

Allogeneic stem cell transplants

A guide for patients and their support people

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

This booklet has a list of contents, useful resources and a glossary. Your treatment team can answer further questions. You can also call our Blood Cancer Support Coordinators on 1800 620 420.

You will meet many healthcare professionals working as a team to provide you with the best available treatment. You will need to have a regular GP throughout your treatment. In this booklet when we refer to 'your treatment team' we usually mean haematologist and haematology nurses.

There is some information about treatments in this booklet, but it does not recommend any particular treatment. You must discuss your circumstances and treatment options with your haematologist.

Booklets for Aboriginal and Torres Strait Islander patients and their families can be found here: www.leukaemia.org.au/how-we-can-help/information-and-education-services/booklets-for-indigenous-australians/allograft-transplants/

The Leukaemia Foundation acknowledges the Traditional Owners of Country throughout Australia and recognises their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

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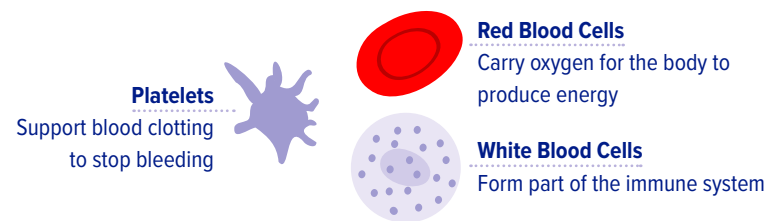
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All about blood

What is blood?

Blood travels to all parts of the body, carrying oxygen and nutrients and removing waste products. It's made up of cells and plasma. Plasma is the straw-coloured liquid part of the blood that carries blood cells and other substances around your body.

The main types of blood cells are red and white. Platelets are talked about like blood cells, but they are *fragments* of blood cells.



Red blood cells

Most blood cells in your total blood volume (40-45%) are red blood cells.

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives the blood its red colour and carries oxygen from the lungs to all parts of the body. Anaemia is the term used when there is a reduction in the number of red cells or low haemoglobin.

White blood cells

There are five types of white blood cells, also known as leukocytes or WBCs.

Although they make up only a small part (1%) of the blood, white blood cells protect us against and fight off infection. While all of them are important, you will hear the most about neutrophils and lymphocytes. Neutrophils fight bacteria and are especially important in recovering from chemotherapy. If you have a neutrophil count lower than 1 ($1 \times 10^9/L$), you are at an increased risk of developing more frequent infections. This is termed neutropenia.

Platelets

Platelets, also known as thrombocytes, are small pieces of cells. They help your blood clot or stick together, a process called coagulation. They help stop bleeding when you have an injury. If your platelet count drops too low, you are at an increased risk of bleeding and tend to bruise easily. The term used for this is thrombocytopenia.

Where and how is blood made?

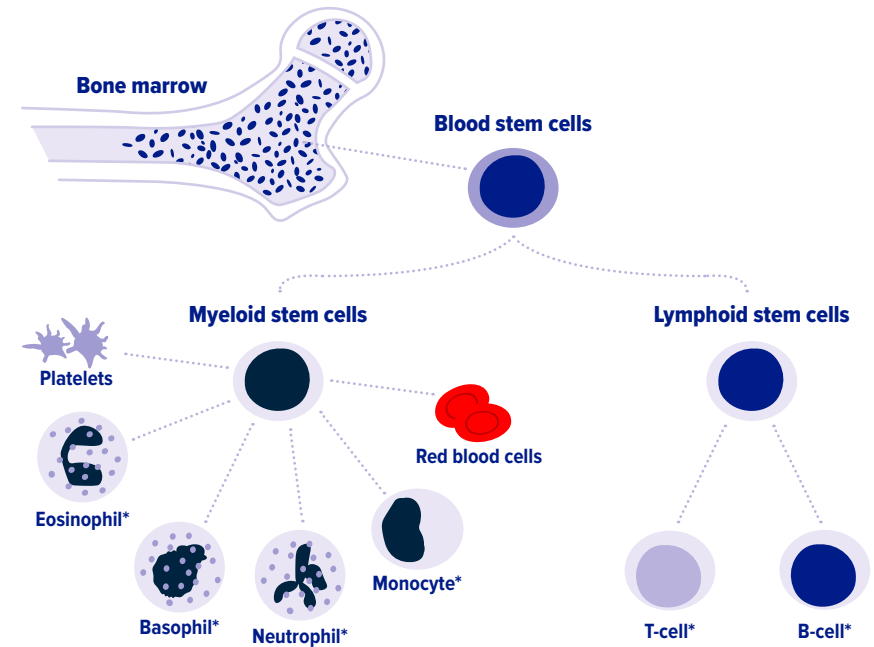
Bone marrow

Bone marrow is spongy tissue in the middle of certain bones. Most blood cells are made in your bone marrow. This process is called haemopoiesis.

In children, haemopoiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae) and hips, ribs, skull and breastbone (sternum). You may have a bone marrow biopsy taken at the back of your hip (the iliac crest).

Think of blood production like a family tree. At the top of the tree are the blood stem cells, which are the youngest (most immature) blood-forming cells. They can make copies of themselves and new cells.

There are two types of progenitor cells that split the family tree: lymphoid cells and myeloid cells. At the bottom of the family tree are red blood cells, white blood cells*, and platelets.



Growth factors

All normal blood cells live a short time: red blood cells 80-100 days, neutrophils 8-14 days, and platelets 4-5 days. They then die off and are replaced by new cells from the bone marrow. This means that your bone marrow remains very busy throughout your life.

Chemicals in your blood called growth factors control blood cell formation. Different growth factors help make the blood stem cells in the bone marrow become different types of blood cells.

Some growth factors can be made in the lab (synthesised) and given to people to help treat blood disorders.

Peripheral blood stem cell and bone marrow 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

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.

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 are some of the blood cancers and related disorders that are treated with stem cell transplantation:

- leukaemia
- lymphoma
- myeloma
- aplastic anaemia
- myelodysplastic neoplasms (MDS)
- myeloproliferative neoplasms (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. The stem cells from a donor are then transplanted 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. Consequently, it also destroys the stem cells which then need to be replaced to allow for the rebuilding of blood cells and your immune system.

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

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

'An allogeneic stem cell transplant, by its nature, is an immunotherapy that uses someone else's immune system to target and fight an underlying blood cancer'. Dr Cameron Curley

A stem cell transplant is where your stem cells are replaced with new stem cells after high dose chemotherapy and/or radiotherapy. The new stem cells will rebuild your body's blood and immune systems. The recovery of these systems is vital for your survival.

A stem cell transplant is not a surgical procedure. On the day of transplant the stem cells are given intravenously, like a blood transfusion. The stem cells travel to the bone marrow, 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)
- allogeneic* (al-o-gen-a-ic)

This booklet mainly describes allogeneic stem cell transplants.

Autologous

In autologous stem cell transplants, the patient donates their own stem cells. The patient's blood stem cells are collected and stored in advance. This is whilst they are in remission or have minimal disease. The collected stem cells are returned to them after receiving high dose chemotherapy.

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 is usually 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 compatible tissue type. This is called a volunteer unrelated donor (VUD) transplant. Previously, 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.

Allogeneic transplants may still offer the best chance of curing a number of blood and bone marrow cancers and other diseases. Transplants are complex procedures that carry significant risks. The complexities and risks may be increased with a mismatched donor.

In 2021, a total of 1928 stem cell transplants were carried out in Australia.

Of these:

- 1233 were autologous
- 695 were allogeneic - 334 of these were related stem cell donors, 351 were unrelated stem cell donors, and 10 unknown (reference ANZTCT Registry Annual Data Summary 2021)

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. An important factor in autologous transplant is the condition of your bone marrow and the ability to collect blood stem cells. The availability of a compatible donor is essential for considering an allogeneic transplant.

Your transplant team will discuss with you the best option for your particular situation.

CAR T-cell therapy

Chimeric antigen receptor (CAR) T-cell therapy, is an immunotherapy that uses your own immune cells (T-cells) to first identify and then attack cancer cells.

The T-cells are collected and sent to a laboratory where synthetically engineered receptors are attached to the T-cells. These modified T-cells are 'grown' in the laboratory and then given back to you to kill the cancer cells.

In 2021, a total of 128 CAR-T therapies were carried out in Australia (reference ANZTCT Registry Annual Data Summary 2021).

More information can be found here: www.leukaemia.org.au/wp-content/uploads/2022/06/CAR-T-Cell-Therapy_Leukaemia-Foundation-Factsheet_June-2022.pdf

Making treatment decisions

Many people feel overwhelmed at the prospect of having a stem cell transplant. Having to make decisions about proceeding with recommended treatments can be very stressful.

In some situations, there is no exact science for when a person should have a stem cell transplant. It depends on each individual situation and personal preference. In other situations there is a clear time when a stem cell transplant is recommended. Making the best decision for you requires extensive discussion with your treatment team and loved ones.

Before going to see your doctor make a list of the questions you

want to ask. Keeping this list or notebook handy enables you to write down questions which may arise at random times of the day.

Sometimes it is hard to remember everything the doctor has said. Bringing a family member or a friend to appointments may help you. Writing down the answers to questions, prompting to ask other questions, an extra set of ears, and being supportive, are ways they can help you. It is easy to forget important information, if you have forgotten ask again.

The best option for you

Your treating doctor (haematologist) will spend time discussing with you and your family what he or she feels is the best option for you. Ask as many questions as you need to at any stage of the transplant process.

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.

If the donor's HLA markers are not similar enough to the patient's, the immune system of the patient may attack the donor cells.

This is called rejection. The closer the match in HLA types, the better the chance of a successful transplant. Graft versus Host

Disease (GvHD) can occur when the donor's cells recognise the HLA mismatch and attack the organs of the patient.

The more compatible the donor- patient match, the less likely there will be rejection or severe GvHD.

More information can be found here: www.leukaemia.org.au/wp-content/uploads/2022/11/Factsheet_Graft-Versus-Host-Disease_Leukaemia-Foundation.pdf

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. 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.

Generally, the next closest tissue type is a full sibling. A brother or sister who has inherited their genetic makeup from the same parents as the patient. As we inherit half of our genetic makeup from our mother and half from our father, there is only a one in four chance that a sibling will be a 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 to donate their stem cells if they are 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 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 overseas. 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 by the transplant team based on your disease, health and location.

Sources of stem cells

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

- blood stream (called a peripheral blood stem cell harvest), or
- bone marrow (called a bone marrow harvest)

Peripheral blood stem cell harvest

Collecting stem cells from the bloodstream is the most common method used for a stem cell donation. It is considered a safe and relatively painless procedure for donating stem cells. 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 colony stimulating factors (such as G-CSF). These injections stimulate the production of stem cells and they overflow out of the bone marrow into the bloodstream. This is called stem cell mobilisation, this enables the stem cells to be collected through the blood.

Growth factors are given for several days as an injection under the skin (subcutaneous). The donor, a family member or friend can be taught to give the injections. The injections can be given at a local medical centre or hospital if preferred. 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 while using G-CSF including:

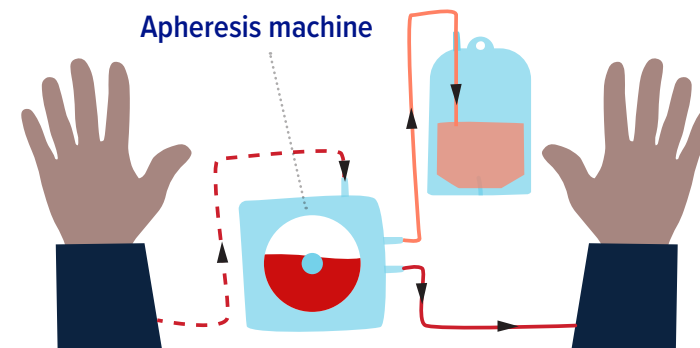
- mild to severe bone pain
- fevers and chills
- headaches

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, also called an Apheresis machine.

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. The rest of the donor's blood is returned to them via another cannula. This is a continuous process.



If the veins in the donor's arm are very small, a special central line may need to be placed into one of the large veins. The doctor will explain how this is done, and any risks.

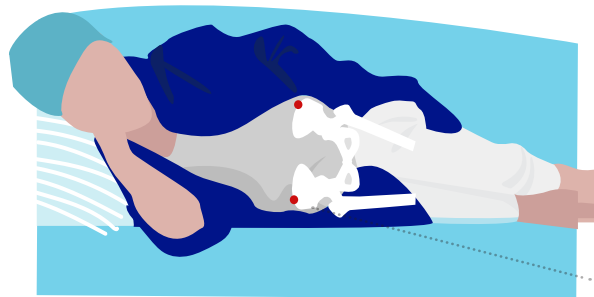
A peripheral blood stem cell collection usually takes three to four hours. Sometimes the donor cannot move their arms much, especially if the cannulas have been inserted in the inside of the elbow. The nurses will make the donor feel as comfortable as possible, they might like to bring along a book,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

A certain number of stem cells are needed for a blood stem cell transplant, they may not all be collected on the first day. Sometimes the donor may need to come back the following day/s until enough stem cells have been collected.

The donated stem cells are commonly given to the patient within 24-72 hours of collection. But the stem cells may also be frozen (cryopreserved) and stored until the day of the transplant. Blood stem cells can remain frozen for many months or years.

Bone marrow harvest

A bone marrow harvest is a surgical procedure carried out in an operating theatre under a general anaesthetic by a haematologist. During a bone marrow harvest stem cells are collected from the bone marrow at the back of the donor's hips (iliac crest). This procedure is not commonly used for adult donors today as it is more invasive to the donor.



Marrow is taken from the back of the hip bones, not the spine

Stages of a stem cell transplant

While people tend to concentrate on the day the stem cells are transplanted, it is important to realise a stem cell transplant is long and complex. In reality, a transplant involves a lot of preparation and aftercare.

The transplant is not always straight forward, you may experience expected and unexpected events. Everybody has a different experience, the unexpected events can be serious and frustrating.

The transplant team is a specially trained group of professionals:

- doctors
- nurses
- social workers
- dietitians
- psychologists
- pastoral care workers
- other allied health personnel

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 throughout your transplant and recovery.

Top tips from people with blood cancer

"Build and use your support network"



There are several stages of a stem cell transplant.

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 having a special family or social event (i.e. holidays, weddings) before your transplant begins.

However, for some people the timing of the transplant may be critical and these events may have to be put on hold.

You can expect to stay in the hospital for three to six weeks. Then you will need to stay near the hospital for at least 100 days after the transplant. This is in case of complications and for follow-up appointments.

This is important for people from regional or remote areas. It 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 in hospital and/on discharge in the outpatients department will vary. This depends on the type of transplant you receive, other treatment you require and 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 with chronic graft-versus-host disease, sometimes long term complications can be 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 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 smart phone, phone credit, electronic tablet, streaming services, radio, books or e-book reader, portable speaker, photographs and videos of your family, and maps of the city if you or your family come from regional or remote areas
- 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
- delegate a 'point of contact' who can provide updates to family and friends. Set up an account on a social network service to keep people informed. Have your principal 'point of contact' assist you in posting updates
- utilise social media to keep in touch with family & friends
- consider learning relaxation techniques, like meditation, yoga and/or breathing exercises. These may be helpful throughout your transplant
- download mindfulness or relaxation apps prior to admission in hospital. They will help pass the time

Accommodation and travel

If your family or carer live far away the hospital social worker can help organise their accommodation whilst you are in hospital.

They may also be able to help with information about travel costs. You may also require accommodation for some time after your transplant. You will need to stay close to the hospital at least until day 100 post transplant so your recovery can be monitored closely. You will need regular blood tests and assessment during this time.

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 or visit:

www.leukaemia.org.au/how-we-can-help/accommodation-services/
www.leukaemia.org.au/how-we-can-help/transport-services/

Fertility decisions

Some types of treatment may affect your fertility, which is your ability to conceive a baby. It is important to talk to your treatment team about future fertility before you start treatment. If you are planning on having a child, there are steps you can take.

Make sure you understand:

- the fertility preservation processes
- success rates
- the risks
- side effects of fertility treatments, and
- any costs

For men

Chemo can stop or lower your sperm production. It can reduce your sperm's ability to move. This can be temporary or permanent. It also affects the hormone testosterone.

The best way to preserve your fertility before treatment is by freezing a semen sample, which contains sperm. This is called sperm cryopreservation.

For women

Chemo can reduce your number of available eggs (ova) and can affect your hormones.

There are several mainstream fertility cryopreservation (freezing) options for women. Egg and embryo freezing are common, less so ovarian tissue freezing. For some young women and their families, it may not be possible to pursue fertility options prior to cancer treatment. Having the opportunity for discussion about your future fertility is important.

Fertility Society of Australia: fertilitysociety.com.au

Future Fertility: futurefertility.com.au

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
- central venous access device (CVAD)

Pre-transplant tests

In the weeks leading up to your transplant you will have a number of tests. This is to make sure your vital organs (heart, lungs, liver and kidneys) are physically fit for the transplant. 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. Some may take longer than others. You might like to bring a book or a friend for company.

The nurse or transplant coordinator will advise you of any special preparations needed for each test. For example not eating beforehand, how long it will take, and if 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 biopsy
- 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.

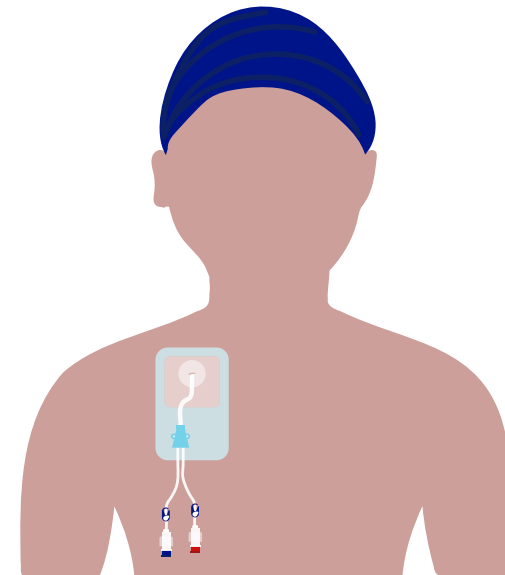
Blood tests

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 central venous access device (CVAD) will be inserted before the transplant. Blood can be taken directly from this special line without causing you discomfort.



Central Venous Access Device (CVAD)

During your transplant you will need to have a number of intravenous (into the vein) therapies. These include fluids, chemotherapy, antibiotics, other drugs, blood and platelet

transfusions, and the stem cell transplant. You will need to have a daily blood test 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 the stem cells cannot be given easily into the smaller veins in your hands and arms. It is for these reasons that a central venous access device (CVAD) is inserted prior to your transplant.

The devices most commonly used for transplant patients have two or three lumens (or tubes). The lumens are thin plastic tubes that are visible on top of your skin, then they group together so only one tube is inserted into the vein. A Hickman catheter is a type of CVAD used for transplant, it usually has two or three lumens. The nurses will take blood and give various infusions through these lumens, without causing pain to you.

During your transplant you will have more than one infusion going through your CVAD at the same time (for example fluids and antibiotics). This is perfectly safe and normal.

Sometimes CVADs need to be taken out, if for example they have become infected and the infection is not responding to antibiotics. Whether or not the CVAD 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 treatment 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. Some people have their conditioning therapy in an outpatient clinic, particularly if undergoing a transplant with reduced intensity conditioning.

There are many different types of conditioning therapies. 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. This reduces the risk of infection in the early post-transplant period.

The reduced dose of therapy also lessens the toxicity to your organs. The reduced intensity conditioning therapy still suppresses your immune system enough for the donor stem cells to grow or engraft.

Generally less intensive conditioning therapies cause less severe side-effects. This type of transplant is potentially a curative option for older and/or less fit patients.

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

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

Transplant protocols

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

Conditioning therapy is given in the week before your transplant:

- Pre-transplant - The days leading up to the transplant, Day -6 (minus six), Day -5, etc. counting down to Day 0 (zero)
- Day 0 - The day you receive the stem cells
- Post-transplant - you count forward: Day +1, +2, etc

In addition to conditioning treatment, sometimes a much lower dose chemotherapy is given for several days following the day of the transplant. This is to help reduce the occurrence 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 CVAD, or in tablet or liquid form. Generally, chemotherapy is not radioactive and is not a danger to others unless they are in contact with bodily fluids.

On the days you receive certain types of chemotherapy you may require up to six litres of intravenous fluid. 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 use a bottle or a pan, so that your urine can be measured and tested.

In addition the nurses will check your weight on a daily basis. Sometimes you may be given fluid medications (diuretics) to help your body get rid of excess fluid, by increasing the amount of urine you produce.

It is important to ask your transplant team about any precautions you or your family should take 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 addition to chemotherapy. This is because it can treat areas of your body like your brain and spinal cord, of which chemotherapy may not effectively reach. It is also very effective at suppressing your immune system, allowing the donor's stem cells to grow.

Before you start TBI, the radiation oncologist will calculate the correct dose of radiation therapy for your body. This will require a visit to the hospital pre-transplant to have a radiation planning procedure called a simulation. During simulation you will have imaging scans and skin markings.

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. You will have TBI in the radiotherapy department of the hospital. Usually you will have TBI twice a day, for two to three days, though this may vary depending on your situation.

It is common to feel nauseated while you are having TBI and for some time afterwards. The nurse may give you anti-emetic (anti-sickness) medication before you go for TBI treatment. Sometimes a mild sedative is 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 cell counts

Your white cell and platelet counts will drop 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 daily and you may need blood or platelet transfusions. Ask for a copy of your blood results so you can monitor your progress.

Some medications to help prevent bacterial, viral and fungal infections will be given to you whilst your white cell count is low. 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. Generally, nausea and vomiting are well controlled with anti-emetics (anti-sickness) medications. You will receive anti-emetics on a regular basis, before and for a few days after your conditioning therapy has finished.

Tell your treatment team 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. 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.

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

Don't be too concerned if you are unable to eat or drink much at this time. The doctors and nurses will closely monitor your condition every day and a dietitian will be involved in your care. If your nausea and vomiting is not well controlled, you may need extra fluid through your central venous access device (CVAD) to prevent dehydration.

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. You may be offered ice to suck (cryotherapy) before, during and after some types of chemotherapy. This can help to reduce mucositis afterwards. It usually starts about three to four days after your conditioning therapy has finished. Mucositis resolves after the transplant, when your new stem cells engraft and your white cell count starts to rise.

Your treatment team will examine your mouth and throat each day. 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 severe, medications like morphine or fentanyl, are given through your central venous access device (CVAD) or via a patch applied to your skin.

It is important to keep your mouth clean to help prevent infection. Different treatment centres recommend different mouth care products. Your nurse will teach you how to care for your mouth, including the use of a soft toothbrush and mouthwash.

You should avoid commercial mouthwashes, like the ones from the supermarket. These are often too strong, or they may contain alcohol which will hurt and sting if you use them. Mouthwashes with salt or bicarbonate of soda base are good alternatives.

Changes in taste and smell

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 a nutritious and tasty diet whilst you are in hospital.

Weight loss/weight gain

Before your transplant you may be encouraged to increase your weight. This is generally for people who are underweight or malnourished. The dietitian will provide information and support.

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 because you are not eating what you normally eat at home.

The dietitian will assess your weight loss. You may need nutritional support to prevent malnutrition and weight loss. The dietitian may encourage you to have high energy and protein drinks. Because they are so nutritious you don't need to drink a lot of these. If you are unable to eat and drink you may need a nasogastric tube or an intravenous food substitute (see Eating in hospital and Nutrition)..

Your body may retain fluid during the conditioning therapy, especially if you are given extra intravenous fluid. This will cause weight gain. This is easily treated with diuretics. Which are medications to help your body get rid of excess fluid, by increasing the amount of urine you produce.

Eating in hospital

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

Try to eat small meals frequently. You may ask your family to bring your favourite food to hospital, but check with your treatment team first. Remind them not to be disappointed if you change your mind when you see the food. Your treatment team may have some foods they prefer you to avoid due to a risk for infection. They will discuss this with you.

Tell your treatment team if you are unable to drink or eat.

You may need to have some intravenous fluids to make sure you don't become dehydrated. An intravenous food substitute called Total Parental Nutrition (TPN) may be needed for people who cannot drink or eat adequate amounts. Nasogastric feeds are another form of food substitute. Feeds are delivered by a tube that runs from the nose directly into the stomach. This may be appropriate in some situations and is 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 your treatment team if you experience any of these symptoms. If you develop diarrhoea, the nurse will ask you for a sample which will be tested in the laboratory to check for infection. If there is no infection you will be given some medication to help stop the diarrhoea and relieve any discomfort.

Your bottom/anus can become quite sore if you have diarrhoea. Using baby wipes to clean your bottom is gentler, as they are soft and less abrasive than toilet paper.

It is important to tell your treatment team if you are constipated or have discomfort when using your bowels. You may need a gentle laxative.

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 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, avoiding heat or chemicals, and using a soft brush can help reduce discomfort. Some people cut their hair short so they lose it in stages, and partly lessen the shock.

You should avoid direct sunlight on your exposed head. Consider wearing a cap, wig, scarf or turban to protect your head. This can make you more comfortable and helps stop your hair from going everywhere.

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

Skin reactions

Total body irradiation (TBI) 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 treatment team if this occurs.

Eye changes

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

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

Tiredness, tension and stress

You will likely feel more tired than usual during the 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 feel mentally exhausted as a result of the 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 to see the social worker, psychologist, physiotherapist or pastoral care worker. These people can help you and give you practical tips to help you cope better.

Some people find relaxation and meditation techniques helpful in coping with tension and stress. The nurse or social worker may be able to provide you with information on relaxation and meditation.

Some transplant centres have a selection of DVDs, audible books and music which can help to pass the time.

Mild exercise, such as walks around the ward, may be beneficial if you feel up to it. Ask for advice on physical activity from the hospital physiotherapist and your haematologist.

“I was in hospital for four and a half weeks. They had a stationary exercise bike in my room so I could exercise on that, a trainer came in every second day and put me through my exercises when I was feeling okay, and I would walk around the confines of the transplant area”

Prevention of infection

Lots of precautions are taken to try to reduce your risk of developing an infection while you are neutropenic.

Preventative medications

Antibiotics, antivirals and antifungals are commonly given before and after transplants to reduce the risk of infection. 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 Valaciclovir 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 gel is available in dispensers throughout the hospital unit. Anyone entering your room should wash their hands first.

Your treatment team will wash their hands with this soap/gel 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 advise you on some light exercise if you feel up to it. Keeping yourself mobile and doing some gentle exercises can:

- make you feel better
- help improve your muscle tone
- help you sleep better
- 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.

Visitors

You can still have visitors while you are neutropenic. Just make sure they wash their hands 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 (one or two 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 treatment team if you have any questions regarding visitors.

Some days you may not feel up to having visitors. Encourage your family and friends to check with the transplant ward before visiting. This will save disappointment if you are not up for visitors on that day.

You may like your visitors to bring photos of happy times to hopefully give you a boost. Messages from your family and friends on your walls can encourage you and remind you of their love and support. You are not going through this alone.

Plants and flowers

Plants and flowers are potential sources of harmful microorganisms that may cause infection. Live plants or flowers should not be kept in your room. Balloons (foil), hampers that do not contain fresh produce and paper bouquets are good alternatives.

Food

Your treatment team may provide advice and printed information on neutropenic and low bacterial diets. This may require restrictions on certain foods or how they are cooked:

- Meat and fish properly cooked.
- Thick-skinned fruit can be eaten once the peel is removed.
- Thin-skinned fruits need to be washed thoroughly.
- Avoid salads, certain yogurts, shellfish, uncooked eggs and soft cheese.
- Food should be freshly cooked, or only reheated once

In spite of all these precautions infections are common. They are usually caused by organisms that normally live on and inside your body, rather than an outside source.

Nutrition

The transplant team will encourage you to eat normally. This may not be possible due to poor appetite or a painful mouth. Many people will need help with nutrition so they do not lose too much weight.

Some transplant centres give liquid supplements through a soft plastic tube. This is called a nasogastric tube and is inserted through the nose into the stomach. This ensures adequate nutrition even when people are unable to swallow due to a sore mouth.

Nutritional supplementation can also be given intravenously through a CVAD. This is called total parenteral nutrition (TPN). Supplementation through a nasogastric tube or intravenously is stopped once you are able to eat and drink normally.

4. The transplant (Day 0)

Your transplant or stem cell infusion is given on day 0 (zero) of the transplant protocol.

Some protocols have two day zeros. This happens when the volume of stem cells is large, and they are divided into two infusions over two consecutive days.

The transplant itself is a relatively straightforward procedure. The stem cells are infused through your CVAD, 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.

Most centres give medications immediately prior to the stem cell infusion to reduce the likelihood of reactions.

Occasionally people have a reaction to the preservative used in the freezing process. Generally, any reactions that occur are quickly managed and the infusion is completed as planned.

If the stem cells have been frozen, you may notice an unusual smell. This smell may resemble garlic, asparagus or sweet corn, and last 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 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 cells being infused to commemorate their 'new beginning'.

5. Pre-engraftment (Day +1 onwards)

The early days

After the stem cells are infused, they 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, it usually takes 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 closely in the early days following your transplant. Your treatment team will examine you daily, and you will have your temperature, pulse and blood pressure taken regularly day and night.

Each day, blood samples will be taken from your CVAD to check your blood counts and to monitor your kidney and liver function.

During this time your immune system will be very compromised. You may be feeling very tired and frustrated from being woken up regularly for monitoring. You may experience feelings of being vulnerable, having a loss of control over your life, and a mixture of other strong emotions.

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 improve, your fevers should settle, and you should be generally feeling better, although still weak.

Remember to talk to your treatment team 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 well informed of what is happening.

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 short life, less than 24 hours.

Transfusions are considered safe and usually don't cause any complications. You will be carefully monitored throughout the transfusion. If you feel hot, cold, shivery, or unwell during the transfusion alert the nurse. This may be a reaction to the blood product. Steps can be taken to reduce these effects.

Blood donors and donated blood are screened in Australia to ensure viruses are not passed on through transfusion. The blood and platelets used for transplant patients is irradiated (treated with radiation). This prevents potential complications like transfusion-associated graft-versus-host disease. Precise checks at the blood bank and the bedside ensure that the blood you receive is compatible with your blood type.

If your donor's blood group is different to yours, your blood group will change to that of your donor in the weeks after the transplant. You will then be given blood products which are compatible with your donor's, and now your blood group.

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 covered here are:

- infections
- cytomegalovirus (CMV)
- graft-versus-host disease (GvHD)

Sometimes many complications occur at the same time after a stem cell transplant. 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 therapy usually destroys the blood stem cells in your bone marrow, which produce infection-fighting white blood cells.

The absence of white cells, and in particular 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 weeks after your transplant, the risk of developing an infection remains for many months whilst your body recovers.

If you develop a temperature while you are neutropenic you are regarded as having 'febrile (meaning fever) neutropenia'.

Fevers

It is important that you tell your treatment team immediately if you are feeling hot, cold or shivery. Your temperature will be checked regularly while you are in hospital, and you will need to check it regularly once you leave hospital. A fever (a rise in your body temperature) is often the first sign that you have an infection. You should also tell them if you are feeling unwell or if you have developed a cough, pain or soreness anywhere.

Sometimes, patients with a fever and low neutrophil count may not feel unwell, even though their temperature may be quite high. 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 swab from the skin around your CVAD or your nose and throat may be taken to find the source of infection. You may also be asked to give a urine, stool/poo and sputum sample, and a chest x-ray may be done.

An infection in a transplant patient is taken very seriously because it can be life-threatening if not treated quickly. 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 given paracetamol to help reduce your temperature. Sometimes it is not possible to find the cause of your infection. If the source of the infection is found, the doctors may need to change the antibiotic to treat that type of infection.

If your temperature has not returned to normal within a few days the doctors may change or add an antibiotic. In case you have developed a fungal infection they may add an anti-fungal medication.

You may be feeling quite miserable and unwell while you are neutropenic and febrile. Remember an infection is an unfortunate but expected side-effect of the transplant.

All measures will be taken to limit the infection and make you comfortable 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 considered to be carriers of the virus. If you are a carrier it is possible that the virus could reactivate during or after the transplant. This is whilst your immune system is not fully recovered. A blood test will be taken before your transplant to check whether you are a carrier. If you are a carrier this is known as 'CMV-positive'. If you have never been exposed to the virus, not a carrier, you are 'CMV-negative'.

If you or your stem cell donor is CMV-positive, you may be given anti-viral medication before and after your transplant. These medications are to help prevent CMV infection. Sometimes regular blood tests are taken 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 CMV. 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 medications.

Graft-versus-host disease (GvHD)

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

The donor cells form the person's new immune system. There are small differences between the new immune system and the cells in the body after an allogeneic transplant. GvHD occurs when the donated cells (the graft) see your body cells (the host) as unfamiliar cells that need to be destroyed. This is different to a solid organ transplant when the host can reject/attack the donated organ.

Your transplant team will prescribe anti-rejection drugs called immunosuppressants. These suppress the 'new' (donor) immune system. You will take these drugs before, during and for some time after the transplant. It is important that you continue to take the immunosuppressant medications as instructed by the treatment team to reduce the likelihood of developing GvHD.

GvHD is a common reason for being readmitted to hospital in the first year following an allogeneic transplant. Your body can be affected in a number of ways, and any changes to your normal should be reported to your treatment team as soon as possible.

More information can be found here: www.leukaemia.org.au/wp-content/uploads/2022/11/Factsheet_Graft-Versus-Host-Disease_Leukaemia-Foundation.pdf

What are the commonly affected organs?

Skin:

- Skin is likely to become dry, red and itchy.
- A rash, often on the palms of hands and soles of feet. Can involve trunk and other extremities
- Thickening and tightening of skin

Eyes:

- Eyes may become itchy, dry and uncomfortable
- Teary eyes
- Blurred vision

Gut (gastrointestinal tract), includes the oesophagus (food pipe), stomach and bowel:

- Loss of appetite
- Unexplained weight loss
- Vomiting
- Diarrhoea
- Abdominal cramping
- Blood in stool

Mouth:

- Dry mouth
- Difficulty eating
- Ulcers

Lungs:

- Abdominal swelling
- Yellow discoloration of the skin/eyes (jaundice)
- Dark (tea coloured) urine
- Abnormalities in result of blood tests that measure liver function

Graft-versus-tumour (GVT) effect

Graft-versus-tumour (GVT) effect is when cancer cells are attacked by the donor immune system. This beneficial effect can occur following allogeneic transplant. GVT effect can occur even if there are no signs of GVHD.

The donor's lymphocytes (a type of white blood cell) may be given to the patient after the transplant. This is called a donor lymphocyte infusion (DLI), it is hoped it will cause GVT and reduce the risk of relapse.

7. Leaving hospital

The transplant team will monitor you closely with weekly blood tests for up to 3 months post transplant. This is commonly mentioned as day 100. Day 100 is a time point where you undergo a repeat of some of the pre-transplant testing. This is to determine response to the transplant and impact of your treatment.

After you leave hospital, you will need to take some medications. You may also require intravenous fluids and transfusions. It is very important that you notify your doctor or the hospital if you stop taking any of your medications.

Don't feel that you are bothering 'busy' people at the hospital. It is important that you recover well from your transplant. Notify the transplant team of any problems as soon as possible. The sooner they are treated the sooner you will recover.

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.
- 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.

If you are travelling interstate, ask your doctor for the contact details of key hospitals if you need help.

If you have any concerns or questions contact your transplant team.

Readmission to hospital

It is not unusual for people to be readmitted to hospital more than once after discharge. 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.

Your treatment centre will have a protocol 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 a fever: you need to advise the staff at the desk of your situation as an urgent priority.

Graft rejection/failure of engraftment

Graft rejection is rare, it 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 increases when there is a tissue type mismatch between the donor and patient.

Relapse

Unfortunately the transplant is not always successful. 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. In some cases a drug to stimulate your immune system or a donor lymphocyte infusion (DLI) may be given.

You may also be asked to stop taking your immunosuppressive drugs, or to reduce the dose over a period of 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 be at risk of infection for some time after your transplant.

Infections can develop anywhere but common sites of infection include:

- mouth
- central venous access device
- lungs

Causes of infections include:

- bacteria
- viruses
- fungi

Shingles, develops from the chicken pox virus, can be common. It can be painful and sometimes requires admission to hospital for treatment.

Cytomegalovirus (CMV) can cause serious infection while your immune system is low. 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 (GvHD)

Chronic graft-versus-host disease (GvHD) affects 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 medications that suppress the new immune system. These medications can increase the risk of infection.

The effects of chronic GvHD can be debilitating. A management plan will be made to minimise the impact on your daily life.

More information can be found here: www.leukaemia.org.au/wp-content/uploads/2022/11/Factsheet_Graft-Versus-Host-Disease_Leukaemia-Foundation.pdf

Early menopause

Some cancer treatments can affect the normal functioning of the ovaries. This can lead to infertility and an earlier than expected onset of menopause, even at a young age. The onset of menopause in this situation can be sudden and 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
- aches and pains
- decreased sexual drive
- anxiety and depressive symptoms

It is important you discuss any changes to your periods with your treatment team. They may refer you to a gynaecologist or clinic for symptom management.

Osteoporosis and Osteonecrosis

Osteoporosis occurs when new bone tissue is not replaced as fast as the loss of old bone. Osteoporosis can affect both men and women. The bone weakens and becomes fragile, causing loss of bone thickness, increasing the risk of fracture. It can occur post allogeneic transplant as it is a side effect of steroids.

Oestrogen is a hormone produced by both males and females but

plays a bigger role in the female body. Oestrogen promotes the activity of the cells that make bone. When oestrogen levels drop during menopause, including early onset menopause, osteoporosis may develop.

There are effective treatments to help prevent and treat osteoporosis. Physical activity, including weight-bearing exercise (walking) helps to prevent osteoporosis. Talk to your doctor about monitoring and management of osteoporosis.

Osteonecrosis occurs when blood is prevented from flowing to your bone tissue. The section of bone is unable to be replaced, it eventually dies and collapses. This can be caused through trauma to the bone or from an illness or medical condition. It generally requires surgical management. Long term use of steroids is often a necessary treatment for allogeneic transplant. But it can lead to an increased risk of osteonecrosis in the years after transplant.

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 (TBI) 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. This may take up to six months. You can take simple precautions to reduce your risk of infection including:

- regular hand washing
- daily showering

- regular mouth care
- avoid people with suspected colds, flu and other viruses
- avoid close contacts and people with chicken pox, measles or other viruses.
- avoid people who have had a live vaccine such as polio
- avoiding garden soil and potting mix
- washing your hands after handling animals. It is okay to pat the dog or cat but don't let them lick you

If you have any questions about reducing the risk of infection speak to your doctor. You may have questions about travelling overseas or attending an event or gathering. Your doctor will be able to advise you on measures to take for these and similar scenario.

Central Venous Access Device (CVAD) care

You will need regular blood tests and possible transfusions when you leave hospital. Your central venous access device (CVAD) will remain in for these procedures. The nurse will teach you how to care for your CVAD. Removal of your CVAD will be organised when you no longer need frequent blood tests and transfusion.

Mouth care

Keeping your mouth clean is still important after you leave the hospital. Mouth care, particularly after eating, will help to prevent infections in your mouth. You may be given mouth care products and instructions on discharge from the hospital. Report soreness in your mouth, bleeding gums, ulcers or cold sores to your transplant team.

Reduced energy levels and exercise

Tiredness and 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 usually lead an active and busy life. Try to get plenty of rest but also try to do a little light exercise each day.

Top tips from people with blood cancer

"Doing something is better than nothing"

Fresh air and gentle exercise are important for your general wellbeing. This may also help increase your energy levels. Some hospitals have exercise departments. Talk to a physiotherapist or exercise physiologist about an exercise program for you. The hospital or Leukaemia Foundation could help you with arranging this appointment.

Top tips from people with blood cancer

"Stay active and move daily - walk the dog/dance/stretch/Qi Gong"

Discuss when to increase your exercise with your physiotherapist and doctor. Check with your doctor before going to a gym or sporting club as these areas can often be sources of infection.

Fatigue can be a symptom of anaemia. Your blood count will be monitored in the weeks and months following the transplant. You will be given a blood transfusion if required.

Appetite

More information can be found here: www.leukaemia.org.au/wp-content/uploads/2022/08/Eating-Well_Leukaemia-Foundation_FINAL.pdf

Most people's appetite improves once they leave hospital. But it takes time before they are able to eat like they used to.

Many people find that food doesn't taste or smell as it did before the transplant. It takes some time for sense of taste and smell to return to normal. Cleaning your mouth before eating and adding a little more sugar or salt can help improve the taste of food.

Try eating small amounts frequently. It is important to drink fluids, about six to eight glasses a day, to stay hydrated. Nutritious drinks like milkshakes, smoothies and soups are good substitutes for solid foods.



Top tips from people with blood cancer

"Eat well" and "Use a meal service to stay nourished without having to cook each day"



A healthy nutritious diet is important to help your body recover from a stem cell transplant. Talk to your dietician, doctor or nurse if you have any questions about your diet. Discuss if you are considering making any changes to your diet. Devise a plan with your dietitian for a balanced and nutritious diet.

Skin care

If your skin is dry and sensitive after the transplant you may need to use a moisturising cream or oil. Ask your treatment team 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. Your skin is particularly sensitive and can burn easily. Especially if you have had total body irradiation (TBI).

You need to protect your skin from the sun by:

- wearing a hat
- wearing a long sleeved top and pants
- applying sunscreen to any exposed areas

Even for short periods of time, like hanging the washing on the line, or travelling in the car.

The immune-suppressing medications may also increase the risk for skin cancers. Regular skin checks are a vital part of your ongoing follow up.

Sexuality and sexual activity

It is likely the experience of the transplant will have some impact on how you feel about yourself. 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. It may take some time for things to return to 'normal'. It is 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 for some time after the transplant. Some of the treatments given can harm the developing baby. You will need to use a suitable form of contraception. Condoms (with a spermicidal gel) provide good contraceptive protection. This also protects against infection or irritation.

Partners are sometimes afraid that sex might harm the patient. This is unlikely, as long as the partner is free from infections and the sex is gentle. This is especially important if your platelet count is low. If you experience vaginal dryness and irritation the use of lubricants is helpful.

If you have questions or concerns about sexual activity and contraception talk to your treatment team. You may 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. The program focuses on how to manage the appearance-related side-effects of cancer treatments. You might like to visit their website at lgfb.org.au or call them on 1800 650 960.

You will not always look like a patient in a hospital. Your physical appearance will improve. In the meantime do things that make you feel good about yourself. This might include enjoying time with friends, regular exercise and relaxing.

Getting back to work

The decision about when to return to work is a very personal one. It will depend on many factors:

- how well you are feeling
- the type of work you do
- personal circumstances
- financial circumstances

More information can be found here: <https://www.leukaemia.org.au/blood-cancer/journey/living-well-with-blood-cancer/practical-matters/returning-to-work-or-study/>

Many people take six months or more off work. On return to work they may go back part-time, increasing their hours when they feel up to it. Discuss timeframes for returning to work with your doctor.

Top tips from people with blood cancer

"Make a plan with your workplace or LF Return to Work program"



Vaccinations

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. 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 are vaccines that your haematologist may consider unsafe to give, especially live vaccines. In the meantime it is important that you avoid people who are sick or a close contact to someone with

a 'catching' illness. You also need to avoid people who have had a live vaccine such as polio.

If you are planning to travel overseas, vaccinations may be required to prevent serious infections. Some of these vaccinations may not be safe for you to have, let your doctor know in advance about your plans, so a vaccination schedule can be organised. Advice from an infectious diseases or travel health specialist may be required.

Social and emotional issues

For some people things are never quite the same after transplant. Many people find they have a 'new normal'.

The journey you and your family have taken may have involved 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 serious complications and the risk of the disease relapsing.

There are many new challenges to face during a transplant:

- coping with the side-effects
- feeling uncomfortable
- feeling isolated
- disrupted family routines
- family fulfilling roles (cooking, cleaning and taking care of children)
- relocating family near the hospital

All 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.

Top tips from people with blood cancer

"Keep connections with people and keep yourself psychologically safe"

If you have a psychological or psychiatric condition inform your doctor and request support from a mental health professional.

Most people benefit from the support and love of their family and friends, and the care provided by the members of the transplant team.

Top tips from people with blood cancer

"Build and use your support network"

Many centres have psychologists, social workers and pastoral care workers. They can assist you with psychological, emotional or financial difficulties. They can identify strategies to help you and your family to cope throughout the transplant.

The Leukaemia Foundation's Blood cancer support coordinators are available to help (1800 620 420 or support@leukaemia.org.au).

Some people benefit from talking to others who have been through a similar experience. Support groups can be invaluable. The Leukaemia Foundation can help put you in touch with a support group.

Focus on the things you can do to help yourself recover both physically and emotionally. Enjoy simple pleasures every day. Look to better times, make plans and have hope. Many people have positive feelings about their transplant experience. Some people learn what is important to them in life and let go of emotional 'baggage'.

Top tips from people with blood cancer

"If you look at limitations, that's a limitation of its own"

After a transplant some people report:

- Personal growth
- increased empathy for others
- closer relationships to loved ones
- a better understanding of their own strength as a person

Every person's experience is different. Don't judge yourself, be aware of how you are doing, and work with others to help you find tools to manage emotions.

Recovery takes time. Sometimes your recovery seems slow. It may feel like you are taking one step forward and then two steps back. Look forward to things getting a little better each day and each week. Look back to see how far you have come and consider the improvements you have made.

Top tips from people with blood cancer

"Celebrate the small things"

No one can go through the transplant for you, but there are people who care for you. They will be by your side to help you through the journey.

Top tips from people with blood cancer

"Everyone has tough things to deal with - this is one of yours"

More information & help

Glossary

You can find any **bold** terms in the definitions also defined in this glossary.

anaemia	A lower-than-normal number of red blood cells in the blood. It causes tiredness, paleness, and sometimes shortness of breath.
baseline	A first measurement of a condition taken early on, used to compare over time to look for changes.
biotherapy	A type of treatment that uses substances made from living organisms to treat disease. These substances may occur naturally in the body or may be made in the laboratory.
blast cells	Immature blood cells normally in the bone marrow in small numbers.
bone marrow	Soft, sponge-like tissue in the centre of most bones. It contains stem cells that make all blood cells.
bone marrow biopsy	Also called a bone marrow aspirate and trephine or BMAT. The removal of a small sample of bone marrow . This is sent to the lab for a pathologist to look at under a microscope.
bone marrow aspirate	A sample of bone marrow fluid.
bone marrow transplant	Also called a stem cell transplant . A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).
bone marrow trephine	A sample of bone marrow tissue.
cancer	Diseases where some of the body's cells become faulty, begin to multiply out of control, can invade and damage the area around them, and can also spread to other parts of the body to cause further damage.

central venous access device (CVAD)	A catheter inserted into a central vein (usually in the chest) to provide long term access to administer medications and blood products as well as taking blood for regular blood tests.
chemotherapy	The use of drugs to treat cancer.
chimeric antigen receptor (CAR) T-cell therapy	A form of immunotherapy that uses a patient's own specifically altered T cells.
chromosome	Part of a cell that contains genetic information.
coagulation	Process of changing from a liquid blood to a solid. Also called <i>clotting</i> . Platelets help with coagulation.
cytogenetic tests	The study of the structure of chromosomes . These tests are carried out on samples of blood and bone marrow . The results help with diagnosis and getting the most appropriate treatment.
cytopenia	Where there is a lower-than-normal number of a type of blood cell in the blood.
dysplasia	Also called dysplastic cells. A change in size, shape, and arrangement of normal cells seen under a microscope.
erythrocytes	Also called red blood cells. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.
full blood count	Also called FBC or complete blood count. A routine blood test that measures the number and type of cells, and the haemoglobin and haematocrit in the blood.
graft versus host disease (GvHD)	Happens when the donor's cells recognise the patient's body as foreign and causes an immune reaction.
growth factors	Proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.
haematocrit	The amount of blood that is made up of red blood cells .
haematologist	A doctor who specialises in diagnosing and treating blood disorders.
haemoglobin	A protein inside red blood cells that carries oxygen around the body.

haemopoiesis	The formation of new blood cells.
hypogammaglobulinaemia	A problem with the immune system in which not enough gamma globulins are produced in the blood. This results in a lower antibody count, which impairs the immune system, increasing risk of infection.
immune system	The body's defence system against infection and disease.
immunosuppression	The use of medication designed to suppress the immune system .
immunotherapy	Immunotherapy, sometimes called biological therapy, is a type of cancer treatment that works by boosting a person's own immune system to fight the cancer. Immunotherapy is currently approved in Australia for some types of cancers and is also being trialled for other cancers.
leukaemia	Cancer that begins in blood-forming tissue, such as the bone marrow . It causes large numbers of abnormal blood cells to be made and to enter the bloodstream.
leukocytes	Also called white blood cells. These blood cells are made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system . Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).
megakaryocytes	Very large bone marrow cells that break apart to form platelets .
mucositis	An inflammation of the lining of the mouth, throat or gut.
mutation	A harmful change in 'normal' DNA (the building blocks of all cells).
neutropenia	A lower-than-normal number of neutrophils in the blood. It increases the risk of infection.
neutrophils	The most common type of white blood cell . They help fight infection.
pancytopenia	Where there are lower-than-normal numbers of a type of all blood cells and platelets in the blood.

pathology	The study of diseases to understand their nature and their cause. A specialist in this field is called a pathologist . In cancer, histopathology/histology involves examining tissue under a microscope. Haematopathology involves blood and lymph.
petechiae	Tiny, unraised, round red spots under the skin caused by bleeding.
platelets	Also called thrombocytes. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.
prognosis	An estimate of the likely course and outcome of a disease.
purpura	Bleeding and bruising under the skin.
radiotherapy (radiation therapy)	Uses high-energy radiation from X-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells or injure them so they can't grow or multiply.
red blood cell	Also called an erythrocyte or RBC. A type of blood cell made in the bone marrow and found in the blood. Haemoglobin makes these cells red in colour.
relapse	Return of the original disease after it has improved for a time.
remission	Where the signs and symptoms of cancer decrease or disappear. Remission can be <i>partial</i> (a reduction in some or many symptoms) or <i>complete</i> (all symptoms have disappeared). Remission is not the same as a cure. Even in complete remission cancer cells may still be in the body.
rigor	Also called a chill. Feeling cold with shivering or shaking and looking pale, but with a high temperature. A symptom of infection.
stem cells	Young (immature) blood cells that can develop into more than one type of cell. Bone marrow stem cells grow and produce red blood cells, white blood cells and platelets .

stem cell transplant	Also called a SCT or bone marrow transplant. A procedure where a patient is given healthy stem cells to replace their own damaged stem cells. The healthy stem cells may come from the bone marrow of the patient or a donor. There are three types: autologous (using a patient's own stem cells that were collected from the marrow and saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stem cells donated by an identical twin).
T-cell	A type of white blood cell called a lymphocyte. They are part of the immune system and help the body fight infection.
thrombocytes	Also called platelets. Tiny pieces of cells (megakaryocytes) found in the blood and spleen. They help form blood clots (coagulation) to slow or stop bleeding and to help wounds heal.
thrombocytopenia	A lower-than-normal number of platelets in the blood. It causes bruising and bleeding.
tissue typing	matching the tissue type of the donor and patient.
white blood cells	Also called leukocytes or WBCs. Blood cells made in the bone marrow and found in the blood and lymph tissue. They help the body fight infection and are part of the immune system . Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

Useful websites

Leukaemia Foundation:	leukaemia.org.au
Australian Bone Marrow Donor Registry:	abmdr.org.au
Australian Cancer Trials:	australiancancertrials.gov.au
Cancer Australia:	canceraustralia.gov.au
eVIQ Cancer Treatments Online:	eviq.org.au
Australian New Zealand Clinical Trials Registry:	anzctr.org.au
Australian Red Cross Blood Service:	mytransfusion.com.au
The Pharmaceutical Benefits Scheme:	pbs.gov.au
ClinTrial Refer:	clintrial.org.au

Question builder

- Who will be my main contacts? How do I best contact you/ them?
- What can I do to avoid infections?
- Can I have the flu shot, COVID shot and other vaccinations?
- Is it safe to take my supplements or vitamins?
- Can I eat normally, is there anything I need to avoid or special diets that will help me?
- Can I exercise and what is the best frequency and type for me?
- Could this treatment affect my sex life? If so, how and for how long?
- Will my treatment send me into menopause?

How you can help

The Leukaemia Foundation ensures every Australian with blood cancer gets access to the trusted information, best-practice treatment, and essential care they need. With no ongoing government funding, we rely on the generosity of the community to help support all Australians living with blood cancer.

We understand that everyone's personal situation is different, so below are some of the ways you and your family may like to get involved.

Give

Your donations help provide free support services to Australians affected by blood cancer, (like financial and practical assistance, education, counselling and accommodation), and drive some of Australia's most important—and life-saving—cancer research.

Join our valued Regular Giving community

With your regular monthly gift, you can be there every step of every day in every way, for people living with blood cancer. Your ongoing support helps ensure everyone everywhere has access to the life-saving treatment and support they need.

Leave a gift in your Will

After taking care of your loved ones, a gift in your Will is a direct and valuable way of helping transform the future for Australians with blood cancer allowing your support to live on as a lasting legacy.

Fundraise

Get involved in World's Greatest Shave, plan a special Light the Night or celebrate your Best-Birthday-Ever! You can even create your own personal fundraising initiative that is completely unique.

Volunteer

Our wonderful volunteers are a crucial part of our success—helping at our signature fundraising events, maintaining our accommodation centres or providing support with specialised skills.

Become a Leukaemia Foundation Member

You can make a difference to the future of blood cancer by joining a networked community who care about people living with blood cancer. Members are the lifeblood of the Leukaemia Foundation and play an important role in shaping the future of the organisation.

Partner with us

There are many ways your business can help people with blood cancer. Together, we can create a bespoke partnership that aligns with your organisation's objectives and corporate social responsibility.

Give blood, marrow and tissue

Stem cell transplants and blood donations save the lives of many people facing blood cancer. Visit donateblood.com.au to register today.

**To find out more contact us today supporters@leukaemia.org.au
1800 620 420**

The Leukaemia Foundation gratefully acknowledges those who assisted in the development of this information: Leukaemia Foundation Blood Cancer Support Coordinators, nursing staff, clinical haematologists, and bone marrow transplant physicians representing the various states and territories of Australia.

The Leukaemia Foundation values feedback. If you would like to make suggestions or tell us about your experience in using this booklet, please contact us via email: info@leukaemia.org.au or phone us on **1800 620 420**.

**Leukaemia
Foundation[®]**

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The Leukaemia Foundation cares about our environment.
Please recycle or dispose of thoughtfully.