ALLOGENEIC STEM CELL TRANSPLANTS
(also called bone marrow transplants)

A guide for patients and families
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People who have experienced blood cancer as a patient or carer, Leukaemia Foundation support staff, haematology nursing staff and clinical haematologists.

The Leukaemia Foundation values feedback from people affected by blood cancer and the healthcare professionals working with them. If you would like to make suggestions, or tell us about your experience of using this booklet, please contact us at info@leukaemia.org.au.

November 2017
INTRODUCTION

This booklet has been written to help you and your family understand more about allogeneic stem cell transplants.

Some of you may be feeling anxious or a little overwhelmed if you or someone you care for has been diagnosed with blood cancer. This is normal.

Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family.

Whatever point you are at, we hope this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

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 you think will be most useful at a particular point in time.

We have used some medical words and terms which you may not be familiar with. Their meaning is explained in this booklet and/or in the glossary of terms at the back of the booklet.

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

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

We hope you find this booklet useful in providing support and information. We would appreciate any feedback from you so we can continue to help you and your family in the future.
THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life.

It exists only because of the generous and ongoing support of the Australian community.

Each year, the Leukaemia Foundation helps more than 750 families from regional and rural Australia by providing free accommodation in our capital cities so they can access life-saving treatment at major hospitals.

Our transport service helps thousands get to and from medical appointments, driving more than one million kilometres each year to ensure people get the medicines they need to beat their blood cancer.

The Leukaemia Foundation also provides counselling, comprehensive information, education and support programs and financial assistance to help the 60,000 Australians who are currently living with a blood cancer.

The Leukaemia Foundation also funds researchers who are working tirelessly to discover safer and more effective treatments that will save lives and help people lead a better quality of life.

Supporters ensure the Leukaemia Foundation can continue to give those impacted by blood cancer a strong voice, advocating for change and ensuring all Australians who need them have easy access to the very best blood cancer treatments.
Support Services

The Leukaemia Foundation has a team of highly trained and caring support staff with qualifications and experience in nursing or allied health who work across the country.

We 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 free booklets, DVDs, fact sheets and other resources. These can be ordered via the form at the back of this booklet or downloaded from leukaemia.org.au.

Education & Support programs

The Leukaemia Foundation offers you and your family both 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 wellbeing.

Emotional support

A diagnosis of blood cancer can have a dramatic impact on a person’s life. At times it can be difficult to cope with the emotional stress involved. Leukaemia Foundation support staff can provide you and your family with much needed support during this time.
**Blood Buddies**

This is a program for people newly diagnosed with blood cancer to be introduced to a trained ‘buddy’ who has been living with blood cancer for at least two years, to share their experience, their learning, and to provide some support.

**Telephone discussion forums**

This service enables anyone throughout Australia who has blood cancer to share their experiences, provide tips, and receive education and support in a relaxed forum. Each discussion is facilitated by a member of the Leukaemia Foundation support team who is a trained health professional.

**Accommodation**

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

**Transport**

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

*With the cost of hospital car parking and how difficult it can be to find a car park, the Leukaemia Foundation’s transport service has made my hospital visits so much easier.*
Practical assistance
The urgency and lengthy duration of medical treatment can affect everyday life for you and your family and there may be practical things the Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for people who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

Advocacy
The Leukaemia Foundation is a source of support for you as you navigate the health system. While we do not provide treatment recommendations, we can support you while you weigh up your options. We may also provide information on other options such as special drug access programs, and available clinical trials.

Contacting us
The Leukaemia Foundation provides services and support across Australia. Every person’s experience of living with blood cancer is different. Living with blood cancer is not always easy, but you don’t have to do it alone.

Please call 1800 620 420 to speak to a support 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 leukaemia.org.au.
To understand allogeneic transplants it is important to understand stem cells, where they are made and what they do.
Getting to Know Your Bone Marrow, Stem Cells and Blood

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 haematopoiesis. There are three main types of blood cells: red cells, white cells and platelets.

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

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

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

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

Lymphoid (‘lim-foid’) stem cells develop into other types of white cells including T-cells, B-cells and Natural Killer Cells.
Blood cell formation:

- Myeloid Stem Cell Line: Red Cells, White Cells, Platelets
  - Neutrophils, Eosinophils, Basophils, Monocytes
- Lymphoid Stem Cell Line: B Cells, T-cells, Natural Killer Cells
  - Plasma Cells

Growth factors and cytokines

All normal blood cells have a limited lifespan in the circulation and need to be replaced on a continual basis. This means that the bone marrow remains very active throughout life. Natural chemicals circulating in your blood called growth factors, or cytokines, control this process of blood cell formation. Each of the different blood cells is produced from stem cells under the guidance of a different growth factor.

Some of the growth factors can now be made in the laboratory (synthesised) and are available for use in people with blood disorders. For example, granulocyte colony-stimulating factor (G-CSF) stimulates the production of certain white cells, including neutrophils, while erythropoietin (EPO) stimulates the production of red cells.

Blood

Blood consists of blood cells and plasma. Plasma is a straw-coloured fluid that blood cells use to travel around your body and also contains many important proteins and chemicals.
Blood cells

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.

Haematocrit
About 99% of all blood cells in circulation are red blood cells. The percentage 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.

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

If you are anaemic you may feel rundown 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 blood transfusion may be given to restore the red blood cell numbers and therefore the haemoglobin to more normal levels.

Normal ranges for adults:

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
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<tbody>
<tr>
<td>Haemoglobin (Hb)</td>
<td>130 – 170 g/L</td>
<td>120 – 160 g/L</td>
</tr>
<tr>
<td>Haematocrit (Hct)</td>
<td>40 – 52%</td>
<td>36 – 46%</td>
</tr>
<tr>
<td>White cell count (WBC)</td>
<td>3.7 – 11.0 x 10⁹/L</td>
<td></td>
</tr>
<tr>
<td>Neutrophils (neut)</td>
<td>2.0 – 7.5 x 10⁹/L</td>
<td></td>
</tr>
<tr>
<td>Platelets (Plt)</td>
<td>150 – 400 x 10⁹/L</td>
<td></td>
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White cells
White cells, also known as leukocytes, fight infection. The following is a list of some of the different types of white cells:

**Neutrophils:** mainly kill bacteria and remove damaged tissue. Neutrophils are often called the first line of defence when infections occur. They are often the first white blood cell at the site of infection and attempt to destroy the foreign pathogen before it becomes a problem to the body.

**Eosinophils:** mainly kill parasites.

**Basophils:** mainly work with neutrophils to fight infection.

**Monocytes:** mainly work with neutrophils and lymphocytes to fight infection; they also act as scavengers to remove dead tissue. These cells are known as monocytes when found in the blood, and called macrophages when they migrate into body tissue to help fight infection.

**B-cells:** mainly make antibodies that target microorganisms, particularly bacteria.

**T-cells:** mainly kill viruses, parasites and cancer cells and produce cytokines which can recruit other cells to make antibodies which target microorganisms.

These white cells work together to fight infection as well as having unique individual roles in the fight against infection.

**Neutropenia**
Neutropenia is the term given to describe a lower than normal neutrophil count. If you have a neutrophil count of less than 1 (1 x 10⁹/L), you are at an increased risk of developing more frequent and sometimes severe infections.

To reduce infections, regular washing of my hands has become part of my new normal.
**Platelets**

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

If a blood vessel is damaged (for example by a cut) the platelets gather at the site of the injury, stick together and form a plug to help stop the bleeding. They also release chemicals, called clotting factors, that are required for the formation of blood clots.

**Thrombocytopenia**

Thrombocytopenia is the term used to describe a reduction in the platelet count to below normal. If your platelet count drops too low, you are at an increased risk of bleeding and tend to bruise easily. Each treatment centre will have their own guidelines on the specific platelet count level when interventions may need to be taken. Platelet transfusions are sometimes given to return the platelet count to a safer level.

### Normal ranges for children:

<table>
<thead>
<tr>
<th></th>
<th>1 month</th>
<th>1 year</th>
<th>3 years</th>
<th>5 years</th>
<th>9 years</th>
<th>16 years</th>
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<tbody>
<tr>
<td><strong>Haemoglobin g/L</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 month</td>
<td>102-130</td>
<td>104-132</td>
<td>107-136</td>
<td>110-139</td>
<td>113-143</td>
<td>115-165 (f)</td>
</tr>
<tr>
<td><strong>White cell count x10^n/L</strong></td>
<td>6.4-12.1</td>
<td>5.4-13.6</td>
<td>4.9-12.8</td>
<td>4.7-12.3</td>
<td>4.7-12.2</td>
<td>3.5-11</td>
</tr>
<tr>
<td><strong>Platelets x10^n/L</strong></td>
<td>270-645</td>
<td>205-553</td>
<td>214-483</td>
<td>205-457</td>
<td>187-415</td>
<td>150-450</td>
</tr>
<tr>
<td><strong>Neutrophils</strong></td>
<td>0.8-4.9</td>
<td>1.1-6.0</td>
<td>1.7-6.7</td>
<td>1.8-7.7</td>
<td>1.8-7.6</td>
<td>1.7-7.0</td>
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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

The terms bone marrow transplant and stem cell transplant are both used to describe the same process:

» collecting stem cells that were created in the bone marrow

» giving the patient chemotherapy to deplete the blood-forming cells in their bone marrow

» infusing the collected stem cells into the patient, to create a new bone marrow population of blood-forming stem cells.
Strictly speaking, a peripheral blood stem cell transplant (PBSCT) refers to the use of blood stem cells which have been collected from the bloodstream (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.

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.

Often, haematological conditions are able to be treated with other therapies and do not require a stem cell transplant.

Occasionally, some people’s disease gets worse during regular treatment (refractory disease), the treatment does not make the disease go away entirely, or the disease type is known to recur after other treatments. These people may require a stem cell transplant.

The following list gives you some examples of blood cancers and related disorders that are treated with stem cell transplantation:

» leukaemia
» lymphoma
» myeloma
» aplastic anaemia
» MDS/MPN
» some immune system disorders.
How does it work?

A stem cell transplant uses chemotherapy and at times radiotherapy to kill off the affected bone marrow cells and disease, before transplanting the stem cells from a donor to regenerate the bone marrow and create a new donor immune system.

When high-dose chemotherapy is administered, it aims to destroy faulty cells within the bone marrow. As an unwanted effect, it may also destroy the precious population of stem cells which then need to be replaced to allow for the re-building of blood cells and your immune system.

Allogeneic transplants are more complicated than autologous transplants in the way that they work. The new immune system from the donor often has an important role to play in killing any leftover tumour cells.

This is called the graft-versus-malignancy effect, and is discussed later in this booklet.

In short, a stem cell transplant is necessary to ensure that the bone marrow is repopulated with healthy blood stem cells following high-dose chemotherapy treatment. The new stem cells will rebuild your body’s blood and immune systems. The recovery of these systems is vital for your survival.

The word transplant can be a little misleading here and conjures up inaccurate images of a surgical procedure. In reality, on the day of the transplant stem cells are simply given intravenously, almost like a blood transfusion. From here the stem cells travel to the bone marrow, and in time set up home and begin to rebuild your body’s blood and immune systems.
Types of Transplants

There are two main types of stem cell transplants: autologous (au-tol-o-gus) and allogeneic (al-o-gen-a-ic). The focus of this booklet is allogeneic stem cell transplants.

Autologous

In autologous stem cell transplants, the patient donates his or her own stem cells. The patient’s blood stem cells are collected in advance (while they are in remission, or the disease level has been reduced as much as possible) 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 the disease coming back (relapsing) in the future in some conditions.

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.

Sometimes there is a slight mismatch between the donor and patient’s tissue type. This is called a mismatched transplant.

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.

A syngeneic transplant is when stem cells are donated from an identical twin. This type of transplant is very rare, and has more similarities to an autologous stem cell transplant.

Stem cells can also be collected from donated umbilical cord blood through a cord blood banking program, and used as part of a cord blood transplant. The number of stem cells that can be collected in this way are limited, and therefore this method may not always be sufficient for use in adult patients.

In 2015, a total of 1,746 stem cell transplants were carried out in Australia. Of these:

» 1,133 were autologous
» 573 were allogeneic – 222 of these were related stem cell donors, and 351 were unrelated stem cell 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, your age and general health. Other important factors are the condition of your bone marrow and the ability to collect blood stem cells. 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.
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 they have enough information to make such decisions while others feel overwhelmed by the amount of information they are given, or feel that they are being rushed into making a decision.

Sometimes there is no exact science behind when a person should have a stem cell transplant and it comes down to your specific situation and personal preference. Other times there is a clear time when a stem cell transplant is recommended. Making the best decision for you may require extensive discussion with your doctor and your loved ones.

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 using chemotherapy alone, may offer some people a 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 can 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.
SOURCES OF STEM CELLS

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

» the bloodstream (peripheral blood stem cell harvest)
» the bone marrow (bone marrow harvest)
» umbilical cord blood.

Peripheral blood stem cell harvest
Collecting stem cells directly from the bloodstream is the most common method used for a stem cell donation. It is considered a safe and relatively painless method of donating precious stem cells, but like all medical procedures, there are some potential risks.

Stem cell mobilisation
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 replicate in large numbers where they overflow out of the bone marrow and into the bloodstream, 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 bloodstream by passing the donor’s blood through a special machine called a cell separator.

This procedure is usually performed in an Apheresis Unit in the hospital. 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 collarbone, in the neck, or in the groin. 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/s to repeat the procedure until a sufficient number of stem cells have been collected.

The stem cells are commonly used fresh (infused into the patient within 24-72 hours of collection) but may be frozen (cryopreserved) and stored until they are infused on the day of the transplant. Blood stem cells can remain frozen for many months or years before they are used.
Bone marrow harvest

Bone marrow harvests (collecting stem cells directly from the bone marrow) are not commonly used for adult donors today, as they are more invasive to the donor. A 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.

Umbilical 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 although you would have to check which hospital offered the service in your state. Some private cord collection services also exist for people who would like to save the cord cells for a potential use. Umbilical cord blood transplants are most commonly used in children but double cord transplants for adults are increasing.
Tissue Typing—Matching Donors to Recipients

One function of the immune system is to identify what belongs in your body and what doesn’t. Your immune system will identify markers on your cells that belong to you. If your immune cells identify markers that are not yours, or are faulty, they will destroy those cells.

If you are having an allogeneic transplant, time will be taken to ensure the best possible donor match is found; that is, they have as many similar cell markers as you as possible. 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), which is an immune system reaction commonly seen after an allogeneic transplant. In graft-versus-host disease, the donor’s immune system does not recognise the patient’s body as its own 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 on page 56.

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 (e.g. blood type A, B, O). There is no need to match the blood type of the transplant patient and the stem cell donor.
More information on tissue typing

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 the ideal donor to ensure the recipient did not get GVHD. It has been shown that in some cases an identical twin donor’s immune system may also not recognise the cancer cells as foreign and may not attack and kill the cancer cells.

The next closest tissue type is often found in a full sibling, that is, a brother or sister who has inherited their genetic makeup from the same parents as the patient.

As we inherit half of our genetic makeup 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 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 that have a slightly different tissue type (mismatch) are used, but these may still be regarded as the best possible match for the patient.
What if I don’t have a matched donor?

Most of the time, a matched donor can be found either amongst your siblings, or from the many unrelated donor registries in Australia or abroad. In circumstances where no matched donor can be found, a number of options are available that could still allow you to have a transplant. These options will be considered based on your disease, your health, and the hospital where you are looked after.

One such option is to use stem cells from a mismatched unrelated donor. Not all mismatches are thought to have the same risk for increased complications, so your doctor may advise this as the best approach for you.

Another option is to use a close, but non-matched, family member, such as a sibling, a parent, or even a child. These transplants are called “Haplo-identical” transplants, and are often more complex than fully matched transplants. Haplo-identical transplants will usually involve additional modifications to the stem cells, or extra medications, to reduce the risk of complications.

Remember that the decisions regarding the best choice of transplant are highly intricate, and will be made taking into account all of your individual circumstances.
STAGES OF A STEM CELL TRANSPLANT

While we tend to concentrate on the day the stem cells are transplanted as the most crucial day, it is important to realise 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.

The transplant experience is not always straightforward and you may experience many expected and unexpected events along the way. Everybody has a different transplant experience and the unexpected events can be both serious and very frustrating.

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 all there to help you towards your recovery.

A stem cell transplant is a challenging experience. You may find 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.

There are several stages of a stem cell transplant. These have been divided as follows:

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 deals with what you need to consider before you start your transplant.

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 people, however, the timing of the transplant may be critical and these events may have to be put on hold for several months.

You could expect to stay in the hospital for around three to six weeks, and then you may need to stay near the hospital for at least 100 days after the transplant in case of complications and for follow-up appointments.

This is especially important for people in regional or remote areas, as a transplant often means the patient and at least one carer need to relocate close to the hospital for an extended period of time.

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 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 at least 12-24 months to initially recover from an allogeneic transplant. However for patients who experience chronic graft-versus-host disease, longer-term complications can sometimes be persistent and ongoing.

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:

» you will need somebody to help support you through the transplant process and beyond. Do not underestimate how challenging a transplant can be. You will need a support person to help you through it.

» organising your financial affairs

» making a Will and organising a Power of Attorney
» sorting out employment issues such as sick leave entitlements, keeping in touch, and 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 or a personal music player, books, phone cards, photographs and videos of your family, and maps of the city if you or your family come from out of town
» setting your own personal targets and goals for the future
» some patients like to keep a diary to keep track of their progress and important information during the transplant process
» 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**

If required the hospital 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 on 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 for cancer.

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. Regardless of future wishes to start a family, many women may wish to discuss options such as Hormone Replacement Therapy for after their transplant.

In men, sperm production can be impaired. The effects of transplant treatments on your fertility may 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.

Below is a brief description of some of the current approaches to protecting your fertility. We realise 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, 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 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 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. Embryo storage 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. 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 is 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.

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 these 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 your treatment commences.
2. PRE-TRANSPLANT ‘WORK-UP’

This section deals with the preparations that need to be made before you start your transplant, including:

» pre-transplant tests
» dental check
» blood tests
» venous access device.

Pre-transplant tests

In 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 circumstances.

While many of the tests can be done on the same day, some may require several visits to the hospital and some may take longer than others. You might like to bring a book or a friend for company.

The nurse or transplant coordinator will be able to advise you about any special preparations you need to make for each 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 or an electrocardiogram)
» 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.

Several tests can often be done on one blood sample. In addition, a venous access device (VAD) will be inserted before the transplant. Blood can be taken directly from this special line without causing you discomfort from frequent needle pricks.

**Central lines - or venous access devices**

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, and the stem cell transplant itself. 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 would not be able to 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 venous access device (VAD) is inserted prior to your transplant.

A VAD is a special line inserted through the skin, into a large vein in your neck or chest. This is usually done under anaesthetic 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 VADs and various terms used relating to them:

» central line or central venous catheter - general terms used to describe VADs where the tip is located deep in the body near the heart

» Hickman’s Catheter - a commonly used device inserted in the chest, which may remain in place for weeks to months depending on your need

» PICC Line - a device inserted in a vein in the arm

» vascath - a short-term central line inserted into the neck

» portacath - a device inserted under the skin of the chest which can be accessed by a small needle. Common for long-term use.

The devices most commonly used for transplant patients have two or three lumens (or tubes). The lumens are the separate thin plastic tubes that hang on the outside, on top of your skin, which are clustered together so only one tube is inserted inside you. The nurses will take blood and give various infusions through these lumens, without causing pain to you.

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 and normal.

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 leftover 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 people have their conditioning therapy as an outpatient in the clinic, particularly if undergoing a transplant with reduced intensity conditioning.

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).
Reduced intensity conditioning allogeneic stem cell transplants

Some patients receive conditioning therapy that is less intense than the standard conditioning. This 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: this is called engraftment.

It is hoped that the less intensive 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 by 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
» fludarabine and cyclophosphamide
» fludarabine and busulfan.

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 allogeneic) that you are having.

Transplant protocols

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

Conditioning therapy is given in the week before your transplant. The days leading up to the transplant (pre-transplant) are called Day -6 (minus six), Day -5, etc. counting down to Day 0 (zero) being the day when you receive the stem cells. You then count forward: Day +1, +2, etc. (post-transplant).
In addition to conditioning treatment, a much lower dose chemotherapy is also commonly delivered for a number of days following the day of the transplant, to help reduce the significance of GVHD.

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. Chemotherapy is not (as a general rule) radioactive and is not a danger to others if they are not in contact with any of your bodily fluids.

Some chemotherapy drugs require you to have up to six litres of intravenous fluid a day, on the days 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 medications (diuretics) to increase the amount of urine you produce.

It is important to ask your doctor and nurse about any special precautions that 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 (as well as) chemotherapy because it can penetrate and treat areas of your body less easily reached by chemotherapy (for example your brain and spinal cord). 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 during the pre-transplant ‘work-up’ to be measured (height and weight) and assessed for radiation therapy.
TBI itself is painless; it is similar to having an x-ray. You do not feel anything during the treatment, although side-effects afterwards may be unpleasant. TBI is often given twice a day, for two to three days, in the radiotherapy department of the hospital, though other protocols may be issued depending on your situation. To make sure 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**

The following outlines some of the more common 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 make a diary note and 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, be sure to ask.

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 the 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 that 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, including the use of a soft toothbrush to keep bacteria in the mouth to a minimum.

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.
Because they are so nutritious, you don’t need to drink a lot of these fluids.

Sometimes your body can hold on to 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, which are drugs that make you pass more urine.

Eating in hospital
There are many reasons why you may not feel like eating much while you are in hospital. This is normal. Your appetite should start to improve once you go home but it can take some time to return to normal.

Try to eat small meals as frequently as you feel like it. You might like to ask your family to bring your favourite food to hospital, but 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 the food. Your treatment team may have some foods that they prefer you to avoid as they may carry a risk for infection. They will discuss this 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. An intravenous food supplement/substitute called TPN may be used for some people who cannot take in adequate amounts of food and liquids over time. Nasogastric feeds (another form of food substitute, delivered by a tube that runs from the nose directly into the stomach) may be appropriate in some situations and are commonly used in children.

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.

**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 make you feel more comfortable at this time. Some people get their hair cut short so they can lose it in stages, and slightly lessen the shock.

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 TBI.
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.

Some people may also experience dry eyes and discomfort due to the reduced tear production which can occur, particularly following radiation.

Following TBI, patients also have a greater chance of developing cataracts longer term.

**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. Listen to your body: if you feel tired, sleep.

It is important to talk to someone about how you are feeling. Ask your doctor or nurse about seeing the social worker, psychologist, physiotherapist 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 information on relaxation and meditation, which might be useful at this time. Some transplant centres have a selection of DVDs, talking books and music which can help to pass the time if you are feeling bored.

Mild exercise, such as walks around the ward, may also be beneficial at this time if you feel up for it. Ask for advice for your circumstance from the hospital physiotherapist and your haematologist.
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 line, rather like a blood transfusion. This can take between thirty minutes and four hours, depending on the volume of cells being infused.

Sometimes previously frozen stem cells are used. If this is the case, the stem cells are defrosted at the bedside before being infused.

Reactions to stem cell infusions are rare but you will be carefully monitored during the infusion just in case.

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 using frozen stem cells, you and your visitors may also 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. Many people like to have a photo of the stem cell being infused to commemorate their ‘new beginning’.
## 5. PRE-ENGRAFTMENT

### The early days

After they are infused, the stem cells travel through your bloodstream and find their way to your bone marrow. Here they set up home and begin to repopulate the bone marrow with families of immature white cells, platelets and red cells.

This process is known as engraftment and it usually takes anywhere between 10 and 28 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 your doctor and nurses every day and having regular temperature, pulse and blood pressure measurements taken throughout the day and night.

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.

During this time your immune system will be very compromised and a number of tests will be performed to monitor how you are doing. You may be feeling very tired and frustrated from being woken up day and night for monitoring. You may experience feelings of being vulnerable, having a loss of control over your life, and a mixture of other strong emotions at this time.

It is not easy waiting for the stem cells to engraft. 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 that may occur in the first few weeks after your transplant.

The following issues are covered here:

» infections
» 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 all 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. Despite the recovery of your white cells in the early weeks after your transplant, the risk of developing an infection remains for many months while your body continues to recover.

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 their 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**

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 once you have commenced the antibiotics.

Sometimes it is not possible to find the cause of your infection. 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. Your transplant team are very experienced at managing infections and will do all they can to minimise the impact of the infection.
Cytomegalovirus (CMV)

Cytomegalovirus (CMV) is an opportunistic virus. This means 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 is 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.

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 infections 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 Septrin), 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 is 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 when 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. Alternatively, it may be suggested that you wear a mask if you are permitted to walk around the ward during this period.

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 the ward 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 they wash their hands well before entering the room. During this time you should avoid contact with anyone with colds, flu, chicken pox, measles or any other ‘catching’ illness, or anyone who has had a live vaccine.
You may only be allowed 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 young children visiting transplant wards. Ask your nurse or doctor if you have any questions regarding visitors.

Some days you may not feel up to having visitors. You should encourage your friends and family to check with the transplant ward before coming to visit, to save disappointment if you are not up for visitors at that time.

You may like your visitors to bring some photos of happy times together that may give you a boost when you are not feeling so positive. Messages of support are also good to place on your walls to encourage you and remind you of the love and support of people who care about you. You are not going through this alone.

**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 ones that are 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, certain yogurts, shellfish, uncooked eggs and soft cheese, which can all harbour bacteria.

Please check with your dietitian, 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 central line; 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 24 hours).

Transfusions these days are considered 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 at the blood bank and at the bedside to ensure that the blood you are receiving is compatible with your blood type.

If your 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 donor’s (and your new) blood group.
Veno-occlusive disease (VOD) or Hepatic Sinusoidal Obstruction Syndrome (HSOS)

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 hepatic sinusoidal obstruction syndrome (HSOS), and was formerly called veno-occlusive disease (VOD).

HSOS 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 HSOS. Other factors that can increase this risk include types of treatments given prior to the transplant, and pre-existing liver problems.

HSOS 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.

With chemotherapy known to cause this side-effect, to reduce the risk of haemorrhagic cystitis extra intravenous fluids and sometimes a preventive drug are given together. 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, 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. Mycophenolate is another drug used in some circumstances and may be used if cyclosporin is not tolerated.

If you have an allogeneic transplant it is vital 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. Chronic GVHD can be experienced by some people and this may last for many years. Your body can be affected in a number of ways, and any changes to your normal should be reported to your haematologist.

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 leftover disease might be destroyed in the immune reaction that follows (see graft-versus-malignancy effect on the next page).
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. It is very important to report any bowel/gut changes to your doctor so that appropriate treatment can be started, if required.

Many people who develop GVHD of the gut need intravenous fluid therapy to replace fluids that are lost and to prevent dehydration. If the GVHD 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 line. 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 may present 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 100 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: Potential late side-effects).

**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 GVM 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 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. The length of time you will need to be away from home will be dependent on your recovery and can be up to 6-12 months.

You may need to return to the hospital’s outpatient department several times a week after 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 may still need to take some medications for an extended period. 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 and professional care of the transplant unit. It is also important to ask your doctor or nurse for any special instructions or advice you should follow after you leave the hospital.

Before you leave the unit, you may be given a special card or pamphlet with important hospital and 24 hour emergency numbers written on it 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 not unusual 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 you are given every chance to recover fully from the transplant. This may mean a little more time in hospital.

Make sure you are aware of your treatment centre’s protocols for being seen quickly in the emergency department after a transplant. Do not wait in an emergency queue for a time if you are experiencing fever; you need to advise the staff at the desk of your situation as an urgent priority.

**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 or bowel motions, coughing up blood, bleeding gums or a persistent nose bleed
- **nausea** or **vomiting** that prevents you from eating or drinking or taking your normal medications
- **diarrhoea**, **stomach cramps** or **constipation**
- **persistent coughing** or **shortness of breath**
- the presence of a new **rash**, **reddening of the skin** or **itching**
- a **persistent headache**
- a **new severe pain** or **persistent unexplained soreness** anywhere
- if you **cut or otherwise injure** yourself
- if you notice **pain**, **swelling**, **redness or pus** around your central line.

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 given. 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 bloodstream. It is hoped that this will boost the beneficial graft-versus-malignancy effect of your transplant.

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. You will have a plan with your treating centre to monitor and manage these late-effects.

Infection

It can take a year or even longer for the immune system to fully recover following an allogeneic transplant. You will therefore 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 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 (GVHD) 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 GVHD 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 GVHD 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 GVHD 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 women.

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 you discuss any changes to your periods with your doctor or nurse. He or she may be able to advise you or refer you to a specialist doctor (a gynaecologist) or clinic that can suggest appropriate steps to take to reduce your symptoms.

**Osteoporosis & Osteonecrosis**

Osteoporosis can occur as a side-effect of steroids, which are sometimes used following a transplant. It can affect both men and women.

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.

There are effective treatments to help prevent and treat osteoporosis. Simple physical activity, including weight-bearing exercise (walking) helps to prevent osteoporosis.

Prolonged use of steroids can be a part of necessary treatment but can also unfortunately lead to an increased risk of osteonecrosis developing in the years to follow. Though relatively rare, this is a condition whereby the interruption of blood supply to the joints leads to sections of the bone drying and collapsing, sometimes requiring surgery or joint replacement.

**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 showering
» regular mouth care
» avoiding close contact with people with suspected colds, flu and other viruses
» avoiding people who have been in contact with children with chicken pox, measles or other viruses, or children who have had a live vaccine such as polio
» avoiding garden soil and potting mix
» washing your hands after handling animals - patting the dog or cat is okay but if they lick you, wash the area as soon as possible.

It is important you use your common sense when it comes to the prevention of infection. Ask your healthcare team 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 line 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.

**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 do 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 exercise program 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 these areas 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.

**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 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.

**Skin care**

If you find 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 wellbeing.
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. You therefore need to ensure that you or your partner use 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 (this is especially important if your platelet count is low). 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 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, doing regular exercise and spending some time relaxing.
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 six months or more 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, as it will vary greatly from person to person.

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 six to 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 effects

While we like to talk about things getting ‘back to normal’ after a transplant, for some people things are never quite the same again. Many people find they have a ‘new normal’.

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 and feeling uncomfortable and isolated can all take their toll on your sense of wellbeing.

Normal family routines are often disrupted and other members of the family may suddenly have to fulfill roles they are not familiar with, for example cooking, cleaning and taking care of children. In some cases, families from rural areas relocate to accommodation near the hospital in the city where the transplant is taking place so that they can be together. All of these things can be very disruptive, stressful and upsetting.

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

If you have 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 from 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 staff are also 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. Support groups can therefore be invaluable. The Leukaemia Foundation can 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.

Interestingly, many people state that they have positive feelings about their transplant experience. They have learned what is important to them in life and have let go of emotional ‘baggage’ that they have been carrying with them needlessly.

They report personal growth, increased empathy for others, closer relationships to loved ones, and a better understanding of their own strength as a person.

Every person’s experience is different. Try not to judge yourself on how others have coped, but be aware of how you are doing, and work with others to help you find tools to manage your emotions as best you can.

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

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

There is an enormous amount of information about allogeneic stem cell transplants on the internet. Many of these sites are based in the United States, United Kingdom or Europe and the quality of information is enormously variable.

It is therefore important to use reputable and up-to-date sites and to discuss information that you have gained from these sites with your doctor and other members of your healthcare team.

Leukaemia Foundation
www.leukaemia.org.au

American Cancer Society
www.cancer.org

CanTeen
www.canteen.org.au

Blood & Marrow Transplant Information Network (USA)
www.bmtinfonet.org

Bloodwise (UK)
www.bloodwise.org.uk

Cancer Council of Australia
www.cancer.org.au

Leukemia & Lymphoma Society of America
www.lls.org

Look Good...Feel Better program
www.lgfb.org.au

MacMillan Cancer Support (UK)
www.macmillan.org.uk

National Cancer Institute (USA)
www.cancer.gov

Australian Bone Marrow Donor Registry
www.abmdr.org.au
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 the 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 adults 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.

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**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 the bone marrow’s stem cells to produce more white cells, particularly neutrophils.

**Graft rejection**
When the new graft fails to grow.

**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.

**Growth factors**
A complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some are now available as drugs as a result of genetic engineering and may be used to stimulate normal blood cell production following chemotherapy or bone marrow or peripheral blood stem cell transplantation.
Haematologist
A doctor who specialises in the diagnosis and treatment of diseases of the blood, bone marrow and immune system.

Haemopoiesis
The process involved in blood cell formation.

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 leftover (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 defence system against infection and disease.

Immunocompromised
When someone has decreased immune function.

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

Leukaemia
A cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal blood cells. These cells take over the bone marrow often causing a fall in blood counts. If/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 has 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 bloodstream.

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

**Prognosis**
An estimate of the likely course of a disease.

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

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

**Relapse**
The return of the original disease.

**Sibling donor**
A brother or sister of the donor, who share the same mother and father as the patient.

**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 bloodstream.
**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.
# MAKING A DONATION

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders survive and then live a better quality of life. It exists only because of the generous and ongoing support of the Australian community.

## How can I give?

- **ONLINE** [leukaemia.org.au](http://leukaemia.org.au)
- **PHONE** 1800 620 420
- **POST** (complete this form or enclose cheque/money order and return)
  
  The Leukaemia Foundation, Reply Paid 9954 in your capital city

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I enclose my gift of (please tick box)

- [$30](#)
- [$50](#)
- [$75](#)
- [$100](#)
- [$250](#)
- [Other $](#)

- [☐] My cheque/money order made payable to the Leukaemia Foundation is enclosed.
- [☐] I wish to pay with my credit card and my details are included below:
  - [☐] Visa
  - [☐] MasterCard
  - [☐] Diners
  - [☐] Amex

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Your privacy is important to us. That is why we treat your personal information with confidence. To learn more about how and why we collect and use any personal or sensitive information about you, please view our Notification Statement at [www.leukaemia.org.au/privacy](http://www.leukaemia.org.au/privacy)
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Name

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Postcode

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POST TO The Leukaemia Foundation, Reply Paid 9954 in your capital city

PHONE 1800 620 420 EMAIL info@leukaemia.org.au

FURTHER INFORMATION ONLINE leukaemia.org.au
This information booklet is produced by the Leukaemia Foundation and is one in a series on leukaemia, lymphoma, myeloma, MDS, MPN and related blood disorders.

Copies of this booklet can be obtained from the Leukaemia Foundation by contacting us.

The Leukaemia Foundation is a not-for-profit organisation that depends on donations and support from the community. Please support the Leukaemia Foundation today.

November 2017

CONTACT US

1800 620 420

GPO Box 9954, IN YOUR CAPITAL CITY

info@leukaemia.org.au

leukaemia.org.au

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE