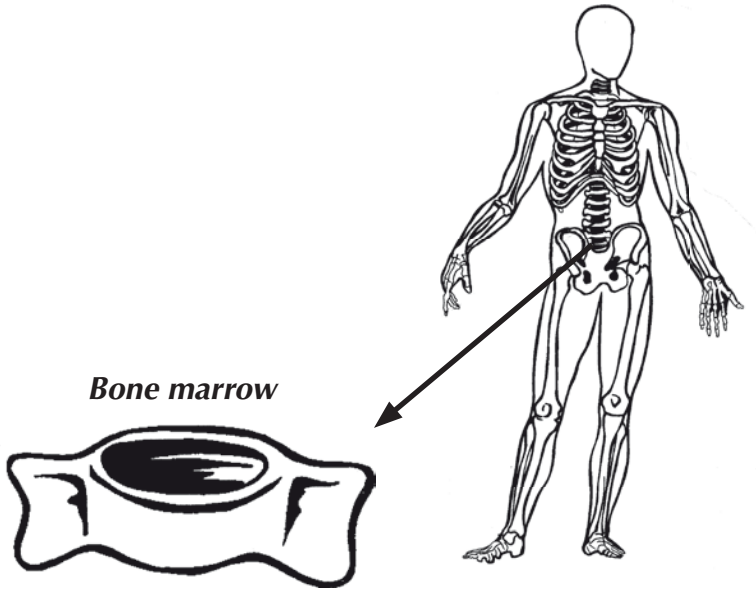
Young adults

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*.

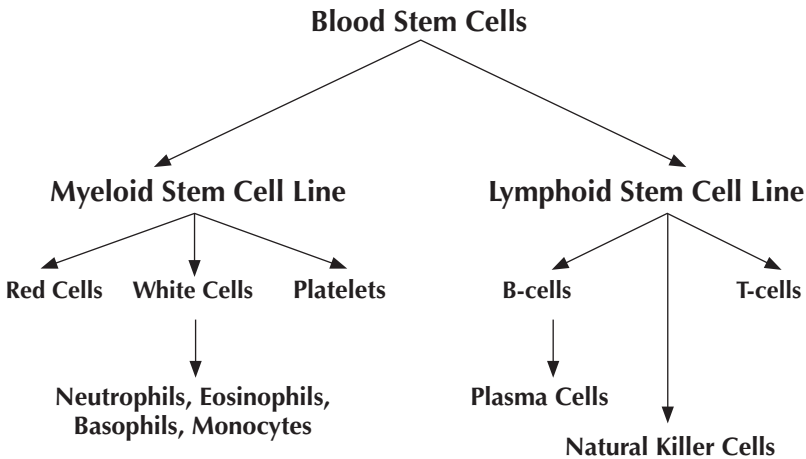
As an infant, haemopoiesis takes place at the centre of all bones. In later life, it is limited to the hips, ribs, spine, skull and breastbone (*sternum*). Some of you may have had a *bone marrow biopsy* taken from the bone at the back of your hip (the *iliac crest*) or the breastbone.

You might like to think of the bone marrow as the blood cell factory. The main workers at the factory are the *blood stem cells*. They are relatively small in number but are able, when stimulated, to reproduce vital numbers of *red cells*, *white cells* and *platelets*. All blood cells need to be replaced as they have a limited life span.

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-lymphocytes and B-lymphocytes.



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.

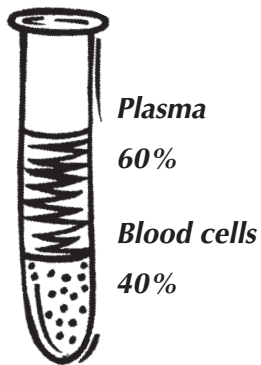
These days some growth factors can be made in the laboratory (synthesised) and are available for use in people with blood disorders. For example, *granulocyte colony stimulating factor* (GCSF) stimulates the production of white cells called *neutrophils* while erythropoietin (EPO) stimulates the production 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 (Hb) 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 red 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 range of the haematocrit (HCT) in a man is between 40% and 52%

The normal range of the haematocrit in a woman is between 36% and 46%

Anaemia

Anaemia is a condition caused by 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>	kill bacteria and fungi
<i>Eosinophils</i>	kill parasites
<i>Basophils</i>	work with neutrophils to fight infection
<i>Monocytes</i>	work with neutrophils and <i>lymphocytes</i> 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>T-cells</i>	kill viruses, parasites and <i>cancer</i> cells; produce cytokines
<i>B-cells</i>	make <i>antibodies</i> which target microorganisms

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

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

Neutropenia

Neutropenia is the term used to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1 (1 x 10⁹/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 x 10⁹/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 (e.g. 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 x 10⁹/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 x 10⁹/L) you are at risk of bleeding and tend 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 treatment centre. You can ask for a copy of your blood results, which should include the normal values for each cell 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 marrow and blood stem cell transplantation (commonly called *stem cell transplantation*) is used to treat a range of diseases. These include haematological (blood) diseases such as *leukaemia*, as well as non-haematological diseases. The following list gives you some examples of conditions which are treated with stem cell transplantation.

- acute and chronic leukaemias
- lymphomas
- myeloma
- some solid tumours (rarely)
- aplastic anaemia
- some immune system disorders (for example severe immunodeficiencies in children)

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 haemopoietic stem cells in our bone marrow. These stem cells can be likened to 'baby' cells which have not yet decided which type of blood cell they want to be when they grow up. Under the right kind of stimulation blood stem cells develop and mature into red cells, white cells or platelets.

High-dose *chemotherapy* aims to destroy disease. As an unwanted, but expected, effect, it may also destroy the precious population of blood stem cells, which then need to be replaced to allow for the re-building of blood cells. In some cases, these stem cells are defective because of disease (for example *aplastic anaemia*) 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 blood 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.

By the way, the word *transplant* is a little misleading here and conjures up inaccurate images of a surgical procedure. In reality, on the day of the *transplant*, stem cells are simply given intravenously over about half an hour to four days, depending on the volume being given (through a vein) almost like a blood transfusion. From here they travel to the bone marrow, set up home and begin to rebuild your body's blood and immune systems.

Strictly speaking, a *peripheral blood stem cell transplant (PBSCT)* refers to the use of blood stem cells which have been collected from the blood stream (i.e. peripheral) while a *bone marrow transplant (BMT)* refers to the use of stem cells collected directly from the bone marrow. You can also have stem cells collected from *umbilical cord blood*. These stem cells are all the same - they have simply been collected in different ways.

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



TYPES OF TRANSPLANTS

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

Autologous

In autologous stem cell transplants, the patient donates his or her own stem cells for infusion. The patient's blood stem cells are collected in advance (while they are in remission) and then returned to them after they receive high-doses of chemotherapy.

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

Allogeneic

In allogeneic stem cell transplants (also called allografts) the stem cells are donated by another person whose tissue type is compatible with the patient.

- *The donor is often a brother or a sister with a compatible tissue type. A compatible sibling, if available, would generally be the first choice as a donor. This is called a sibling transplant or sibling allograft. Other immediate family members can also be used as stem cell donors.*
- *Sometimes there is a slight mismatch between the donor and patient's tissue type. This is called a mismatched transplant.*

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

- *The donor may be unrelated to the patient, but with a similarly matched tissue type. This is called a Volunteer Unrelated Donor (VUD) transplant. Previously they were referred to as Matched Unrelated Donor (MUD) transplants.*
- *Stem cells can be donated from an identical twin. This is called a syngeneic transplant. This type of transplant is rare.*
- *Stem cells can be collected from donated umbilical cord blood, through a cord blood banking program, and used as part of a cord blood transplant.*

Allogeneic transplants may still offer the best chance of curing a number of blood and bone marrow cancers and other diseases. Nevertheless they are complex procedures that carry significant risks. The complexities and risks may be increased even more with a mismatched or Volunteer Unrelated Donor (VUD) transplant.

In 2008, a total of 1207 stem cell transplants were carried out in Australia. Of these:

- 785 were *autologous*
- 422 were *allogeneic* (222 of these were *related* stem cell donors and 200 were *volunteer unrelated* donors)

The type of transplant you will receive depends on a number of factors. The most important factors are the type of disease you have, and your age and general health. The condition of your bone marrow, and the ability to collect blood stem cells are other important factors. Of course, the availability of a suitably matched donor is essential for considering an allogeneic transplant. Your *haematologist* will discuss with you the best option for your particular situation.

MAKING TREATMENT DECISIONS



Many people feel overwhelmed at the prospect of having a stem cell transplant. Having to make decisions about proceeding with recommended treatments can be very stressful. Some people do not feel that they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given, or that they are being rushed into making a decision.

It is important that you feel you have enough information about your illness and all of the treatment options available, so that you can make *your own* decisions about which treatment to have.

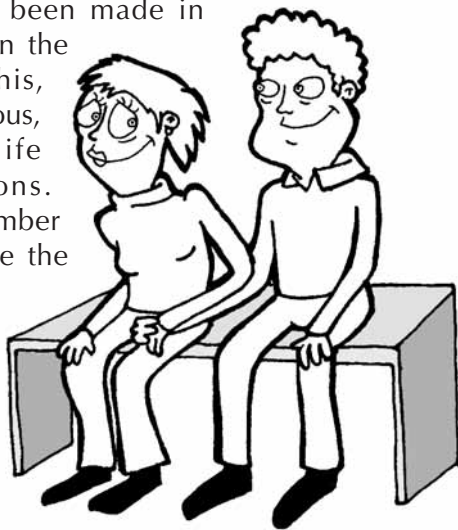
Before going to see your doctor make a list of the questions you want to ask. It is handy to keep a notebook or some paper and a pen handy as many questions are thought of in the early hours of the morning.

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. It is easy to forget important bits of information. If you have forgotten something, make sure you ask again.

The best option for you

It is important to remember that everyone is different. For some, a transplant is not considered the best way to treat their disease. Other approaches, such as 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 is the only option which offers a prospect of *cure* or long term survival.

Important advances have been made in stem cell transplantation in the past 10 years. Despite this, some transplants cause serious, ongoing and possibly life threatening complications. Unfortunately, a small number of patients will not survive the transplant process.



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

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

Standard therapy

Standard therapy refers to types of treatment which are commonly used and have been tried and tested both in clinical trials and through long-term clinical use and have been proven to be reasonably safe and effective.

Clinical trials

These trials (also called research studies) test new treatments and compare them to established treatments both to see if the new treatment works better and to compare the side effects. Some clinical trials are randomised, so that some patients will be receiving the new treatment and others the old treatment. Clinical trials are important because they provide vital information about how treatment could be improved. Clinical trials sometimes give access to new therapies that have been trialled elsewhere but are not yet available locally.

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 consent. Talk to your doctor who can guide you in making the best decision for you.

Informed consent

Giving an **informed** consent means that the potential risks and potential benefits of a proposed procedure or treatment have been fully explained to you. You will then be asked if you are willing to comply with the requirements of the trial, including treatments, tests and the collection of relevant information about you and your disease. If you feel happy that you have adequate information to make such a decision, you may then give your informed consent.

You should never feel compelled to be in a clinical trial. The decision to participate must always be voluntary, after you have received all the necessary information. Even after you have agreed to be in a clinical trial and signed the consent form, you can change your mind, whether or not trial treatment has already started.

SOURCES OF STEM CELLS

In allogeneic transplantation stem cells can be harvested (or collected) from:

- bone marrow (bone marrow harvest)
- blood stream (peripheral blood stem cell harvest)
- umbilical cord blood

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, by a haematologist. Stem cells are collected from the back of the donor's hip (iliac crest). A special needle is passed through the skin and into the centre of the bone. The bone marrow fluid is then drawn into a syringe attached to the end of the needle. This is done repeatedly until enough bone marrow fluid has been collected. The whole procedure takes about one or two hours to complete.

The bone marrow is processed to remove fragments of bone, red cells, fat and other unwanted tissue. After this it may be used immediately, or it may be frozen (*cryopreserved*) to be used at a later date.

Peripheral blood stem cell harvest

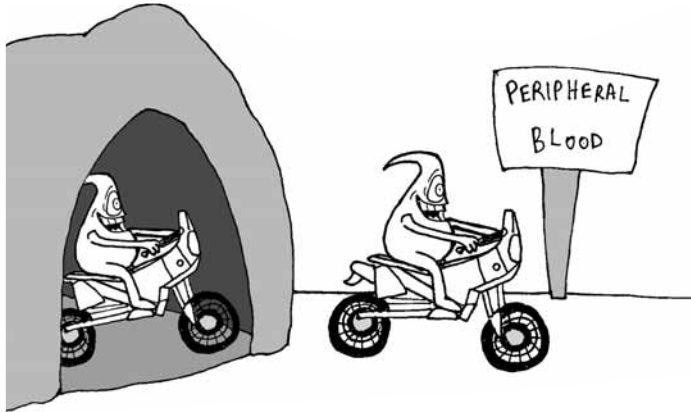
Stem cell mobilisation

It is more common these days to collect blood stem cells from the blood stream (peripheral blood). Stem cells normally live in the bone marrow, and are only found in the blood in very low numbers. However, donors can be given injections of growth factors, such as *G-CSF*, which stimulate the stem cells to move into the blood stream, where they can be collected. This is called *stem cell mobilisation*.

Growth factors are usually given for several days as an injection under the skin (subcutaneous). The donor or a family member (or friend) can be taught how to do this by the nurse, or it may be given by a local doctor or the hospital. Regular blood tests are taken over the following week to help identify the best day to start collecting

the donor's stem cells. This is generally around the time that the number of stem cells in their blood starts to increase.

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



Stem cell collection

Stem cells are collected from the blood stream by passing all the donor's blood through a special machine called a cell separator.

This procedure is usually performed in an Apheresis Unit. The blood is drawn from a *cannula* (plastic needle) placed in a vein in one arm. The machine spins the blood very quickly and removes the part that contains the blood stem cells. This is a continuous process. While the stem cells are being removed the rest of the donor's blood is being returned to them via another cannula, placed in their other arm. Sometimes, if the veins in the arm are very small, a special collection line called a *vascath* may need to be placed into one of the large veins under the collar bone, in the neck, or in the groin. This line is inserted by medical staff who are very experienced with this procedure. Your doctor will explain how this is done, and any risks it may entail.

A *peripheral blood stem cell collection* usually takes three to four hours. Sometimes the donor cannot move their arms much, especially if the cannulas have been inserted in the middle of both forearms. The nurses will make the donor feel as comfortable as possible but they might also like to bring along a book, a video, some music or a friend for company.

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

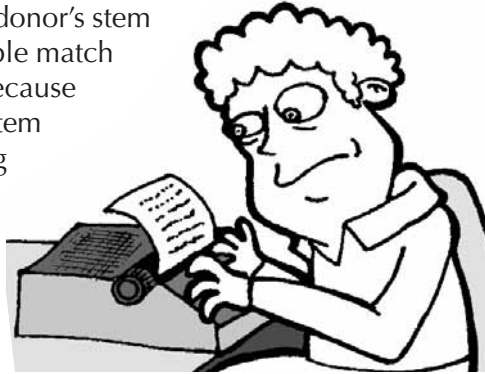
The stem cells may be used immediately or frozen (*cryopreserved*) and stored until they are infused on the day of the transplant. Blood stem cells can remain frozen for many months or years before they are used.

Umbilical (placental) cord blood collection

In newborn babies, the umbilical cord and placenta contain a rich supply of blood stem cells. These stem cells are capable of repopulating the bone marrow and producing blood cells. Cord blood can be collected by the midwife, doctor or other designated collector immediately after delivery and cutting of the umbilical cord without causing any harm to the newborn baby. Cord blood banks are located in most of Australia's capital cities. *Umbilical cord blood transplants* are most commonly used in children but increasingly in adults as well.

ALLOGENEIC TRANSPLANTS AND TISSUE TYPING

If you are having an allogeneic transplant it is essential that your donor's stem cells are the best possible match for *your* body. This is because the donor's immune system is transplanted along with the donor's stem cells.



Matching the donor and patient helps to reduce *graft versus host disease* (GVHD), an immune

system reaction commonly seen after an allogeneic transplant. In graft versus host disease, the donor's immune system recognises the patient's body as foreign and attacks it.

A good match also reduces the risk of *graft rejection*, a rare complication of an allogeneic transplant where the donor stem cells fail to grow.

Graft versus host disease and graft rejection are discussed further in a later section of this booklet dealing with post-transplant complications.

Despite having a good tissue type match with the donor, transplant recipients are routinely given drugs called *immunosuppressants* (anti-rejection drugs), which suppress the function of the donor's immune system for a long time after the transplant. Again, this is to help reduce graft versus host disease and the risk of graft rejection. If you have had an allogeneic transplant it is very important that you continue to take these drugs until your doctor tells you to stop.

Determining a patient or potential donor's tissue type is done with a blood test. There is no need to take any 'tissue' or for the donor to undergo a bone marrow biopsy. Tissue type is **not** the same as blood group (ABO). There is no need to match the blood type of the transplant patient and the stem cell donor.

More information

Tissue typing is the process of matching the donor's and patient's tissue type. Special 'markers' in the patient's blood are compared with those found in a donor's blood, to see if they are the same. These markers are also known as human leukocyte antigens (HLA), and they determine each individual's tissue type. Each one of us has our own unique tissue type which is determined by genetic information supplied by both of our parents. Your tissue type is like your own personal barcode. Unless you have an identical twin, your tissue type is different to the tissue type of almost everyone else in the world.

Your tissue type can be likened to a flag flown on the surface of most of the cells in your body, including the cells of your immune system (white blood cells). This flag identifies them as belonging to you, and no one else. Your white blood cells protect your body by comparing the flag they are carrying with flags held by any other cells they encounter, for example transplanted tissue or bacteria. If they do not find a matching flag (tissue type), your white blood cells will attempt to destroy what they consider to be foreign.

Searching for the best match



Identical twins have identical tissue types. As such, an identical twin could make, in some ways, the ideal donor. Few of us, however, have an identical twin. The next closest tissue type is often found in a *sibling*, a brother or sister who has inherited their genetic makeup from the same parents as the patient.

As we inherit half of our genetic make-up from our mother and half from our father, there is only a one in four chance that a sibling will be a really good match. In reality, only about 30% of people find a full sibling match. If a sibling match is not found a search may be started for a matched (volunteer) unrelated donor (VUD) through the *Bone Marrow* and/or *Cord Blood Donor Registries* in Australia and overseas. These donors are volunteers who have registered as willing to donate their stem cells if they are found to be compatible with a patient who is in need of a transplant.

For more information on national and international bone marrow donor registries you might like to contact the Australian Bone Marrow Donor Registry through your city's Red Cross Blood Bank or by visiting their website at: www.abmdr.org.au

Whether using a family member or a volunteer donor, it is not always possible to find a perfect tissue match. Sometimes sibling or donor stem cells which have a slightly different tissue type (mismatch) are used, but these may still be regarded as the best possible match for the patient.

STAGES OF A STEM CELL TRANSPLANT

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

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

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

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

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

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

1. PLANNING FOR YOUR TRANSPLANT

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

- timing
- things to consider
- fertility



Timing

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

Things to consider

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

As a general guide it takes about twelve months to fully recover from an allogeneic transplant. However it may take even longer to recover, particularly if graft versus host disease occurs.

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

- organising your financial affairs
- making a will, organising a power of attorney
- sorting out employment issues such as sick leave entitlements, keeping in touch, possibilities 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
- ask the hospital staff if you can use Skype or something similar so you can keep in contact with family and friends

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 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 information about 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 Freecall 1800 620 420.

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 when ill 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.

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

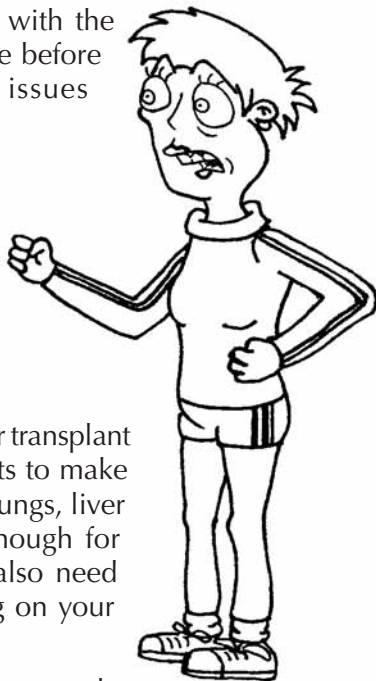
It is important to understand that the methods are still at early stages of development and use and for many reasons achieving a pregnancy and subsequently a baby is not guaranteed by using any of them. In addition, some are time consuming and costly while others may simply not be acceptable to you or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

Speaking with 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 preparations that need to be made before you start your transplant. The issues covered here are:

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



Pre-transplant tests

During the weeks leading up to your transplant you will undergo a number of tests to make sure that your vital organs (heart, lungs, liver and kidneys) are physically fit enough for the transplant process. You may also need to see other specialists depending on your particular circumstance.

While many of the tests can be done on the same day, some may require several visits to the hospital. Some take longer than others. You might like to bring a book or a friend for company. The nurse or the transplant coordinator will be able to advise you about any special preparations you need to make for the test (for example not eating beforehand), how long it will take and whether or not you will have to wait around afterwards.

The following is a list of the tests which are likely to be carried out, and may differ according to the type of transplant and the nature of your illness:

- chest x-ray
- heart function tests (for example a gated heart pool scan, an electrocardiogram and/or ECG)
- CT scans
- lung function tests
- eye tests
- bone density scan
- 24-hour urine collection

- bone marrow examination
- lumbar puncture

Dental check

A dental check-up is needed to ensure that any potential dental problems are cleared up **before** the transplant. Any problems with your teeth and gums may become more serious after the chemotherapy treatment. The nurses will teach you how to properly care for your mouth and teeth during and after your transplant.

Blood tests

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

- full blood count
- blood group
- kidney function
- liver function
- thyroid function
- clotting screen
- iron levels
- blood glucose
- screening for viral and bacterial infections - to test for human immunodeficiency virus (HIV), hepatitis, *cytomegalovirus* (CMV), syphilis, etc.

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

Central venous catheter (CVC)

During your transplant you will need to have a number of intravenous (into the vein) therapies. These may include fluids,

chemotherapy, *antibiotics*, other drugs and blood and platelet transfusions. You will also need to have blood taken, often every day, to check your progress. As well as being painful, the veins in your hands and arms may not cope with frequent needle pricks. In addition, some drugs and in fact, stem cells themselves, cannot be given easily into the smaller veins in your hands and arms. It is for these reasons that a central venous catheter (CVC) or central line is inserted prior to your transplant.

A central venous catheter is a special line inserted through the skin, into a large vein in your neck or chest (this is usually done in a procedure room or an operating theatre). From here it travels all the way down the vein and enters the top of the heart. Here any infusions which have been given through the central line enter the central blood circulation and are safely diluted with large amounts of your blood.

There are several different types of central lines used. The ones most commonly used for transplant patients have two or three lumens (or tubes). The lumens are the separate thin plastic tubes connected together that hang on the outside, on top of your skin, so only one tube is inserted inside you. 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.

3. CONDITIONING THERAPY

Before you receive your transplant you will have a few days of what is known as *conditioning* therapy. Conditioning therapy is used to help destroy any left over cancer cells in your body and make space in your bone marrow for the new stem cells. Conditioning therapy is also used to suppress your immune system to reduce the risk of the donor stem cells being rejected by your immune system.

It is common to be admitted to hospital for this part of the transplant, but some patients have their conditioning therapy as an outpatient, in the clinic, particularly if undergoing a transplant with reduced intensity conditioning (formerly known as a “mini” transplant).

There are many different types of conditioning therapies but as a general rule they involve between three and eight days of high-dose chemotherapy, alone or in combination with radiation therapy in the form of *total body irradiation* (TBI).

Commonly used conditioning therapies in allogeneic transplantation include:

- *Busulphan and Cyclophosphamide* (Bu/Cy)
- *Cyclophosphamide and total body irradiation* (TBI)

Reduced intensity conditioning allogeneic stem cell transplants

Some patients receive conditioning therapy that is less intense than the standard conditioning. These were formerly described as mini-transplants but this term is rarely used now as it is misleading. One form of these conditioning therapies described as “non-myeloablative” involves a conditioning regimen that doesn’t completely destroy the function of your bone marrow, making you less susceptible to infections in the early post-transplant period. The reduced dose of therapy also lessens the toxicity to important organs in your body. Meanwhile, the conditioning therapy still suppresses your immune system enough to allow the donor stem cells to grow (engraft).

It is hoped that the reduced intensity conditioning therapies used will cause less severe side-effects, making this type of transplantation a potentially curative option for older and/or less fit patients who might otherwise benefit from having an allogeneic

transplant. Although the side-effects from the conditioning therapies are reduced with this type of transplant, other complications such as infections and graft-versus-host disease (GVHD) can still occur.

Commonly used conditioning therapies in reduced-intensity conditioning allogeneic transplantation include:

- *Fludarabine* and *Melphalan*
- *Cyclophosphamide* and *Fludarabine*

Occasionally, a single dose (single 'fraction') of total body irradiation (TBI) is used in combination with chemotherapy (particularly fludarabine) as part of the conditioning therapy for these transplants.

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

Transplant protocols

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

The conditioning therapy is given in the week before your transplant. The days leading up to the transplant (pre-transplant) are called Day -6, Day -5, etc. with Day 0 (zero) being the day when you receive 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 lumens of your central line, or in tablet or liquid 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 system, once it has done its job. This helps to lessen

any damage by the chemotherapy to your kidneys and bladder. In some cases, other drugs are also given to help reduce the toxic effects of chemotherapy on these important organs. With so much fluid going in, it is important to monitor the amount of fluid in your body and your urine output. The nurses may ask you to pass all 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 very common to need assistance with passing all that fluid back out, using fluid medication (diuretics), to increase the amount of urine you produce.

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

Total body irradiation (TBI)

Total body irradiation (TBI) involves exposing your whole body to high doses of ionising 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). This is generally used when a Volunteer Unrelated Donor (VUD) transplant is going to be performed. It is also very effective at suppressing your immune system therefore allowing the donor's stem cells to grow.

Before you start TBI, the radiation *oncologist* will carefully calculate the correct dose of radiation therapy for your body. This will require a visit to the hospital to be measured (height and weight) and assessed.

TBI itself is painless. It is similar to having an x-ray. In fact you do not feel anything during the treatment. TBI is usually given twice a day, for two to three days, in the *radiotherapy* department of the hospital. To make sure that you are receiving the correct dose of radiation therapy in the correct places, gel packs and blocks are placed at particular points between you and the radiotherapy machine.

You will need to stay perfectly still for a few minutes while the treatment is being given. This can be difficult or even uncomfortable for some people, particularly if they find it difficult to stay in one position. The radiation therapy staff will try to make you feel as comfortable as possible. You might like to bring along your own music to help you relax.

It is common to feel nauseated while you are having TBI and for some time afterwards. The nurse may give you special *anti-emetic* (anti-sickness) medication before you go for your TBI treatment. Sometimes a mild sedative is also used to control nausea and vomiting. This will help you to relax and may even make you a little sleepy.

Common side-effects of conditioning therapies

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

Low blood counts

Your white cell and platelet counts will usually 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. Some of the reduced intensity conditioning transplants do not lead to a large drop in blood counts.

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 cell count is low over the next couple of weeks. Infections and their management are discussed in more detail later in this booklet.

Nausea and vomiting

Nausea and vomiting are often associated with chemotherapy and total body irradiation. 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, and some may work better for you than others. 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.

Don't be too concerned if you are unable to eat or drink much at this time. The doctors and nurses will closely monitor your condition every day and a dietitian will also be involved in your care. 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.

Mucositis

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

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

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 and sting if you use them.

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

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 dietitian 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 they are not eating what they normally would at home. The doctors and the dietitian 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.

Bowel changes

Chemotherapy and radiotherapy can cause damage to the lining of your bowel wall. This may lead to cramping, wind, bloating and/or diarrhoea. Be sure to tell 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 (anus) when you are trying to move your bowels. You may need a gentle laxative to help soften your bowel motions.

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, check with the nurses or doctors first. Remind them, however, not to be surprised or too disappointed if you change your mind when you see it. Your team may have some foods that they prefer you to avoid as they may carry a risk for infection. They will discuss these with you.

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, pubic area, 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. Some people get their hair cut short so they can lose it in stages, and for it not to be such a big shock for them.

You should avoid direct sunlight on your exposed head. You may wish to consider wearing a cap, wig, scarf or turban on your head if this makes you feel more comfortable and stops your hair from going everywhere, such as your pillow.

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

Skin reactions

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

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

Parotitis

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

Infertility

As we mentioned previously, conditioning therapy can damage your fertility. See page 30-31 for more details.

Tiredness, tension and stress

You will probably feel more tired than usual during the days (and weeks) following your conditioning therapy. 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 audio tapes 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 infusion) is carried out on day 0 (zero) of the transplant protocol. Some protocols have two day zeros. This happens when the volume of stem cells is large. Some cells are infused on one day and the remainder on the next.

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

If the stem cells have been frozen, they 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. Most centres will give some medications to reduce the likelihood of reactions, immediately prior to the stem cell infusion. 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.

If you are receiving previously frozen stem cells, you and your visitors may notice an unusual smell (resembling garlic, asparagus or sweet corn) during and for up to twenty four hours after the infusion. You may also have a strange taste in your mouth, which may be relieved by sucking mints. These effects are due to a preservative used in the original freezing process.

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

5. PRE-ENGRAFTMENT

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, depending on the type of transplant you have. Engraftment generally takes longer after a cord blood transplant.

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 engraftment is seen in a rise in the number of normal cells (usually 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
- cytomegalovirus (CMV)
- blood transfusions
- veno-occlusive disease (VOD)
- haemorrhagic cystitis
- graft versus host disease (GVHD)

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 (meaning fever) neutropenic patient*'.



Fevers

It is important that you tell the doctor or nurse immediately if you are feeling unusually hot or cold or shivery. A fever (a rise in your body temperature) is often the first sign that you have an infection. Sometimes patients with a fever and low neutrophil counts may not feel very unwell, even though the temperature may be quite high. You should also tell your doctor or nurse if you are feeling unwell or if you have developed a cough, pain or soreness anywhere.

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, stool and sputum sample and a chest x-ray may be done.

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



Antibiotics

Sometimes it is not possible to find the cause of your infection. If you develop a temperature while your white cell count is low you will be given intravenous antibiotics straight away. 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 that 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 side-effect of the transplant process. All measures will be taken to limit the infection and to make you as comfortable as possible until it subsides.

Cytomegalovirus (CMV)

Cytomegalovirus (CMV) is an opportunistic virus. This means that it takes the opportunity to cause infection while your immune system is weak. When your immune system is functioning properly, CMV causes symptoms resembling a mild flu. When your immune system is weak, CMV can cause a serious infection in any organ in your body.

Without knowing it, many of us have been exposed to CMV in the past and are therefore considered to be carriers of the virus. In this case, it is possible that the virus could become reactivated during or after the transplant, whilst your immune system has not fully recovered. Before your transplant, a blood test will be done to check whether you are a carrier and therefore considered 'CMV-positive' or if you have never been exposed to the virus and are therefore considered to be 'CMV-negative'.

If you or your stem cell donor is CMV-positive, you may be given *anti-viral* drugs before, and for some time after your transplant to help prevent CMV infection. Another strategy is to take regular blood tests, particularly in the first few months after your transplant, to check for early signs of the virus. If early signs are found steps

can be taken to prevent the virus from spreading and causing infection in your body.

If you or your stem cell donor are CMV-negative, you will only receive blood products that have been tested and do not contain any traces of the virus. This helps to reduce your chances of being exposed to the virus while your immune system is weak.

If a CMV infection does develop it can usually be treated effectively with intravenous antiviral drugs.

Prevention of infection

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

Preventive antibiotics

Antibiotics are commonly given before and after transplants to reduce the risk of getting an infection due to bacteria, fungi or viruses. Some transplant centres use antibiotics given by mouth to reduce the risk of bacterial infection spreading from the bowel into the blood. Most will use an antifungal drug to prevent serious fungal infections occurring. Another important drug is Bactrim (or Septrim), which is used to prevent a potentially serious lung infection due to a microbe called Pneumocystis. Most centres also give antiviral drugs such as aciclovir or valtrex to prevent herpes virus infections.

Hand washing

Hand washing is the single most effective way of reducing the spread of microorganisms that cause infection. Antibacterial soap and/or lotion are available in dispensers throughout the hospital unit so that anyone entering your room can wash their hands first. Your doctors and nurses should 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 'catching' illness or anyone who has had a live vaccine such as polio.

Some hospitals do not let children under the age of 12 enter the transplant ward. You should investigate this before you are admitted so you will not be shocked or disappointed if this is the case.

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. Some units may also have restrictions on very young children visiting the treatment part of the ward. 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. Thick-skinned fruit (e.g. oranges and bananas) can be eaten once the peel is removed. Thin-skinned fruits need to be washed thoroughly. You should avoid salads, yogurts and

soft cheese, which can all harbour bacteria. Please check with your doctors or nurses before food is brought in for you. 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.

Nutrition

While the transplant team will encourage you to eat as normally as possible during your hospital stay, many people will be unable to do so because of poor appetite or a painful mouth, and will require some help with nutrition in order to not lose too much weight. Some transplant centres now routinely use liquid nutritional supplements, which are given from the time of transplant through a soft plastic tube placed through the nose into the stomach; this ensures proper feeding even when people are unable to swallow liquids due to a sore mouth. Other transplant teams give nutritional solutions through the CVC; this is called parenteral nutrition. In either case, these alternative forms of nutrition, although helpful, are artificial, and can be stopped when it is possible to eat and drink normally again.

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 transfusion of platelets 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 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.

If your stem cell donor's blood group is different to yours, you will find that your blood group changes to that of your donor in the weeks after the transplant. Because of this you will be then given blood products which are compatible with your stem cell donor's (and your new) blood group.

Veno-occlusive disease (VOD)

High-dose chemotherapy and radiotherapy can damage small blood vessels in the liver, which become gradually clogged up with tiny blood clots. As a result, the liver is unable to function properly. This is known as *veno-occlusive disease* (VOD). VOD can occur at any time after treatment is given but it usually occurs within the first three weeks of the transplant. Some conditioning regimens are associated with higher risks for VOD. Other factors that can increase this risk include types of treatments given prior to the transplant, and pre-existing liver problems.

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, viruses and graft versus host disease. To reduce the risk of haemorrhagic cystitis, extra intravenous fluids and sometimes a preventive drug are given together with chemotherapy known to cause this condition. You will also be encouraged to drink plenty of fluids if possible. If it does occur, haemorrhagic cystitis can be effectively treated.

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

Graft versus host disease (GVHD)

Graft versus host disease (GVHD) is a common complication of allogeneic transplants.

GVHD generally appears once the donor stem cells start engrafting and re-establishing the body's (new) immune system. In simple terms the new immune system, in particular a group of the donor's white blood cells known as T-lymphocytes, recognises your body as foreign and begins to attack it. Amazingly, the new immune system is only doing its job and believes it is protecting its new home.

If you are having an allogeneic transplant, you will be given special drugs called immunosuppressants (anti-rejection drugs) to suppress the 'new' (donor's) immune system and to reduce GVHD. You will be given these drugs before, during and for some time after the transplant. The main drug used is called *cyclosporin*, which is given intravenously, starting a day or so before the transplant, and continued until you are able to take it by mouth in the form of capsules.

If you have an allogeneic transplant it is vital that you take your immunosuppressants every day until your doctor tells you to stop. Not taking these drugs can be life threatening.

If GVHD does develop, you will be given other drugs, including steroids to further suppress the new immune system and reduce the symptoms you are experiencing.

GVHD can affect any organ but the organs most commonly affected (particularly, before Day 100) are the skin, the gut and the liver. It varies in severity and can sometimes be life threatening.

GVHD is a common reason for being readmitted to hospital in the first year following an allogeneic transplant.

Skin

GVHD commonly affects the skin. It presents here as a red and sometimes itchy rash, which initially appears on the palms of the hands and the soles of the feet. A little GVHD is often regarded as a good thing as it indicates that engraftment is taking place and that any left over disease might be destroyed in the immune reaction that follows (see *graft versus malignancy effect* below).

If GVHD of the skin worsens it can cause blistering and scaling all over the body. Special creams may be prescribed which can help to reduce this effect and any discomfort you may be feeling. Sometimes a skin biopsy is done to confirm a diagnosis of GVHD of the skin.

Gut and liver

GVHD of the gut usually presents as diarrhoea with cramps and abdominal pains. Nausea and vomiting can also occur.

Many people who develop GVHD of the gut need intravenous fluid therapy to replace fluids that are lost and to prevent dehydration. If GVHD of the gut is severe or persistent, the doctors may decide to give your gut a rest. In this case you may be asked not to eat anything while all the nutrition you require is given directly into your blood through your central venous catheter. This is called parenteral nutrition or total parenteral nutrition (TPN). All the proteins, minerals, electrolytes, vitamins and calories that your body needs are supplied in the form of a special infusion while your gut recovers.

GVHD of the liver often presents as jaundice (yellowing of the skin and eyes) and abnormalities in the results of routine blood tests that measure liver function.

GVHD is regarded as acute when it occurs within the first sixty to one hundred days after the transplant. It is regarded as chronic when it persists or presents after this time. The chronic form of GVHD can often be very complex, and can involve as diverse

organs as the eyes, mouth, skin, liver, lungs, gut and genito-urinary tract. (See section 8)

Graft versus malignancy (GVM) effect

You may find that the doctors are pleased to see 'a little' graft versus host disease following an allogeneic transplant. This is because of the graft versus malignancy (GVM) effect whereby leftover cancer cells are mopped up by the new, activated immune system. This beneficial effect is seen after allogeneic transplantation for certain cancers including acute and chronic *leukaemias*, *myeloma* and *lymphomas*. You should not be disappointed if you do not develop GVHD, however, as it has been shown that a GVM effect can occur even when no signs of GVHD have developed.

In some cases the donor's lymphocytes (a type of white blood cell) are given to the patient after the transplant to bring on a graft versus malignancy effect. This is called a donor lymphocyte infusion (DLI) and is usually done to reduce the risk of *relapse* soon after the transplant.

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 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 don't 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, so do give them a call.

Readmission to hospital

It is common 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 (rigor)
- **bleeding** or **bruising**, for example blood in your urine, bowel motions, coughing up blood, bleeding gums or a persistent nose bleed

- **nausea** or **vomiting** that prevents you from eating or drinking or taking your normal medications
- **diarrhoea, stomach cramps** or **constipation**
- **persistent coughing** or **shortness of breath**
- the presence of a new **rash, reddening** of the skin, **itching**
- a persistent **headache**
- a new severe **pain** or persistent unexplained **soreness** anywhere
- if you **cut** or otherwise injure yourself
- if you notice **pain, swelling, redness** or **pus** around your central venous catheter
- 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 like polio**

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

Graft rejection / failure of engraftment

Graft rejection is rare and as the name suggests, occurs when the new donor stem cells fail to engraft. Sometimes the stem cells seem to engraft only to fail soon afterwards. The risk of graft rejection is increased when there is a tissue type mismatch between the donor and patient.

Relapse

Unfortunately the transplant is not always successful and some people are 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 in some cases a drug to stimulate your immune system to fight the relapsed disease.

A donor lymphocyte infusion (DLI) may also be used. This involves giving you an intravenous infusion of some of your donor's lymphocytes (a type of white blood cell), which have been collected from your donor's blood stream. It is hoped that this will boost the beneficial graft versus malignancy effect of your transplant (see above). You may also be asked to stop taking your immunosuppressive drugs, or to reduce the dose for some time.

Your doctor will advise you on your chances of relapse following the transplant.

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

It can take a year or even longer for the immune system to fully recover following an allogeneic transplant. As such you will be at risk of infection for some time after your transplant.

Infections can develop anywhere but common sites of infection at this stage include your mouth, central venous catheter and chest. Causes of infections include bacteria, viruses and fungi.

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.

As we mentioned previously, cytomegalovirus (CMV) can cause serious infection while your immune system is weak. You will have regular blood tests to check for CMV. If CMV is detected you will need intravenous treatment with antiviral drugs.

Chronic graft versus host disease

Chronic graft versus host disease affects a number of people who have had an allogeneic transplant. It is sometimes a continuation of acute GVHD which developed at a much earlier stage but it can develop without much acute graft versus host disease to begin with.

Many organs can be affected by chronic GVHD. The effects can be mild and resolve over time or they can be more severe, persistent and debilitating.

Chronic GVHD of the skin can cause some scarring and thickening of the skin in the affected areas. Some hair loss is not uncommon in these areas which may also take on a darker appearance. In severe cases, chronic graft versus host disease of the skin can be painful and limit movement.

Chronic GVHD of the gut can lead to ongoing problems with absorbing nutrients and gaining weight. You may experience diarrhoea and or constipation.

Dryness of the lining of the mouth and oesophagus, eyes, lungs, urethra and vagina is another feature of GVHD. Using artificial saliva, sucking hard lollies and increasing the amount of fluids you drink each day can help in relieving dryness in your mouth. Artificial tears may help alleviate dryness of the eyes.

In women, the effects of treatment and chronic graft versus host disease of the vagina can lead to **vaginal stenosis**. This is a condition characterised by vaginal dryness and inflammation. The walls of the vagina become more narrow and rigid than normal leading to difficult and painful intercourse for the woman. It is important to talk to your doctor if you are experiencing any of these symptoms. He or she may refer you to a gynaecologist who can best advise you on how to manage this problem. Vaginal lubricants which can be purchased over the counter and vaginal dilators can be useful.

Chronic GVHD can be controlled with drugs that suppress the body's immune system to help it accept the new stem cell graft. This in turn can make people more prone to infection so care needs to be taken to reduce this risk.

While the effects of chronic GVHD can take their toll, you and your doctor will be able to take positive steps to minimise their impact on your daily life.

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.

Cataracts

A *cataract* is a clouding of the lens of the eye and makes it difficult to see properly. Cataracts are a late complication of total body irradiation and usually occur within six months to five years after the transplant. Prolonged use of corticosteroids, such as prednisone, may also increase the risk for their development. Cataracts can be corrected with minor surgery.

9. RECOVERY - TAKE GOOD CARE OF YOURSELF!

Prevention of infection

Although the 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 with chicken pox, measles or other viruses, or children who have had a live vaccine such as polio
- avoiding garden soil, 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 line 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 then 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 as time goes by. It is important that you report any soreness in your mouth, bleeding gums or if an ulcer or a cold sore develops.

Appetite

Most people find that although their appetite improves once they leave hospital, it takes some time before they are able to eat as much as they used to. Many people find that food just doesn't taste or smell the same as it did before the transplant. It can take some time for your sense of taste and smell to return to normal. In the meantime, cleaning your mouth before eating and adding a little more sugar or salt can help to improve the taste of food.

If you are having difficulty eating large amounts at mealtimes, try eating small amounts more frequently. It is always important to drink fluids so that you don't become dehydrated (about six to eight glasses a day). Nutritious drinks like milkshakes, 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.

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.

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 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 or exercise physiologist about an appropriate program of exercise or physical activity for you. The hospital or Leukaemia Foundation could help you with arranging this appointment.

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. Always check with your doctor before going to a gym or sporting club as they can often be sources of infection.

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. 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 do try to avoid the sunniest parts of the day. The immune-suppressing medications may also increase the risk for skin cancers, so regular skin checks are a vital part of your ongoing well-being.

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, weight gain or weight loss and fatigue can all interfere with feeling attractive. You may experience a decrease in libido, which is your body's sexual urge or desire, sometimes without there being any obvious reason. It may take some time for things to return to 'normal'.

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

Partners are sometimes afraid that sex might in some way harm the patient. This is not likely as long as the partner is free from any infections and the sex is relatively gentle. 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.

Vaccinations

In general, following an allogeneic transplant you will lose the immunity to many of the diseases you were vaccinated against as a child. These include measles, mumps, rubella and polio. Your doctor will assess when your immune system has recovered enough to allow you to be re-vaccinated as the vaccinations need to be able to stimulate the immune system to work. This will usually be no earlier than twelve months after the transplant. There may be some vaccines that your haematologist may consider unsafe to give (especially live vaccines), and these will be discussed with you. In the meantime it is important that you avoid anyone who is sick or has had contact with someone with a 'catching' illness. You also need to avoid children who have had a live vaccine such as polio.

Also, if you are planning to travel overseas, vaccinations may be required to safely prevent some serious infections. Once more, some of these vaccinations may not be safe to be given to you, so please let your doctor know well in advance about your plans, so a vaccination schedule may be organised. Advice from an infectious diseases or travel health specialist may be required.

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.

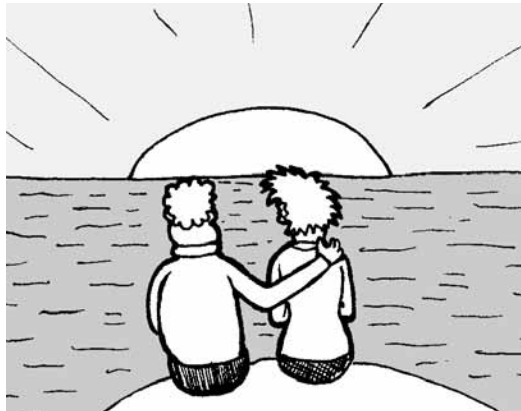
Most people benefit greatly by the support and love of their family and friends and the care provided by the members of the transplant team. Many centres have psychologists, social workers and pastoral care workers who can assist you and your family in coping better with any psychological, emotional 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.

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. The Support Services Coordinators can also help put you in touch with a local support group.

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

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

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



USEFUL INTERNET ADDRESSES

- Leukaemia Foundation
www.leukaemia.org.au
- American Cancer Society
www.cancer.org
- Australian Bone Marrow Donor Registry
www.abmdr.org.au
- Australian Cord Blood Bank
www.sch.edu.au/departments/acbb
- Australian Organisation for Young People Living with Cancer
www.canteen.org.au
- Bone & Marrow Transplant Information Network
www.bmtinonet.org
- Bone Marrow Transplant Network NSW
www.bmtnsw.com.au
- CancerBACUP (A UK cancer information site)
www.cancerbacup.org.uk
- Cancer Council of Australia
www.cancer.org.au
- Centre for Grief and Loss
www.grief.org.au
- Leukaemia Foundation's Network for Young Adults
www.teamrevive.com
- Leukaemia Foundation's online discussion forum
www.talkbloodcancer.com
- Leukemia & Lymphoma Society of America
www.leukemia-lymphoma.org
- Leukaemia Research Fund (UK)
www.lrf.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.

Aplastic anaemia

A bone marrow disorder characterised by failure of normal blood stem cell growth and development.

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 stem cells

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

Bone marrow

The tissue found in the centre of our bones. Active or red bone marrow contains stem cells from which all blood cells are made. In the adult this is found mainly in the hips, ribs, spine, skull and breastbone/sternum. Other bones contain inactive/yellow fatty marrow.

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.

Cataract

A cataract is a cloudy film that develops over the pupil of the eye and makes it difficult to see properly.

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.

Cyclosporin

An immunosuppressive (anti-rejection) drug commonly used after an allogeneic blood stem cell transplant to help reduce graft versus host disease and graft rejection. Side-effects include hirsutism (extra hair growth), fluid retention and high blood pressure.

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.

Graft versus host disease (GVHD)

An immune reaction which occurs when cells of the donor's immune system recognise the patient's body as foreign and attack it. The skin, gut and liver are common targets of GVHD. Acute GVHD occurs within the first 100 days after transplant. Chronic GVHD occurs after this time.

Graft versus malignancy effect

The killing of leftover cancer cells by the donor's immune system.

Graft rejection

When the new graft fails to grow.

Growth factors

A complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy or bone marrow or peripheral blood cell transplantation.

Haemopoiesis

The process 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 left over (or residual) 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 defense 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/when they 'spill out' into the bloodstream, they can cause 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.

Matched unrelated donor (MUD) transplant

An allogeneic stem cell transplant where the donor is unrelated to the patient, but with a similarly matched tissue type. Also called voluntary unrelated donor (VUD) transplant.

Menopause

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

Mini allogeneic (mini allo stem cell transplant)

A blood stem cell transplant involving the use of reduced doses instead of high-dose chemotherapy.

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.

Parotitis

An inflammation of the saliva-producing parotid or submandibular glands situated at the top of the jaw line, in front of the ears.

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.

Tissue typing

Matching the tissue type of the donor and patient.

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.

Voluntary unrelated donor (VUD) transplant

See matched unrelated donor (MUD) transplant.

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
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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 .





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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:

- 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 Lymphomas
(non-Hodgkin's lymphomas or B-cell & T-cell lymphomas)
- Understanding Myelodysplastic Syndrome
- Understanding Myeloma
- Understanding Myeloproliferative Disorders
- Young Adults with a Blood Cancer
- Eating well: a practical guide for people living with leukaemias, lymphomas & myeloma

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:
Leukaemia Foundation
GPO Box 9954
in your capital city

January 2010

