

# Autologous 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 autologous 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/](http://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.*

# Contents

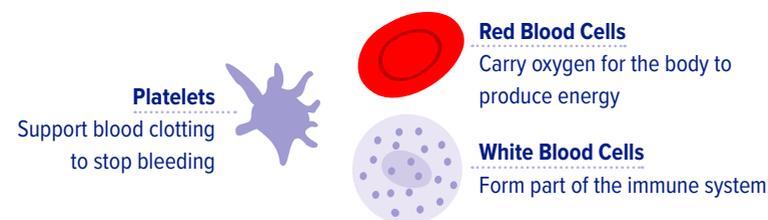
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# All about blood

## 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

Red blood cells (also known as erythrocytes or RBCs) contain haemoglobin (Hb), which gives blood its red colour and carries oxygen from the lungs to all parts of the body.

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

### 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.

## 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.

Condition	Cause	You might notice
Anaemia	Low RBCs or Hb	Tiredness, weakness, pale skin, shortness of breath, heavy legs
Leukopenia	Low WBCs	More frequent or severe infections
Thrombocytopenia	Low platelets	Bruising and bleeding, like nosebleeds
Pancytopenia	All three types low	A mix of symptoms from all three conditions

## Where and how is blood made?

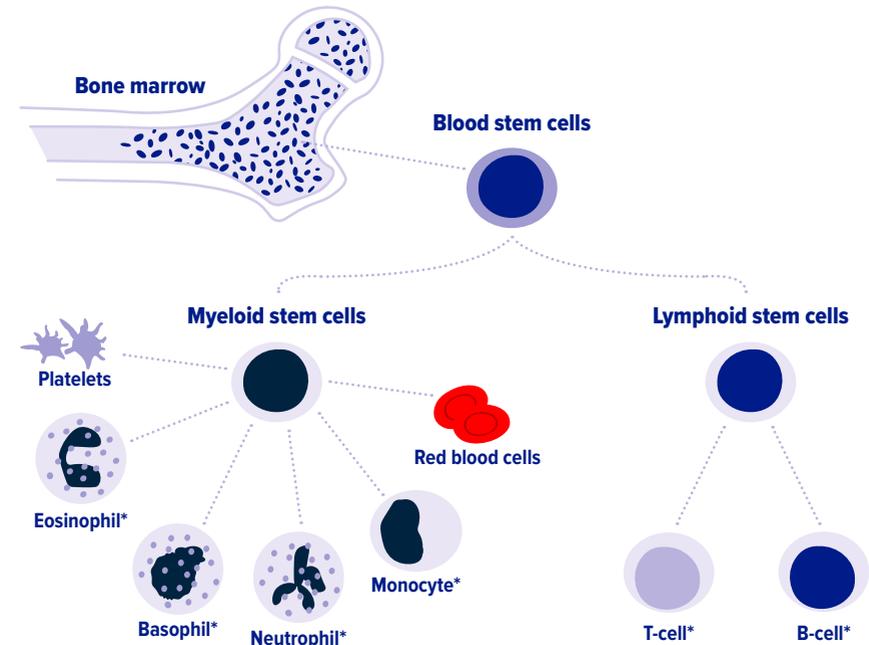
### Bone marrow

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

In children, haematopoiesis takes place in the long bones, like the thighbone (femur). In adults, it's mostly in the spine (vertebrae), 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 as 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 for 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 laboratory (synthesised) and given to people to help treat blood disorders.

# Peripheral blood stem cell and bone marrow transplantation

A stem cell transplant uses stem cells collected directly from the bone marrow whereas a peripheral blood stem cell transplant (PBSCT) refers to the use of blood stem cells which have been collected from the peripheral blood stream.

You will find that many people will use the terms bone marrow or stem cell transplant regardless of the source of the stem cells.

Bone marrow and stem cell transplantation is used to treat a range of diseases. These include haematological (blood) diseases as well as some non-haematological diseases.

**The following list gives you some examples of conditions that are treated with stem cell transplantation:**

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

## How does it work?

A stem cell transplant uses high-dose chemotherapy and at times radiotherapy. It aims to destroy the affected bone marrow and disease. 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.

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 autologous stem cell transplants.

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).

### 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.

Most people have a single autologous transplant. Some types of blood cancer require tandem autologous transplants, two (or more) transplants over a period of a few months. This is also called a staged autologous transplantation. It minimises the possibility of the cancer coming back (relapsing).

### Allogeneic

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

The type of transplant you will receive depends on a number of factors. These include:

- type of disease
- age
- general health
- condition of your bone marrow
- whether you would benefit by receiving donated blood stem cells (allogeneic transplant)
- whether your own stem cells can be used (autologous transplant)

Your treatment team will discuss the best option for your particular situation.



You can find more information on allogeneic transplants on our website.

### 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.

**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](http://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. Making 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 specialist doctor, make a list of the questions you want to ask. Keeping this list 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.

## 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.

## Standard therapy

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

## Clinical trials

Clinical trials, or research studies, test new treatments or re-test previous treatments. They are important as they provide information on how to improve treatment. Clinical trials test how to achieve better results with fewer side-effects. Clinical trials help people access new therapies not yet funded by the government, or not otherwise available.

When considering taking part in a clinical trial ensure you understand the reasons for the trial and what it involves. It is important to understand the benefits and risks of the trial. Talk to your doctor who can guide you in making an informed decision.

## Informed consent

Giving informed consent means you understand and accept the risks and benefits of a procedure or treatment. It means that you have adequate information to make such a decision. Informed consent is required if you agree to take part in a clinical trial. If you have doubts or questions regarding proposed procedures or treatments talk to the doctor or nurse.

# Sources of autologous stem cells

Stem cells are usually collected when the patient's disease is in remission or have minimal disease.

In autologous stem cell transplantation, stem cells are collected in advance of the transplant. They are 'harvested' from the:

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

These stem cells are all the same but differ in the way they are collected. Your doctor will help determine the method that is best for you.

## Peripheral blood stem cell harvest

### Stem cell mobilisation

Collecting stem cells from the bloodstream is the most common method used for a stem cell collection. It is considered a safe and relatively painless method of collecting stem cells. Like all medical procedures, there are some potential risks. Stem cells normally live in the bone marrow and are only found in the blood in very low numbers. However, patients are given chemotherapy and 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.

You may be admitted to hospital for your mobilising chemotherapy or it may be given in an outpatient department. The chemotherapy helps to treat your disease and affects the function of your bone marrow. A few days after chemotherapy your blood cell counts will decrease. Your blood cell count will increase as your bone marrow stem cells begin to 'recover' from the chemotherapy. G-CSF injections are given for several days starting 24-72 hours after completing the chemotherapy. The nurse can teach you, a family member or a friend on how to inject the G-CSF.

Regular blood tests are taken over the following week to see when the numbers of stem cells increase and when to start collecting them. It is important to keep taking your injections of growth factors at the same time every day until you are told to stop.

Some people experience flu-like symptoms while using G-CSF including:

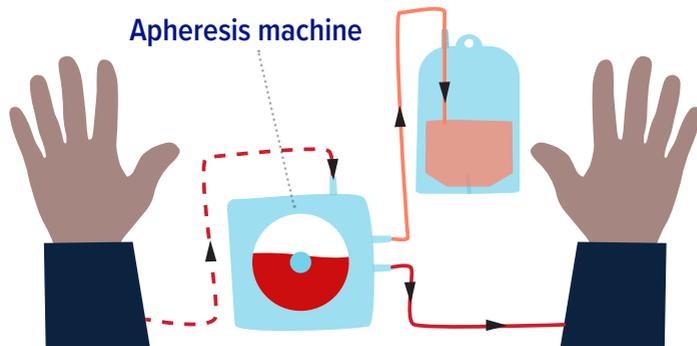
- mild to severe bone pain
- fevers and chills
- headaches

The doctor may recommend paracetamol to relieve any discomfort you may be feeling.

### Peripheral blood stem cell collection

Stem cells are collected from the bloodstream by passing your 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 your blood is returned via another cannula. This is a continuous process.



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

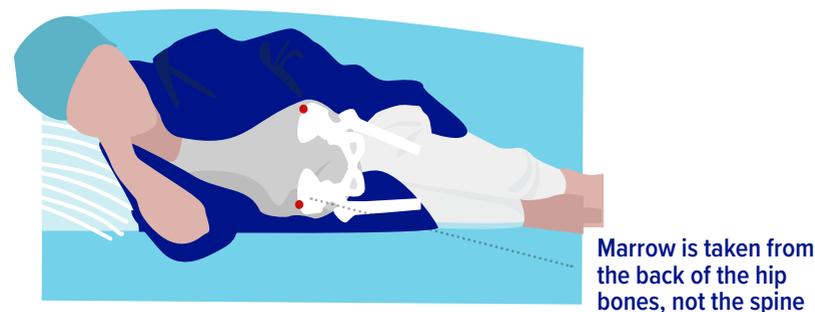
A peripheral blood stem cell collection usually takes three to four hours. Sometimes you cannot move your arms much, especially if the cannulas have been inserted inside of the elbow. The nurses will make you feel as comfortable as possible, you might like to bring along a book, a video, some music or 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 you may need to come back the following day/s until enough stem cells have been collected. Your doctor will determine the amount of stem cells that are required to be collected for your transplant.

Once your stem cells have been collected they are frozen (cryopreserved) and stored until the day of your transplant. Blood stem cells can remain frozen for many months or years before they are used.

## 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 your hips (iliac crest). This procedure is not commonly used as it is more invasive.



## 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 and 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 of the booklet deals with the things you need to consider before you start your transplant.

The issues covered here are:

- timing
- things to consider
- fertility

### Timing

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

### Things to consider

The time in hospital and on discharge in the outpatients' department will vary. This depends on the type of stem cell transplant you receive, other treatment you require and complications you experience.

Most people find that the stem cell transplant has a significant impact on their lives. The time it takes to recover from the stem cell transplant varies from person to person.

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

It is important to feel that you are prepared as much as possible for your transplant.

The following is a list of things you should consider before you begin:

- organising your financial affairs.
- making a Will, organising a power of attorney.
- sorting out employment issues such as sick leave entitlements, keeping in touch, plans for returning to work.
- arranging leave from school, keeping in touch, postponing school or university study/exams.
- organising health insurance and Centrelink benefits.
- organising child care while you are in hospital.
- organising help at home after your discharge.
- collecting things to entertain yourself while you are in hospital including a smart phone, phone credit, electronic tablet, streaming services, radio, books or e-book reader, portable speaker, photographs and videos of your family, maps of the city if you or your family come from a regional or remote area.
- setting your own personal targets and goals for the future.
- 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.
- ask the hospital staff if you can use Skype, FaceTime or something similar to keep in contact with family and friends.
- consider learning relaxation techniques, like meditation, yoga and/or breathing exercises. These may be helpful throughout your transplant.

### 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 on travel costs. You may also require accommodation for some time after your transplant. You will need to stay close to the hospital for a few weeks 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 1800 620 420.

or visit [www.leukaemia.org.au/how-we-can-help/accommodation-services/](http://www.leukaemia.org.au/how-we-can-help/accommodation-services/) and <https://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](http://fertilitysociety.com.au)

**Future Fertility:** [futurefertility.com.au](http://futurefertility.com.au)

## 2. Pre-transplant 'work-up'

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

- pre-transplant tests
- dental check
- blood tests
- central venous access device (CVAD)

### Pre-transplant tests

During the weeks leading up to your transplant you will have a number of tests. This is to make sure that 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 take longer than others. You might like to bring a book or a friend for company.

The nurse or the 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, an electrocardiogram and/or ECG)
- 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.

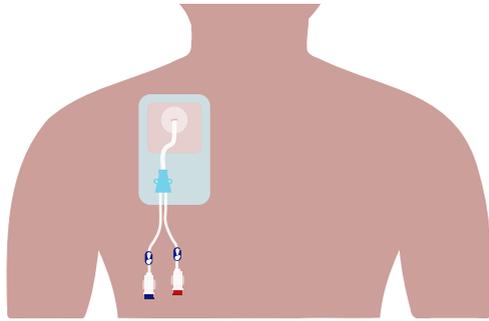
- full blood count
- blood group
- kidney function
- liver function
- thyroid function
- clotting screen
- iron levels
- blood glucose
- screening for viral and bacterial infections - to test for human immunodeficiency virus (HIV), hepatitis, cytomegalovirus (CMV), syphilis, etc

Several of these tests can be taken at the same time.

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 the stem cell transplant process you will need to have a number of intravenous (into the vein) therapies. These include fluids, chemotherapy, antibiotics, drugs and blood transfusions including red cells and platelets. You will need to have a daily blood test to check your progress.



Having blood tests daily from your arms and regular cannula changes can be painful. A CVAD is inserted before a stem cell transplant for blood tests and intravenous medication.

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

There are several different types of CVADs used. The ones most commonly used for transplant patients have one, two or three lumens or tubes. The lumens are the separate thin plastic tubes

that are visible on top of your skin, then they group together so only one tube is inserted into the vein. The nurses will take blood and give 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.

Your treatment team will examine your CVAD every day, paying particular attention to the surrounding skin. Report any pain, redness or swelling around your CVAD to your treatment team, this may indicate an infection.

The nurses will flush the lumens of your CVAD regularly to keep them open and flowing freely. They will also change the dressing which covers the site where the line enters your skin.

You may be taught how to care for your own line, especially if you are going home with the line in place.

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.

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

## 3. Conditioning therapy

Before your own stem cells are transplanted (re-infused), 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 to make or create a space in your bone marrow for the new stem cells to grow. It is more common to be

admitted to hospital for this part of the transplant. Some patients have their conditioning therapy in an outpatient clinic.

There are many different types of conditioning therapies used in autologous stem cell transplantation. It involves high-dose chemotherapy (and in some cases with radiation therapy). Single chemotherapy drugs or a combination of two or more chemotherapy drugs may be used over a number of days. There are many different combinations of chemotherapy drugs used.

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

### **Conditioning (transplant) protocols**

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

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

### **Chemotherapy**

Chemotherapy may be given as an infusion through one of the lines (or lumens) of your CVAD, or in tablet form.

Some chemotherapy drugs require you to have extra intravenous fluids. This is to ensure that the chemotherapy is quickly flushed out of your body, once it has done its job. This also helps to lessen any damage by the chemotherapy to your kidneys and bladder.

In some cases, other drugs are also given to help reduce the

toxic effects of chemotherapy on these important organs. With so much intravenous fluid, it is important to monitor the amount of fluid going in and coming out of your body. This can be measured through your urine output and your weight. The nurses may ask you 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.

It is important to ask your transplant team about any precautions which you or your family should take while you are having chemotherapy.

### **Radiation therapy**

Total body irradiation (TBI) involves exposing the 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. TBI is more commonly used in combination with high-dose chemotherapy as conditioning therapy for people undergoing an allogeneic transplant. It is occasionally used in people undergoing an autologous transplant.

Some people may require localised radiation therapy to specific sites if they have bulky disease.

### **Common side-effects of conditioning therapies**

This section looks at some of the common side-effects of conditioning therapies. Some may last for a short time, while others can last longer.

#### ***Nausea and vomiting***

Nausea and vomiting is often associated with high-dose 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.

Do not be too concerned if you are unable to eat or drink much at this time, but report any changes to your treatment team. Your treatment team will closely monitor your condition every day. If your nausea and vomiting is not well controlled, you may need extra fluid through your central venous access device (CVAD) to prevent dehydration.

### **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.

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.

### **Mucositis**

Mucositis is the inflammation of the cells lining your mouth and throat causing mouth ulcers. Your gut may also become inflamed causing diarrhoea. Mucositis is a common side-effect of both chemotherapy and radiotherapy. 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 appears about three to four days after your conditioning therapy has been completed. Mucositis begins to get better when your new stem cells re-grow (engraft) and your white cell count starts to rise.

Tell your treatment team when your mouth or throat is starting to feel dry, sore, or when your saliva is getting thick or if you are having difficulty swallowing. It is also important to tell your treatment team when you have diarrhoea. All these changes can be signs of mucositis.

Mouth ulcers can be very painful. Soluble paracetamol and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger drugs like morphine are often used in your central line.

It is important to keep your mouth clean to help prevent infection. Different treatment centres recommend different mouth care products. Your nurse will teach you how to care for your mouth.

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

### ***Bowel changes***

High-dose treatment can cause damage to the lining of your bowel wall. This may lead to cramping, wind, bloating and/or diarrhoea. 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.

### ***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.

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 doctors and the dietitian may encourage you to have special high energy and protein drinks during the day. Because these drinks are so nutritious, you don't need to drink a lot of them.

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***

There are many reasons why you may not feel like eating at this time. This is normal. Your appetite should start to improve after the transplant but it can take some time to return to normal. Try to eat small meals frequently. You may like to ask your family to bring your favourite food. Remind them not to be disappointed if you change your mind when you see it.

Be sure to tell your treatment team if you are unable to drink or eat. You may need to have intravenous fluids or a food substitute to make sure you don't become dehydrated or malnourished.

### ***Hair loss***

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

Many people with straight hair are surprised to find 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 to hospital with you as your head can get very cold without hair.

### ***Infertility***

As mentioned previously, treatment can damage your fertility. See page 21 for more details.

### ***Tiredness, tension and stress***

You may feel more tired than usual during the weeks following treatment. Initially, you may find it difficult to concentrate on reading, watching television or even keeping up with a conversation. You may be also feeling mentally exhausted as a result of the huge emotional and physical build up to the transplant. This is all very normal.

It is important to talk to someone about how you are feeling. Ask your doctor or nurse to see the social worker, psychologist, occupational therapist or pastoral care worker. Your treatment team can help and will provide 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 audiotapes or other information on relaxation and meditation which might be useful.

## **4. The transplant (Day 0)**

Your transplant, or stem cell infusion is given on day 0 (zero) of the transplant process. Some protocols may have two day zeros. This happens when the volume of stem cells is too large to be re-infused in one day.

The transplant itself is a relatively straight forward process. The stem cells are infused through your CVAD, like a blood transfusion. This can take between thirty minutes and four hours, depending on the volume of cells being infused.

Your frozen (cryopreserved) stem cells are defrosted at the bedside before being infused. Reactions to stem cell infusions are rare, but you will be carefully monitored during the infusion.

Occasionally people have a reaction to the preservative used in the freezing process, so you may be given a drug to prevent this before the infusion starts. Generally, any reactions that occur are quickly managed and the infusion is completed as planned.

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 or infused. The whole process may even seem like a bit of an anticlimax. For others, the day of the transplant is a highly emotional one. For many, it signifies a new beginning.

## **5. Pre-engraftment - the early days**

After the stem cells are infused, they travel through your blood stream and find their way to your bone marrow.

Here they set up home and begin to repopulate the bone marrow with families of immature white cells, platelets and red cells. This process is known as engraftment, it usually takes between 10 and 28 days.

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

### **Waiting for engraftment**

You will be monitored very 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.

It is not easy waiting for the stem cells to engraft. You may feel a mixture of emotions ranging from anxiety and frustration to boredom. Waiting for the results of blood tests, and constant monitoring, may make you feel vulnerable. You may also 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.

## 6. Potential post-transplant complications

This section of the booklet deals with some of the potential complications which may occur in the first few weeks after your transplant.

The following issues covered here are:

- infections
- prevention of infection
- blood and platelet transfusions

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. 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. If you develop a temperature while you are neutropenic you are regarded as being a 'febrile neutropenic' patient.

### Fevers

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

Infections can develop anywhere, common sites of infection include:

- mouth
- CVAD
- chest
- gut
- bladder

Causes of infections include bacteria, viruses and fungi. You may be prescribed preventive antibiotics, anti-viral and anti-fungal medication during and after the transplant.

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**

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

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 that an infection is an unfortunate but expected side-effect of the transplant. Your transplant team are very experienced at managing infections and will do all they can to minimise the impact of the infection.

### **Prevention of infection**

Lots of precautions are taken to try to reduce your risk of developing an infection while you are neutropenic. Some of them are outlined in this section.

### **Hand washing**

Hand washing is the single most effective way of reducing the spread of microorganisms that cause infection. Antibacterial soaps and/or gels are available in dispensers throughout the hospital unit. Anyone entering your room should wash their hands first.

You will notice that your treatment team wash their hands with this soap/gel before entering your room and on leaving.

### **Protective environment**

Many transplant patients are cared for in single rooms to reduce their risk of infection. If you have a single room you may be advised to try to spend most of your time inside it while you are neutropenic. This does not mean that you should stay in bed.

Try some gentle exercises like stretching, walking around your room and walking to the toilet. The physiotherapist may be able to advise you on some other light exercise if you feel up to it.

Keeping yourself mobile and doing gentle exercise can:

- make you feel better
- improve 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.

Not all transplant patients have single rooms. Some patients share rooms with other patients or are treated in the outpatients' clinic. Regardless of the type of room you are in, every effort is made to ensure that your environment is clean and safe.

### **Visitors**

You can still have visitors while you are neutropenic. Just make sure that they wash their hands before entering the room.

During this time you should avoid close contact with anyone with colds, flu, chicken pox, measles or any other infectious or 'catching' illness, or anyone who has had a live vaccine such as polio. No visitors are allowed if they are sick.

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

### **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.

### **Blood and platelet transfusions**

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

Transfusions are 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.

## **7. Leaving hospital**

Once your blood stem cells have engrafted and you are otherwise well, it is time to leave the transplant unit.

The doctors keep you close to the hospital where you had your transplant for regular monitoring. If you are from a regional or remote area, accommodation will be organised for you and your family. The social worker and the Leukaemia Foundation may help you with these arrangements. The length of time you will need to be away from home will depend on your recovery.

You will need to return to the hospital outpatient department several times a week after you first leave the transplant unit. You will need to have your blood counts checked, and the doctor will check on your progress. You may also require intravenous medications and blood transfusions.

As you continue to recover you will visit the hospital less frequently.

After you leave hospital you will still need to take some medications for a few weeks or longer. It is very important that you notify your doctor or the hospital if you stop taking any of your medications.

### **Mixed feelings**

It is quite normal to have mixed feelings about leaving hospital. It can be both an exciting and stressful time. It is normal to be a little worried about moving away from the protection of the transplant unit. It is also important to ask your treatment team 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.

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 doctor or the nurses at the transplant unit or clinic.

### **Readmission to hospital**

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

### **Managing fatigue**

Many people who have blood cancer treatment get fatigue. It's called cancer-related fatigue. It can be hard to describe to people who haven't felt it. It's more than being tired, it's different to normal everyday tiredness. It is often not resolved with sleep or rest. You will feel tired, but you may also feel weak, sleepy, drowsy, impatient, or confused. For most people fatigue should improve after you finish treatment.

### **Tips for managing fatigue**

Fatigue is a side effect of your blood cancer or treatment, so managing fatigue is an important part of your overall treatment and care. Make sure you talk to your treatment team about it. They may suggest referral to a psychologist who specialises in sleep management. It's very important to explain how you feel to your carers and support people, and to let them know your priorities and discuss how they can help.

Tips to manage fatigue include:

- positive sleep routine
- pre-sleep relaxation techniques
- napping if tired during the day for up to an hour
- regular moderate exercise or movement
- eating well
- drinking plenty of water
- avoiding use of electronic equipment, such as computers late at night

While you're managing your fatigue, jot down what time of day you have the most energy and when you feel most tired. That will help you get into a routine and prioritise your energy. Play games, listen to or play music, read, catch up with friends and family; these things might seem difficult, but they will help distract you from the fatigue.

## Relapse

Unfortunately, an autologous 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 or a drug to stimulate your immune system to fight the relapsed disease.

Your treatment team will advise you on your chances of relapse following an autologous transplant.

The success of your transplant will depend on a number of factors including the type and stage of disease you have, your general health and your age.

## 8. Potential late side-effects

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

### Infection

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

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.

### 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

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.

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.

## 9. Recovery - take good care of yourself

### Prevention of infection

Although your stem cells have engrafted, your immune system will take some time to recover. 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 scenarios.

### 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.

### Appetite

**More information can be found here:** [www.leukaemia.org.au/wp-content/uploads/2022/08/Eating-Well\\_Leukaemia-Foundation\\_FINAL.pdf](http://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.

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

### 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 is important for your general wellbeing. This may also help increase your energy levels. Some hospitals have exercise departments. Talk to an exercise physiologist or physiotherapist about a program of exercise for you.

#### 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.

### 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.

Regular skin checks are 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](http://lgfb.org.au) or call 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

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.

**More information can be found here:** [www.leukaemia.org.au/blood-cancer/journey/living-well-with-blood-cancer/practical-matters/returning-to-work-or-study/](http://www.leukaemia.org.au/blood-cancer/journey/living-well-with-blood-cancer/practical-matters/returning-to-work-or-study/)

### Vaccinations

In general, following an autologous transplant you will lose the immunity to many of the diseases you were vaccinated against as a child. Your doctor will assess when you can be re-vaccinated as the vaccinations need to be able to stimulate the immune system to work. This will usually be no earlier than six to twelve months after the transplant.

There may be some vaccines that your haematologist may consider unsafe to give (especially live vaccines), and these will be discussed with you. In the meantime it is important that you avoid anyone who is sick or has had contact with someone with a 'catching' illness. You also need to avoid children who have had a live vaccine such as polio.

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

### Social and emotional issues

For some people, things are never quite the same after transplant. 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

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.

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

Most people benefit by the support and love of their family and friends and the care provided by 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](mailto: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.

<b>anaemia</b>	A lower-than-normal number of <b>red blood cells</b> in the blood. It causes tiredness, paleness, and sometimes shortness of breath.
<b>baseline</b>	A first measurement of a condition taken early on, used to compare over time to look for changes.
<b>biotherapy</b>	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.
<b>blast cells</b>	Immature blood cells normally in the <b>bone marrow</b> in small numbers.
<b>bone marrow</b>	Soft, sponge-like tissue in the centre of most bones. It contains <b>stem cells</b> that make all blood cells.
<b>bone marrow biopsy</b>	Also called a bone marrow aspirate and trephine or BMAT. The removal of a small sample of <b>bone marrow</b> . This is sent to the lab for a <b>pathologist</b> to look at under a microscope.
<b>bone marrow aspirate</b>	A sample of bone marrow fluid.
<b>bone marrow transplant</b>	Also called a <b>stem cell transplant</b> . 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).
<b>bone marrow trephine</b>	A sample of bone marrow tissue.
<b>cancer</b>	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.
<b>chemotherapy</b>	The use of drugs to treat cancer.

<b>chimeric antigen receptor (CAR) T-cell therapy</b>	A form of immunotherapy that uses a patient's own specifically altered T cells.
<b>chromosome</b>	Part of a cell that contains genetic information.
<b>coagulation</b>	Process of changing from a liquid blood to a solid. Also called <i>clotting</i> . Platelets help with coagulation.
<b>cytogenetic tests</b>	The study of the structure of <b>chromosomes</b> . These tests are carried out on samples of blood and <b>bone marrow</b> . The results help with diagnosis and getting the most appropriate treatment.
<b>cytopenia</b>	Where there is a lower-than-normal number of a type of blood cell in the blood.
<b>central venous access device (CVAD)</b>	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.
<b>dysplasia</b>	Also called dysplastic cells. A change in size, shape, and arrangement of normal cells seen under a microscope.
<b>erythrocytes</b>	Also called red blood cells. A type of blood cell made in the bone marrow and found in the blood. <b>Haemoglobin</b> makes these cells red in colour.
<b>full blood count</b>	Also called FBC or complete blood count. A routine blood test that measures the number and type of cells, and the <b>haemoglobin</b> and <b>haematocrit</b> in the blood.
<b>growth factors</b>	Proteins that control cell division and cell survival. Some are made in the lab and used as treatments, such as G-CSF.
<b>haematocrit</b>	The amount of blood that is made up of <b>red blood cells</b> .
<b>haematologist</b>	A doctor who specialises in diagnosing and treating blood disorders.
<b>haemoglobin</b>	A protein inside <b>red blood cells</b> that carries oxygen around the body.
<b>haemopoiesis</b>	The formation of new blood cells.
<b>immune system</b>	The body's defence system against infection and disease.

<b>immunotherapy</b>	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.
<b>leukaemia</b>	Cancer that begins in blood-forming tissue, such as the <b>bone marrow</b> . It causes large numbers of abnormal blood cells to be made and to enter the bloodstream.
<b>leukocytes</b>	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 <b>immune system</b> . Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).
<b>megakaryocytes</b>	Very large bone marrow cells that break apart to form <b>platelets</b> .
<b>mucositis</b>	An inflammation of the lining of the mouth, throat or gut.
<b>mutation</b>	A harmful change in 'normal' DNA (the building blocks of all cells).
<b>neutropenia</b>	A lower-than-normal number of <b>neutrophils</b> in the blood. It increases the risk of infection.
<b>neutrophils</b>	The most common type of <b>white blood cell</b> . They help fight infection.
<b>pancytopenia</b>	Where there are lower-than-normal numbers of a type of all blood cells and platelets in the blood.
<b>pathology</b>	The study of diseases to understand their nature and their cause. A specialist in this field is called a <b>pathologist</b> . In cancer, histopathology/histology involves examining tissue under a microscope. Haematopathology involves blood and lymph.
<b>petechiae</b>	Tiny, unraised, round red spots under the skin caused by bleeding.
<b>platelets</b>	Also called thrombocytes. Tiny pieces of cells ( <b>megakaryocytes</b> ) found in the blood and spleen. They help form blood clots ( <b>coagulation</b> ) to slow or stop bleeding and to help wounds heal.
<b>prognosis</b>	An estimate of the likely course and outcome of a disease.
<b>purpura</b>	Bleeding and bruising under the skin.
<b>radiotherapy (radiation therapy)</b>	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.

<b>red blood cell</b>	Also called an erythrocyte or RBC. A type of blood cell made in the bone marrow and found in the blood. <b>Haemoglobin</b> makes these cells red in colour.
<b>relapse</b>	Return of the original disease after it has improved for a time.
<b>remission</b>	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.
<b>rigor</b>	Also called a chill. Feeling cold with shivering or shaking and looking pale, but with a high temperature. A symptom of infection.
<b>stem cells</b>	Young (immature) blood cells that can develop into more than one type of cell. Bone marrow stem cells grow and produce <b>red blood cells</b> , <b>white blood cells</b> and <b>platelets</b> .
<b>stem cell transplant</b>	Also called a SCT or bone marrow transplant. A procedure where a patient is given healthy <b>stem cells</b> 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).
<b>T-cell</b>	A type of white blood cell called a lymphocyte. They are part of the immune system and help the body fight infection.
<b>thrombocytes</b>	Also called platelets. Tiny pieces of cells ( <b>megakaryocytes</b> ) found in the blood and spleen. They help form blood clots ( <b>coagulation</b> ) to slow or stop bleeding and to help wounds heal.
<b>thrombocytopenia</b>	A lower-than-normal number of <b>platelets</b> in the blood. It causes bruising and bleeding.
<b>white blood cells</b>	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 <b>immune system</b> . Types: granulocytes (neutrophils, eosinophils, and basophils), monocytes, and lymphocytes (T-cells and B-cells).

## Useful websites

<b>Leukaemia Foundation:</b>	<a href="http://leukaemia.org.au">leukaemia.org.au</a>
<b>Lymphoma Australia:</b>	<a href="http://lymphoma.org.au">lymphoma.org.au</a>
<b>Myeloma Australia:</b>	<a href="http://myeloma.org.au">myeloma.org.au</a>
<b>Cancer Council of Australia:</b>	<a href="http://cancer.org.au">cancer.org.au</a>
<b>Leukemia &amp; Lymphoma Society of America:</b>	<a href="http://lls.org">lls.org</a>
<b>Blood Cancer UK:</b>	<a href="http://bloodcancer.org.uk">bloodcancer.org.uk</a>
<b>Look Good...Feel Better program:</b>	<a href="http://lgfb.org.au">lgfb.org.au</a>

## 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?
- Where can I or my loved ones get any other support?

## 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 [lifeblood.com.au/blood](http://lifeblood.com.au/blood) to register today.

**To find out more contact us today [supporters@leukaemia.org.au](mailto: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](mailto:info@leukaemia.org.au) or phone us on **1800 620 420**.

**Leukaemia  
Foundation<sup>®</sup>**

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