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Patient and Carer's Guide

Allogeneic Stem Cell Transplant

Acknowledgements

This guide has been written in collaboration with Australia and New Zealand Transplant and Cellular Therapies (ANZTCT) and Stem Cell Donors Australia.

Arrow would like to sincerely thank and acknowledge the patients and carers who have generously shared their experiences to help shape this guide.

We also extend our thanks to the many healthcare professionals who have contributed their expertise to the development of this guide.

Contributors have included representatives from ANZTCT, Stem Cell Donors Australia, the Agency for Clinical Innovation BMT and CT Network, St Vincent's Hospital, Austin Hospital, Concord Repatriation General Hospital, Liverpool Hospital, The Royal Children's Hospital Melbourne, Sydney Children's Hospital, The Alfred, Fiona Stanley Hospital, Royal Melbourne Hospital and Peter MacCallum Cancer Centre.

This guide has been published with support from the Chestnut Tree Foundation, in memory of Sylvia Hartog, who was a great fan of Arrow's work.

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Disclaimer
The information in this guide is intended as a general guide and does not take into account your personal situation. You should consult your doctor or specialist about your health and treatment decisions. This guide is not a substitute for your doctor's or other health professional's advice. While every effort has been made to ensure the information is accurate at the time of publication, medical knowledge is constantly evolving. We do not accept liability for any loss or damage resulting from reliance on this guide.

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

About this guide

This guide is about having an allogeneic stem cell transplant. It also has information on practical and emotional issues. Our aim is that this information helps you understand what's involved, answers some of your questions, and helps you talk to your transplant team.

The allogeneic stem cell transplant process described here is a general overview. Every person's experience is different, and yours will depend on your age, the blood disease being treated, the stage of the disease and any previous treatments. Your doctor will explain what an allogeneic stem cell transplant means for you, including the possible benefits, risks and outcomes.

This guide is for adults, but some of the information may also be relevant for children and adolescents having an allogeneic stem cell transplant.

How to use this guide

This guide is divided into chapters so you can easily find the information you need. Everyone approaches a transplant differently and want different levels of detail – some people want lots of details, others prefer just the main points. The guide starts with an overview of the allogeneic stem cell transplant process. If you want to know more, the following chapters take you through each step: finding a donor, how a transplant works, possible side effects and complications, and life after a transplant. At the end of each chapter is a summary of the key points. You can read as much or as little as you are comfortable with.

We've tried to use plain English as much as possible. If there are medical words you don't understand, check the meaning in the glossary (page 78) or ask your transplant team to explain.

You don't have to read the guide from start to finish – just read the parts that are useful now and come back to others when you feel ready. Some people find reading about the transplant process confronting; others find it helps them feel more prepared. Everyone responds in their own way, and it can help to talk about how you're feeling with your transplant team.

About ANZTCT

Australia and New Zealand Transplant and Cellular Therapies (ANZTCT) is the peak professional body for transplant and cellular therapies in Australia and New Zealand.

They provide national leadership in transplant and cellular therapies, including clinical standards, registry development and system wide coordination.

ANZTCT is committed to advancing clinical standards, improving access to care, and supporting better outcomes for all patients undergoing transplant and cellular therapies.

To learn more about ANZTCT, visit anztct.org.au.

About Stem Cell Donors Australia

Stem Cell Donors Australia is the national organisation that manages Australia's blood stem cell donor registry. They recruit and support volunteer donors, coordinate donor searches, and work with transplant centres and international registries to help connect patients with suitably matched stem cell donors.

As part of the global donor network, they facilitate stem cell donations for patients in Australia and around the world while continuing to grow a diverse and committed registry. Their goal is to ensure every patient has the best possible chance of finding a suitable donor match when they need one.

To learn more about Stem Cell Donors Australia, visit stemcelldonors.org.au.

About Arrow

Arrow Foundation is a national not-for-profit organisation dedicated to supporting Australians undergoing bone marrow and stem cell transplants, as well as their families and carers.

For over 30 years, Arrow has worked to:

- provide financial assistance, information resources and emotional support to patients, their families and carers
- support the education, training and professional development needs of nurses and healthcare professionals working in the transplant field
- invest in vital medical research that improves transplant patient outcomes.

Patient support

Arrow provides practical assistance, emotional support, and trusted information resources to help patients navigate every stage of the transplant journey. This includes financial assistance for accommodation, travel, and other out-of-pocket costs related to treatment, as well as educational materials such as booklets, webinars and podcasts. Arrow also facilitates virtual peer support groups, connecting patients, carers and family members with others who understand the transplant experience.

Healthcare professional training

Arrow supports education, training and professional development for healthcare professionals through scholarships, helping to build expertise and improve transplant care for patients.

Research

Arrow also supports research that improves the quality of life and outcomes for bone marrow and stem cell transplant patients, aimed at making treatments safer, kinder and more effective.

To learn more about Arrow, visit arrow.org.au.

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Letter from the CEO

If you or someone you care about is facing an allogeneic stem cell transplant, you may be navigating a time filled with questions, uncertainty and hope. There is a lot to take in, but you don't have to navigate this on your own.

This guide explains what to expect – from preparing for transplant, to the transplant itself, to recovery and life afterwards.

Our aim is to give you clear, reliable information so that you can better understand your treatment, ask the questions that matter to you, and feel more confident in making decisions about your care, including whether a transplant is the right step for you.

This guide is the result of a close collaboration between the Arrow Foundation, Australia and New Zealand Transplant and Cellular Therapies (ANZTCT) and Stem Cell Donors Australia, bringing together the expertise of healthcare professionals from across Australia and New Zealand.

Importantly, the guide has been shaped by people who truly understand the allogeneic stem cell transplant experience. It has been reviewed by patients who have undergone an allogeneic stem cell transplant, as well as by carers who have supported them through this journey. Their combined insights ensure the information is accurate, practical and reflects real-life experience.

On behalf of Arrow, I would like to thank ANZTCT and Stem Cell Donors Australia for their partnership in developing this guide, and acknowledge the many patients, carers and healthcare professionals whose contributions have made it possible.

We hope this guide provides clarity, reassurance and hope as you navigate your transplant journey. You can also share it with your family, friends or carers. Whatever stage you are at, we are here to support you.

For more information about Arrow and how we can help, or learn how you can get involved, please see the previous page of this guide or visit www.arrow.org.au

Yours sincerely,

Richelle

Richelle Koller
Chief Executive Officer
Arrow Foundation

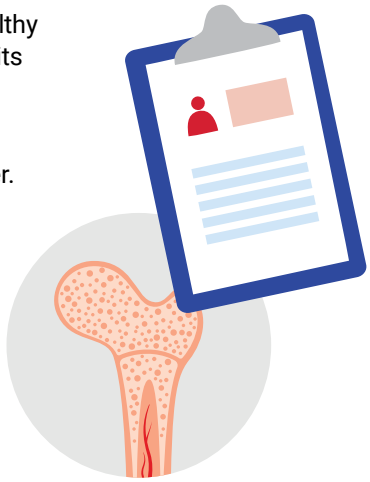
Contents

Overview of an allogeneic stem cell transplant

A stem cell transplant involves replacing unhealthy bone marrow with healthy stem cells. These new cells help restore your body's immune system and its ability to make red and white blood cells and platelets.

A transplant is a complex process, and it often comes after a long and intensive period of treatment for a blood cancer or bone marrow disorder. Reaching this stage can be an important step and a life-saving part of your recovery.

There are 2 main types of transplants:
- allogeneic (al-o-gen-a-ic) – use stem cells from a donor
- autologous (au-tol-o-gus) – use your own stem cells.



Steps in an allogeneic transplant

Finding a donor

Tissue typing is done to find a suitable donor match. A sibling is often the best chance. If no match is found, Australian and International donor registries are searched. Sometimes parents or other family members may be considered.

Pre-transplant 'workup'

Before the transplant, you'll have tests to check your overall health. These include blood tests, scans and checks of your heart, lungs and kidneys. You'll also have a dental check-up to reduce the risk of infection later.

Conditioning therapy

This is the start of the transplant process. High-dose chemotherapy, sometimes with total body irradiation (TBI), is used to destroy unhealthy marrow and suppresses the immune system to prevent rejection.

Common side effects include nausea, mouth sores, fatigue and low blood counts. Your transplant team can help you manage these side effects.

Transplant day

Also called Day Zero, this is an important milestone. A transplant isn't surgery. It involves infusing stem cells into the bloodstream through a central line, which is similar to a blood transfusion. The infusion usually takes 30–60 minutes.

Engraftment

After the transplant, the new stem cells move into your bone marrow and begin making healthy blood cells. This is called engraftment, and can take 2–4 weeks. You'll have blood tests every day to check how your white blood cells, red blood cells and platelets are recovering.

During this time, you're at higher risk of infections. You'll be given antibiotics, antifungals and antivirals. A possible complication is graft-versus-host disease (GVHD). This happens when the donor's cells attack your body. GVHD symptoms can range from mild skin rashes to more significant liver, lung and gut concerns.

Recovery

This continues for several months after you leave hospital. You'll have regular check-ups and continue taking medicines to prevent infection and GVHD.

Having a transplant can feel overwhelming, lonely or uncertain, especially during long hospital stays and while waiting for engraftment. Talking with your transplant team can help. Everyone copes differently; there's no right or wrong way to feel.

What to expect

This table outlines a typical timeframe for an allogeneic stem cell transplant. To help track the transplant process, the days before and after the transplant are recorded using numbers.

TIMEFRAME	WHAT HAPPENS	WHAT THIS MEANS FOR YOU	WHO CAN HELP*
Day -7 to -1	Conditioning with high-dose chemotherapy, sometimes with total body irradiation (TBI)	You're admitted to hospital for treatment to destroy diseased bone marrow and prepare your body for new stem cells.	• Your transplant team will explain each step and provide emotional support and coping strategies
Day 0	Transplant day	Healthy stem cells are given through a drip into your bloodstream (similar to a blood transfusion).	• Nurses and doctors monitor side effects • Medicines are given to manage nausea and mouth sores
Day +1 to Day +14	Waiting for engraftment	Stem cells move to the bone marrow and start making new blood cells. Infection risk is high, and you may need to stay in isolation with limited visitors.	• Nurses will closely monitor you for infections and graft-versus-host disease (GVHD)
Day +14 to 21	Blood counts continue to rise	Your recovery starts to stabilise. You may be able to leave hospital with regular follow-up visits to monitor progress and watch for complications.	• Dietitians support your nutrition • Physiotherapists may help with mobility
After day +30	Ongoing recovery	You're usually at home. You'll be closely monitored for graft-versus-host disease (GVHD) and infections.	
Day +100	First 100 days complete	Your transplant team reviews how well the transplant worked and checks for complications. They plan your long-term care.	• GP and community nurses provide ongoing care • Social workers and counsellors and psychologists can help with emotional adjustment
6 months	Revaccinations start	Your immune system is rebuilding. Vaccinations are restarted, coordinated with your GP or clinic.	• Pharmacists and nurses help manage medicines and vaccination schedules
6 to 12 months	Recovery continues	Side effects may begin to improve. Many people gradually return to usual activities.	• Occupational therapists can help you adapt to daily routines
Ongoing	Long-term monitoring	Check-ups become less frequent as your immune system recovers and GVHD is monitored. At about 2 years, you'll transition to long-term follow-up care.	• Support groups and community services help you reconnect socially and cope with changes after transplant

**Support from health professionals is ongoing throughout your transplant journey.*

CHAPTER 1

Blood and the immune system

Blood is made up of different types of blood cells, each with a specific role. These cells are made in the soft, spongy tissue inside bones called the bone marrow. Every day, the bone marrow makes billions of new blood cells to replace old blood cells. Many blood cells are part of the immune system, which is the body's defence system. Understanding how blood and the immune system work helps explain why a stem cell transplant is needed.

What are stem cells?

All blood cells start as immature cells called stem cells. There are 2 types of blood-forming stem cells:

- myeloid stem cells – develop into red blood cells, platelets and white blood cells called monocytes and granulocytes. Neutrophils are one type of granulocyte
- lymphoid stem cells – develop into white blood cells called lymphocytes.

How blood cells develop

About 95% of blood cells are made in the bone marrow. A small number are also produced in the spleen. Once fully developed, most blood cells enter the bloodstream. T cells, a type of lymphocyte, travel to the thymus to complete their development.

What blood cells do

Red blood cells (RBCs) – Also known as erythrocytes, red blood cells contain haemoglobin (Hb). This carries oxygen around the body and removes carbon dioxide.

White blood cells (WBCs) – Also known as leukocytes, they are an important part of the immune system. White blood cells protect the body from infections by recognising and destroying germs. The main types include:

- neutrophils – rapidly attack bacteria and fungi
- lymphocytes – fight viruses and help manage other infections:
  - B cells make antibodies
  - T cells destroy infected or abnormal cells and help control the immune response

Platelets – Also called thrombocytes, these help the blood to clot and prevent bleeding and bruising.

Blood counts

A blood test called full blood count (FBCs) measures the number of red blood cells, white blood cells and platelets in your blood. A full blood count helps your transplant team monitor your health and check how well your bone marrow and immune system are working.

Typical blood count ranges

These ranges are a general guide. Counts will be much lower after a transplant while new cells engraft.

Red blood cells

4.5–6.0 x10^9/L (men)
3.8–5.4 x10^9/L (women)

Haemoglobin (Hb)

131–180 g/L (men)
115–160 g/L (women)

White blood cells

4.0–11.0 x10^9/L

Neutrophils (N)

2.0–8.0 x10^9/L

Monocytes

0.1–0.8 x10^9/L

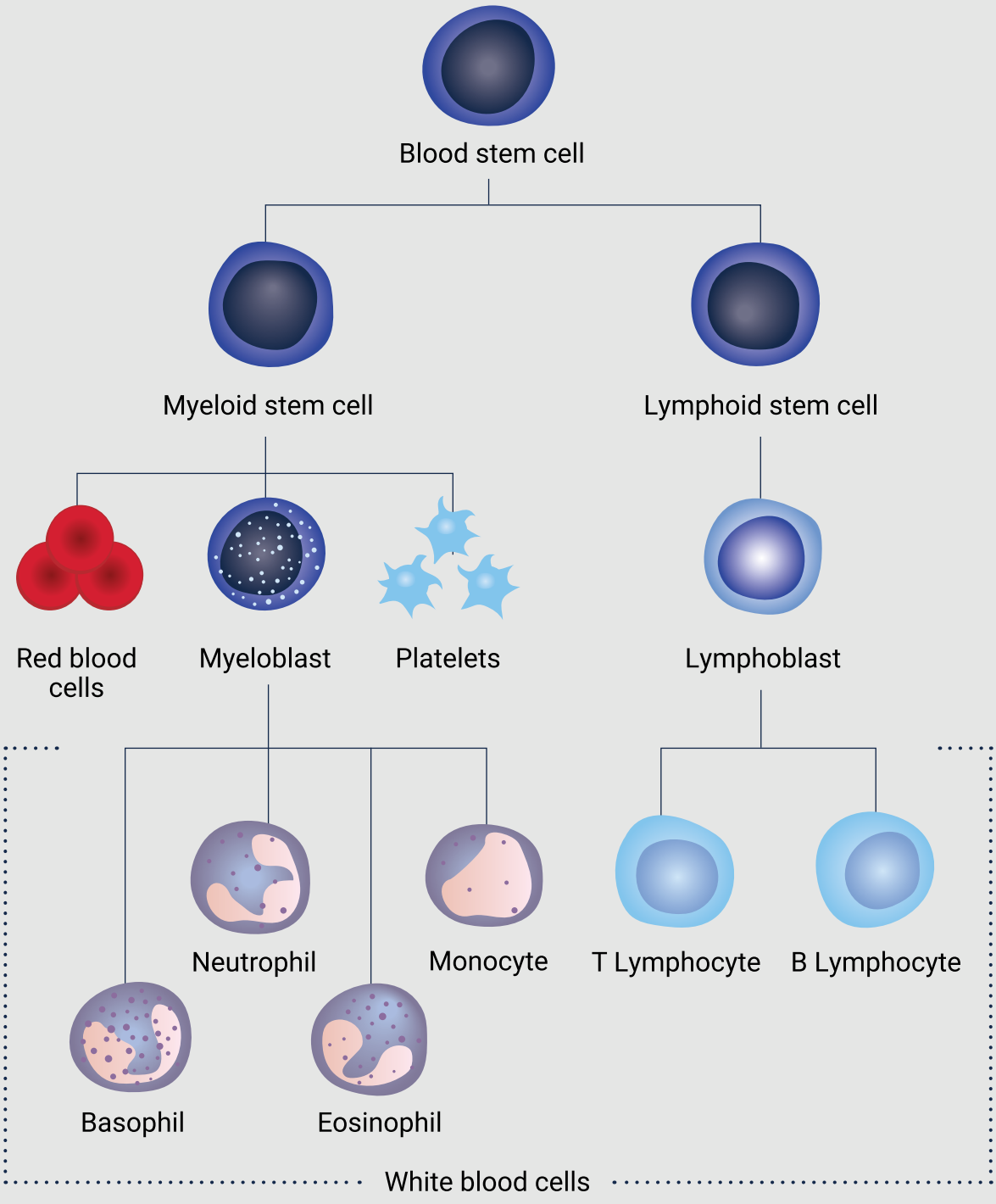
Lymphocytes

1.0–4.0 x10^9/L

Platelets

150–400 x10^9/L

How blood cells are made



CHAPTER 2

About stem cell transplants

A stem cell transplant is a treatment for serious blood cancers and diseases of the bone marrow or immune system that were once incurable. The first successful transplant was performed in 1968, and today stem cell transplants save thousands of lives. Each year, about 2000 Australians have a stem cell transplant. However, not everyone can have a transplant, because sometimes a suitable donor cannot be found or the person is too unwell.

What is a stem cell transplant?

A stem cell transplant replaces unhealthy bone marrow with healthy stem cells.

High-dose chemotherapy and sometimes total body irradiation (TBI) are used to treat the disease. These treatments can also damage bone marrow, so healthy stem cells are given into a vein (intravenously). This helps restore the bone marrow and immune system so the body can make new red blood cells, white blood cells and platelets.

The transplant helps your bone marrow work again and gives you a new healthy immune system.

Where stem cells are collected from

Stem cells can be collected in different ways:

Peripheral blood stem cell transplant (PBSCT) – stem cells are collected from the bloodstream after medicines are given to move them out of the bone marrow. This is the most common method for adults. It is usually done as an outpatient, and you don't need a general anaesthetic.

Bone marrow transplant (BMT) – stem cells are collected directly from the bone marrow under a general anaesthetic. BMT is more commonly used for children.

Cord blood transplant (CBT) – stem cells come from donated umbilical cord blood. This is less common in adults but sometimes used for children.

Types of transplants

There are 2 main types of stem cell transplants:

Allogeneic transplant

This uses stem cells from a donor. There are 3 types of allogeneic transplants:

Myeloablative – uses higher dose treatment to destroy the bone marrow and kill cancer cells.

Reduced-intensity conditioning (RIC) – uses lower dose treatment to weaken the immune system rather than completely destroying the bone marrow. RIC works more like an immune system transplant, where the donor's cells grow and attack cancer cells. This is known as the graft-versus-tumour effect (see page 51).

Non-myeloablative – uses very low-dose treatment to suppress the immune system without destroying the bone marrow.

Autologous transplant

This uses your own stem cells. It's usually offered if the disease is in remission or doesn't affect the bone marrow (e.g. myeloma, Hodgkin lymphoma, non-Hodgkin lymphoma).

Stem cells are collected from the patient's blood, stored and returned after high-dose chemotherapy or radiation therapy.

This book focuses on allogeneic transplants. For more information on autologous transplants, see our *Autologous Stem Cell Transplant: Patient and Carer's Guide*.

CAR-T cell therapy

CAR-T cell therapy is a treatment where your own immune cells are changed in a lab so they can recognise and attack cancer cells. These T cells are then given back to you. They are part of new treatments that use the immune system to treat cancer. For some people, these treatments may be an alternative to an allogeneic stem cell transplant or may be used before a transplant to help control the disease.

Who can have a transplant?

When assessing if you're suitable for a stem cell transplant, your transplant team will consider:

- your age
- general health
- type and stage of your disease
- whether you have a donor
- whether you have people to support you after the stem cell transplant.

Who's on the team?

Stem cell transplants can only be performed in certain hospitals. An expert team of doctors, nurses and support staff will care for you throughout the transplant process. This includes:

- **Haematologist –** oversees your treatment plan
- **Transplant physician –** manages the transplant process
- **Radiation oncologist –** provides radiation therapy if needed
- **Clinical nurse consultant and nurse practitioner –** provide expert clinical care, and support you and your family
- **Nurses –** provide day-to-day care
- **Pharmacist –** helps you and the transplant team manage medicines
- **Cellular therapy scientists –** test, prepare and process donor cells to make sure they are safe and ready for infusion
- **Dietitian –** supports your nutritional needs
- **Social worker –** offers emotional and practical support
- **Physiotherapist –** helps restore movement and mobility
- **Occupational therapist –** helps you adapt to your living environment and daily activities
- **Oncofertility specialist –** provides advice and options for preserving or managing fertility before or after treatment
- **Counsellor, psychologist –** help you manage your response to the transplant and offer coping strategies.

Other people who may care for you include the pain management team, spiritual practitioners and the palliative care team. Your general practitioner (GP) will also provide support.

CHAPTER 3

Making a decision

A stem cell transplant is a major and complex process. Your doctors may recommend it because they believe it offers you the best chance of recovery, but the decision is yours. It's natural to feel uncertain, overwhelmed or even conflicted as you think about your options.

What to consider when making an informed decision

Understand your options

When you're thinking about having a stem cell transplant, there's a lot of information to take in. People make decisions in different ways – some people like to know every detail and do their own research online or on social media, while others prefer just the information their transplant team provides.

Some people find that focusing on positive information helps them stay motivated. There's no right or wrong way, only what works for you.

Whatever your approach, share what you've read or heard with your transplant team. They understand that everyone seeks information differently and can help you make sense of it, answer your questions, and give you advice that's right for you.

Take your time

The lead-up to a stem cell transplant can take weeks or months. Use this time to ask questions, gather information and talk to your transplant team, family and friends. Many people find it helpful to connect with others who've had a transplant. Arrow's patient support groups are an opportunity to meet people who understand what you're going through, as well as their carers.

Talk to your transplant team

Ask your team to explain the risks and benefits in language you understand. It's okay to check information more than once. This can help you weigh up your options and feel more confident about your decision.

Share what matters to you

Let your transplant team know what's important to you – for example, your cultural background, your pronouns, and the roles of your partner, family, friends or wider support team. Sharing this information helps your transplant team provide care and support that's respectful and inclusive.

Make notes

During your first appointments, your doctor will explain the transplant process, including potential side effects and complications. It's easy to forget details, so consider taking notes or bringing a family member or friend for support. You can also ask if it's okay to record the conversation.

Ask questions

It's natural not to understand everything at first. Ask for information to be repeated if needed. It's also important to let the team know how you're feeling, and to report any new symptoms, side effects or concerns.

Before the transplant, you'll be asked to sign consent forms for treatment or research. Take your time, read them carefully and make sure you understand everything before signing.

Talk about long-term side effects

Some side effects can last a long time or even be permanent, such as GVHD, fatigue or infertility. Ask your transplant team about these before the transplant, so you know what to expect and how they can be managed. See pages 42–58.

You have a choice

After weighing up the possible risks and benefits of a transplant, you may decide not to have a stem cell transplant – and that's okay.

Everyone's situation is different, and what feels right for one person may not be right for another. For some people a transplant offers hope of long-term remission or cure, while others choose to focus on quality of life without intensive treatment.

Whatever you decide, your transplant team can talk to you about other treatment options and help you find care that suits your needs and goals.

Focus on your goals

Many people feel that a stem cell transplant is their best chance to return to everyday life.

If you're considering a transplant, think about what matters most to you – family, friends, work, travel or future plans. Keeping your personal goals in mind can help guide your decision and give you a sense of purpose, especially when you're finding the transplant challenging.

Questions to ask

Understanding the treatment

- Why is an allogeneic transplant recommended for me?
- What are the chances of cure or remission with this transplant?
- If I don't have the transplant, what can I expect?
- Are there other treatments options, and how do they compare?
- How is the donor chosen, and what makes a 'good match'?
- What is the protocol for my transplant?
- Are there clinical trials I should consider?

Before the transplant (conditioning)

- What chemotherapy or radiation will I have? What side effects should I expect?
- How long will I have to stay in hospital?
- Will I need a central line, and how is it managed?
- What can I do to prepare my body before the transplant?

The transplant

- What can I expect during my stay in hospital?
- How will we know if the transplant is working?
- What costs are covered by Medicare or my private health insurance?
- Will I have any out-of-pocket expenses? Can the cost be reduced if I can't afford it?

Risks and complications

- What are the main risks and complications of an allogeneic transplant?
- How common is graft-versus-host disease (GVHD), and how is it treated?
- What side effects should I know about?
- What signs or symptoms should I report straight away?
- Are there any long-term side effects or risks I should be aware of?

Recovery and follow-up care

- How often do I need check-ups after the transplant?
- How long will it take for my immune system to recover?
- How will infections be prevented and treated?
- When can I expect to go back to work, study or normal activities?
- What vaccinations will I need after the transplant?
- Do I need to keep taking medicines after the transplant? What will I be given?

Emotional and practical support

- How may my mental health be affected during and after treatment?
- What emotional support can I get?
- Do I need to eat differently or change my daily routines after the transplant?
- What exercises do you recommend?
- How may the treatment affect my menstrual cycle?
- Will the transplant affect my fertility? What can I do to preserve it before treatment?
- Who should I contact if I have urgent problems after hours?
- What do I need to consider if I'm a refugee or on a visa?

CHAPTER 4

Emotional and practical concerns

Being told you need a stem cell transplant can feel overwhelming and life-changing. It affects your body, emotions, relationships and finances. Preparing for a transplant involves both practical and emotional issues. You can find a step-by-step checklist in Chapter 6 to help you organise your hospital stay, support network and self-care.

Common emotional challenges

It's common to experience a range of emotions before, during and after a transplant. Everyone copes differently, and there is no right or wrong way to feel. The table below shows how you may feel at each phase.

Before transplant (Diagnosis to admission)

- Shock, stress, uncertainty
- Fear of the unknown
- Sadness about fertility or life changes
- Overwhelmed by information
- Disruption to work, study or family routines
- See page 29 for more information

During transplant (Hospital stay and infusion)

- Fatigue and low energy
- Loss of privacy or independence
- Isolation
- Hopeless or frustrated
- Disruption of normal routines
- Practical challenges such as hospital rules or limited visitors
- See page 34 for more information

After transplant (At home, long recovery)

- Relief and anxiety
- Fear of relapse, coping with uncertainty
- Frustration with slow recovery
- Grief over changes to identity or appearance
- Joy, hope or gratitude
- Practical challenges such as time off work, paying for treatment, managing medicines
- See page 70 for more information

How you may feel

Putting your life on hold

A transplant takes a long time, with many periods of waiting and uncertainty. Family routines, work, study, social plans, and caring for children or pets may all need to change. Suddenly, your health becomes the focus, and it's natural for you and your family to feel overwhelmed or confused.

Adjusting to these changes takes time, and everyone copes in their own way. Support from family, friends and the transplant team can make a big difference. A social worker can also recommend support services that may help during this time.

Feeling like no one understands

It's common to feel that others don't understand what you're going through. Even close family and friends may not appreciate the emotional and physical impact of having a transplant, which can make you feel lonely and isolated.

Talk to your social worker or a psychologist about how you feel. It can help if you and your family have realistic expectations of each other, and respect each other's way of coping. Even if they don't fully understand what you're going through, your family and friends can still offer support, compassion and recognition that this is a difficult time.

Staying positive

A hopeful outlook can help you get through the transplant process, but you may feel pressure from family and friends to stay strong and positive, even when you don't feel that way. This may mean you hide your fears or doubts, which may make it harder for everyone to understand each other.

Many people find it helpful to share their feelings and concerns with people they trust. Being open can help you cope and build stronger connections.

Try to notice and celebrate the good moments, no matter how small. Whether it's a slight improvement in side effects or a milestone like engraftment. Noticing these changes can lift your mood and help you feel more hopeful about your progress. You could use a diary to track your progress and set goals for the future.

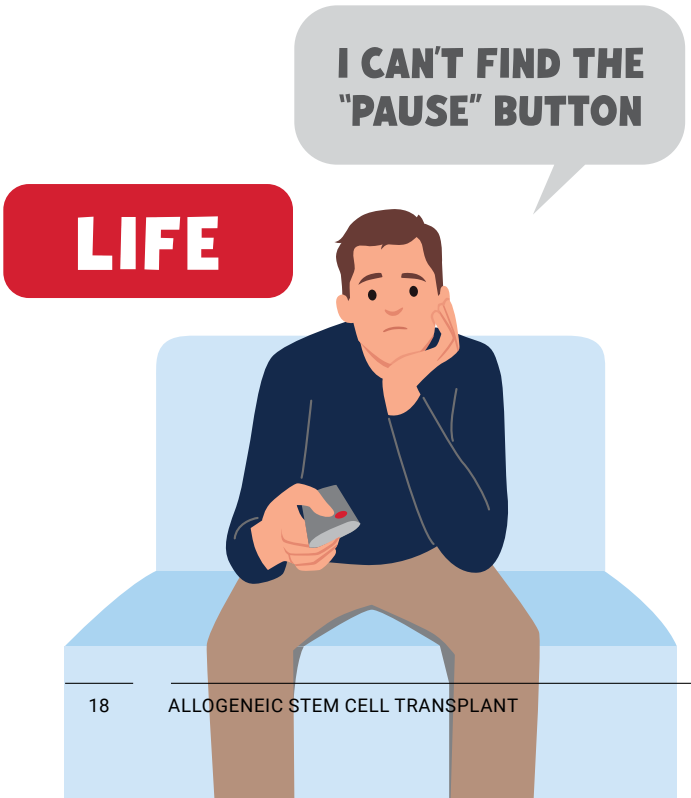
Adjusting to changes in independence

Long hospital stays and needing help with basic tasks, such as showering, walking or going to the toilet, can be frustrating, especially if you're used to managing on your own.

It can help to focus on what you can control. For example, you might choose how to structure your day and what to eat. At the same time, try to accept help when you need it. This doesn't mean you're weak, it means you're allowing others to care for you while you recover.

Coping with stress

A stem cell transplant can be emotionally and physically demanding. You don't have to cope on your own. Social workers, psychologists or psychiatrists are part of your transplant team, and can support you or refer you to other services. You don't need to wait until you feel overwhelmed to reach out.



You may worry that asking for help means you're not coping. There's no right or wrong way to handle the stress of a transplant, only what works for you.

Ways to look after yourself

Look after your body – Eating nourishing food, doing gentle physical activity and getting enough sleep can improve your mood and energy. If you smoke, call Quitline on 13 7848 for help to quit.

Draw on your spiritual beliefs – If you're a spiritual person, your beliefs may offer comfort, strength and inspiration during the transplant process. Practices such as prayer or meditation can help. Ask your nurse or social worker to arrange for you to talk with a spiritual care practitioner or religious leader or a private space in hospital to practise your beliefs.

Clear your mind – Relaxation, meditation, massage, yoga or counselling can help reduce stress, improve mood, and give you a sense of control.

Track your feelings – Writing down how you feel can help you notice patterns and understand your thoughts. You can try free online self-help programs or smartphone apps, e.g. Moodgym, Mindspot or explore the Australian Government's list of health and wellbeing apps: healthdirect.gov.au/health-and-wellbeing-apps.

Try creative activities – Art, music, journalling or other creative activities can help you relax, express your feelings and boost your mood.

Find support – Share your concerns with family, friends or health professionals such as your general practitioner (GP), nurse, social worker, psychologist or online communities such as Arrow's patient support groups. Talking with people who've had a transplant can reduce feelings of isolation.

Stay connected – Keep in touch with friends and family by phone, video or messaging apps. Online communities can also help you feel connected when you can't see people in person.

Accept practical help – Let family and friends help with meals, shopping or transport. Support from others will make it easier to cope and help you save your energy for recovery.

Relationships and support

An allogeneic stem cell transplant affects not just you, but also your family, friends and carers. Roles may change, routines may be disrupted, and it's natural for everyone to feel stressed or worried.

Impact on family roles

A stem cell transplant can change how things work at home. You may need help with cooking, childcare or transport. You may also need to take a break from work or other responsibilities for a while.

Hospital stays and recovery often mean partners or family members take on more day-to-day tasks.

Talking about these changes can help everyone understand what you need and plan how to share tasks.

Different ways of coping

People manage stress in different ways: some talk about their feelings or use relaxation techniques, while others prefer to keep things to themselves. It's important to respect each person's approach.

If someone seems distant, it may be their way of coping, not a sign they don't care.

Sex and intimacy

A transplant can affect how you feel about yourself (body image), your sexual function and your interest in sex (libido). These changes may start before the transplant and can vary from person to person.

You may feel too tired, unwell or worried to think about sexual activity. A low sex drive usually improves as you start to feel better.

Sexual activity isn't recommended during the transplant process because of the risk of infection and potential exposure of your partner to chemotherapy. Your transplant team can guide you on when it is safe to resume sex and give you more information.

Intimacy is important and can still be maintained with touch, closeness, laughter, caring and connection. These can provide comfort and emotional support during treatment.

Get support

Many sources of support are available during and after a transplant.

- **Social workers –** Help with money concerns, legal matters, transport, accommodation, family issues and can connect you with community services.
- **Psychologists and psychiatrists –** Provide emotional support and help for anxiety, depression or sleep problems.
- **Spiritual care practitioners or religious leaders –** Support people of all faiths or none, and provide a safe place to talk about meaning, hope or fear.
- **Support organisations –** Arrow, Leukaemia Foundation and Cancer Council offer resources, counselling and practical help.
- **Support groups –** Connect you with people who have had a transplant – online (including Arrow's patient support groups), by phone or in person.
- **Aboriginal liaison officers –** Provide culturally safe support, advocacy and links to relevant services.
- **Multicultural health workers and interpreters –** Help people from migrant and refugee backgrounds, or anyone who speaks English as a second language navigate care. If you need an interpreter, call the Translating and Interpreting Service (TIS National) on 131 450.
- **Disability liaison staff –** Help people with disability access care, understand their treatment and arrange reasonable adjustments. Call NDIS on1800 800 110.
- **LGBTQ+ inclusive services –** Offer safe, affirming support for LGBTQ+ people, including counselling and peer support. QLife provides free, anonymous support by phone on 1800 184 527 or via webchat, available daily 3pm–midnight.

Talking to children

It can be difficult to explain your transplant to children. As a parent, you know your child best and understand their strengths and needs. If you're unsure how to start these conversations, a social worker or psychologist can help you with what to say and how to say it.

It's natural to want to protect your children by not telling them you need a transplant. But children often sense that something is wrong, and they may imagine things are worse than reality. Explaining what is happening can help reassure them.

How children may react

Children react differently depending on their age and personality. Here are some common responses at different ages:

Babies and toddlers

- Changes in eating, sleeping or toileting habits
- Unsettled by changes in routine

Under 5

- Sadness
- Fear of separation
- Lots of questions when parent is away

Young children

- Confusion about what's happening
- Difficulty adapting to changes at home
- May believe something they did made you sick

Adolescents

- Withdrawal, apathy
- Resentment about taking on extra responsibilities
- Preferring to talk to friends

School and emotional support

Let your child's teacher know what's happening. They can watch for changes in behaviour or mood, and offer support. A school counsellor may also provide emotional support.

For more information, visit canteen.org.au to learn about their programs for teenagers affected by cancer, and their parents or siblings with cancer. Cancer Council has resources on talking to children about cancer at cancer.org.au.

Tips for supporting your children

- Explain the transplant in language your child can understand.
- Encourage your child to ask questions and share their feelings.
- Reassure them about any fears or concerns they may have.
- Give them regular updates about the transplant and your recovery.
- Stay in touch while you're in hospital – use phone calls, video messages or drawings to stay connected.

Family and friends

Your family and friends often want to help, but may not know how. Let them know what you need and what kind of support could make things easier.

If you have a partner or a main carer, others can help by giving them a break or taking on tasks they can't manage alone.

Tips for talking to friends

- Suggest practical ways others can help, e.g. cooking meals, cleaning, shopping, driving you to appointments, doing school pick-ups.
- Ask one person to be the main contact. They can coordinate offers of help and keep others updated, answer calls and emails, or post updates on messaging apps (e.g. Gather My Crew).
- Spend time together, e.g. watching a show, playing a game, doing a puzzle or sitting with you quietly.
- Let people know when you need space, and reassure them that their support still matters.

Planning for the hospital stay and recovery

An allogeneic stem cell transplant will mean staying in hospital for several weeks. Being prepared can make it easier for you and your family.

Understand what to expect – The transplant and recovery period can be physically demanding and affect your independence. As it takes time for your energy to improve, you may need help with daily tasks such as showering or dressing. It's normal to feel frustrated by the slow pace.

Isolation precautions – To reduce infection risk, you may be in a single room with strict hygiene rules. This can make you feel lonely. Plan ways to stay connected with family and friends with phone calls, video chats or messaging apps. Use relaxation techniques (e.g. breathing exercises, meditation, mindfulness apps) to manage stress.

Personal items – Bring items that help you feel more comfortable, e.g. loose clothing, slippers, toiletries, books, headphones or music.

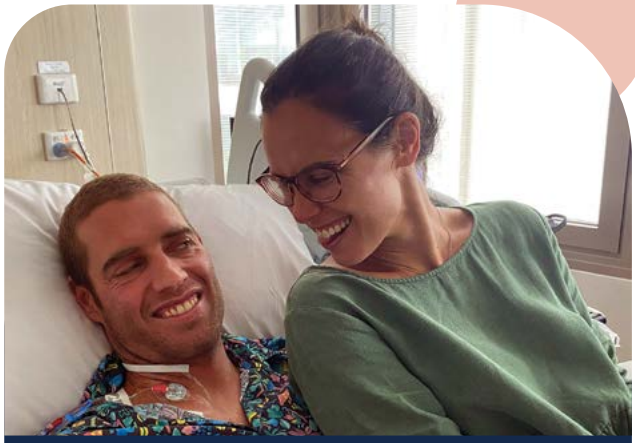
Planning for discharge – After the transplant, recovery will continue at home. Before leaving hospital, make sure you understand what medicines you need to take, details of follow-up appointments, infection precautions, and who to call in emergencies. See Chapter 15, *Life after transplant*.

Practical and financial concerns

Having an allogeneic transplant can often create practical and financial challenges.

For many people, treatment for their initial illness may involve extra costs and loss of income. The transplant process and long recovery can make it harder to work, which may lead to money problems.

If you need to stay in a major city for treatment, this can add to the financial pressure.



For family and friends

Being the main carer can be stressful and exhausting. You may feel frustrated when you're unable to ease their discomfort or unsure how to help.

- **Offer support –** Be there, even if they don't want to talk.
- **Listen without judgement –** Let the person express both positive and negative feelings. The transplant process is difficult, and negative thoughts are a normal part of their situation.
- **Respect their space –** If they ask you to leave, don't take it personally. They may just need rest or some time alone.
- **Ask for help –** If caring becomes difficult, talk to the transplant team about how to get support.
- **Educate yourself –** Learn about the transplant process, medicines and possible side effects.
- **Take care of yourself –** Schedule regular breaks, and have your own support in place, including family, friends or health professionals such as social workers or psychologist. Consider short breaks from caring (respite care), counselling and support groups for carers, or carer payments and entitlements.

Ways to get financial support

- Ask your social workers about any available financial or practical help. If you need to travel for appointments, ask about patient travel assistance.
- Check with Centrelink if you qualify for payments, e.g. if you're unable to work, have a disability, or are caring for children. For more details, visit servicesaustralia.gov.au.
- Speak to your employer about what leave you may be entitled to.
- Contact your utility providers (e.g. electricity, water, gas, phone, internet), loan company or local council to ask about rebates, concessions, payment plans or hardship programs.
- Ask if you can get a concession card to help you pay less for doctors, medicine and transport.
- Speak to your superannuation fund about early access to your super or any insurance benefits attached to your account. Before you decide, talk to a financial counsellor or planner to understand any potential long-term impacts.
- Call the National Debt Helpline on 1800 007 007 or visit ndh.org.au for free, confidential and independent financial counselling.
- Contact charities and organisations such as Arrow, Leukaemia Foundation and Cancer Council to find out what financial aid, accommodation and emotional support they provide.
- A hospital social worker can explain what you may qualify for and help you with applications.

Travel and accommodation

Many people need to travel away from home to have a transplant. In this case, you and your family may need accommodation close to the hospital. Some hospitals offer accommodation.

If you live more than 100 km from the treatment hospital, you may be eligible for help with travel and accommodation costs through a patient travel assistance scheme. Talk to the hospital or transplant team social workers to find out what support is available in your area. They can help you apply and explain what's covered.

Your family will probably visit often while you're in hospital. Find out about parking and public transport near the hospital.

Planning ahead for your care

When living with a serious illness, many people think about what matters most to them. Planning ahead may include preparing paperwork to record your wishes for future care and treatment in case one day you're too unwell to communicate your decisions about care.

You can make plans about your future care at any time, even if you're well. Some people find comfort in knowing their wishes are clear and will be respected. It can also make things easier for families when they understand your values and choices. Research shows families feel less anxious when plans are already in place.

Not everyone wants or needs to plan ahead, but you may want to discuss it with your doctor, especially if your treatment has been complex. Planning ahead may include:

- deciding what treatments you would or wouldn't want
- completing written documents
- nominating a substitute decision-maker
- recording what matters to you (e.g. being comfortable, being at home, your cultural or spiritual values)
- reviewing or updating your will to ensure your financial and personal wishes are clear.

Your plans don't have to be final. You can update them as your health or preferences change.

Making a will – A will is a legal document that sets out what happens to your money, property and possessions after you die. Updating or writing a will can help make sure your wishes are followed and reduce stress for your family. It's best to see a lawyer to prepare a will.

Advance care directive – This is a legal document where you write down your wishes for future medical care. In some states it may be called an advance health directive or advance care plan. If you can't speak for yourself, doctors, family, carers and substitute decision-makers must take your wishes into account.

Appointing a substitute decision-maker – The legal term for being able to make your own decisions is capacity. A substitute decision-maker is someone

you legally appoint to make medical decisions if you lose capacity. This should be a person you trust, and who knows your values and preferences.

The name of the legal document varies by state or territory. It may be called an enduring power of guardianship, appointment of enduring guardian, or medical treatment decision-maker. Sometimes this role is included in an advance care directive.

An enduring power of attorney is a separate document that usually applies only to financial or legal matters not medical decisions.

Getting help – Your GP, transplant team, social workers or palliative care service can guide you through the planning ahead process.

Sharing your documents – Keep copies of documents somewhere safe, and make sure your family, substitute decision-maker, GP and hospital team also have copies. This ensures your wishes are known and respected when needed.

Key points

- There's no right or wrong way to cope. Find what works for you.
- Share your feelings and concerns with your transplant team, family or support services.
- Look after your body and mind – rest, gentle activity, nourishing food, and relaxation can improve wellbeing.
- Talk with your family about how your role and responsibilities may change during treatment and recovery.
- Explain what's happening to children. They often imagine that things are worse than reality. Use language that they can understand.
- Stay connected with family, friends and support groups to ease feelings of isolation.
- Explore ways to manage any money concerns and prepare any legal paperwork before your hospital stay.
- Consider future planning documents (advance care directive, substitute decision-maker, will, enduring power of guardianship, enduring power of attorney).

"Without a carer, I could not have had a bone marrow transplant. The stress they cope with is phenomenal – make sure your carer has their own support person too."

Susanna

CHAPTER 5

Finding a donor

Finding a donor is an important step in an allogeneic transplant. The ideal donor has a tissue type that closely matches yours. This may be a sibling, but only about 1 in 3 people have a fully matched brother or sister. If no match is found in your family, the search will expand to include extended relatives and unrelated donors in Australia and overseas.

What is tissue typing?

To find a suitable donor, doctors use tissue typing, also called HLA (human leukocyte antigen). HLA markers are proteins found on the surface of most cells. They help your immune system tell the difference between your own cells and foreign cells.

Understanding HLA types

You inherit one set of HLA markers from each parent. Since each parent has 2 sets, there are 4 possible combinations of HLA markers in their children. This means you have a 1 in 4 chance of having the same HLA markers as your brother or sister.

HLA matching isn't linked to blood type, sex, appearance or personality. Sharing the same blood type doesn't mean someone will be a good HLA match. However, ancestry does matter. You're more likely to match with someone with the same ethnic background.

How we get our HLA type

PARENT	HLA SET 1	HLA SET 2
Mother	1	2
Father	3	4
Child	Possible combinations: 1+3, 1+4, 2+3, 2+4	

What the HLA results mean

An HLA type has 2 main groups of markers:

- class I antigens (HLA-A, B, C)
- class II antigens (HLA-DR, DQ).

These markers are written as numbers and letters.

Why matching matters

A close HLA match increases the chance of a successful transplant. If the donor's HLA markers are too different, your immune system may reject the transplant. The donor's immune cells (the graft) may also attack your body (the host), which is known as graft-versus-host disease (GVHD).

Matching with a sibling

Doctors look at 5 key HLA markers: A, B, C, DRB1 and DQB1. A full sibling match means all 5 pairs match. This is usually called a 10/10 match. Sometimes results are simplified to 6/6, focusing on A, B and DRB1 because siblings usually share C and DQ automatically.

Example

- Patient: A3, 32; B7,37; DRB1*0101, 1501
- Donor: A3, 32; B7,37; DRB1*0101, 1501

Matching with a mismatched donor

For an unrelated donor, the testing is more detailed, including all 5 HLA markers and their subtypes (called alleles). Because there are hundreds of possible allele combinations, finding a perfect 10/10 unrelated match is more difficult.

Example

- Patient: A3,32; B7,37; DR1,15
- Donor: A3,17; B7,37; DR1,15

How HLA typing is done

HLA typing is done with a blood test. For a related potential donor, a blood sample is taken and white cells are separated for testing. For an unrelated donor, a swab of cells is taken from inside the cheek.

Two types of tests may be used:
- serological testing – uses white cells
- DNA testing – uses DNA from the white cells.

When DNA testing is done, the DNA is used for HLA typing and to monitor how well the donor cells have engrafted (called chimerism).

Initial results are available in about 4 weeks. When a potential donor is identified, you and any potential matched donor may have more detailed tissue typing samples taken. This can take another 2–4 weeks.

The results are sent to your doctor and the transplant coordinator, who will explain what they mean and your next steps.

Searching for a donor

Finding a donor can feel overwhelming, but your transplant team will guide you through the process.

The hospital where you're having treatment will start the search for a donor. A search coordinator from the hospital or from Stem Cell Donors Australia will work closely with HLA scientists to manage the search. The hospital will give you their name and contact details.

Donor types

Matched donor
- Siblings have the highest chance of being a full match.
- The transplant coordinator can contact them, explain the process, arrange for blood testing and answer any questions.
- Testing can usually be done close to where they live.
- They'll have a health check-up to make sure they're suitable.

Half-matched (haploidentical) donor
- May be an option depending on your diagnosis and whether this type of transplant is suitable for you.
- Share one set of HLA markers (one haplotype) with you – a half-match rather than a full match.
- Common among close family: children and parents are always a half-match, siblings have about a 50% chance.
- Advances in transplant technology mean haploidentical donors are now used in many Australian transplant centres.
- Outcomes have improved and are close to those of fully matched donors.

Extended family
- Rarely (about 3% of cases) a match because share fewer HLA markers.
- Aunts, uncles and cousins may be tested if an HLA expert thinks they may be suitable.

Unrelated donor
- For 60–70% of people without a matched related donor, unrelated donor registries and cord blood banks can help.

Mismatched donor
- If no full match donor is found, a partial matched donor (e.g. 5/6 or 9/10) may be considered.

Friends
- Unlikely to be a match and usually not tested.
- Interested friends can contact Stem Cell Donors Australia to join the registry.

To find out more about the donation process, visit Stem Cell Donors Australia at stemcelldonors.org.au.

Donor registries

Stem cell donor registries list people who have volunteered to donate stem cells to anyone in the world who needs a transplant.

The World Marrow Donor Association, an international database based in the Netherlands, lists about 44 million donors from over 58 countries, including more than 767,000 cord blood units.

Registries are also working to recruit donors from different ethnic backgrounds to improve the chances of finding a match. For more information, visit wmda.info.

Types of registries

Stem cell donor registries – These list volunteers who are willing to donate stem cells anonymously to anyone who needs a stem cell transplant. Donors have their tissue type tested, and the results are saved in a database.

Cord blood registries – Blood from the umbilical cord and placenta of newborn babies provides a rich source of stem cells, especially for young children. Registries record information about the cord blood units donated by mothers after their babies are born.

How family and friends can help

Stem Cell Donors Australia encourages family members who've had HLA typing to register as potential donors, as they may be able to save a life. Friends or unrelated volunteers who are healthy and aged 17–35 can also join. If they match someone, they may be asked to donate stem cells, even if the person they match isn't their friend. Visit stemcelldonors.org.au.

Family and friends can also donate blood and platelets through the Red Cross. For more information, visit lifeblood.com.au.

How the donor registry search works

If your doctor thinks you may benefit from an unrelated donor transplant, a registry search is started. Finding a stem cell donor involves several steps, coordinated by your transplant team and Stem Cell Donors Australia. You can't contact the registries yourself.

Steps in searching for a donor

Starting the search – Your transplant team completes a Stem Cell Donors Australia search request form with details like your tissue type, age, sex, ethnicity and diagnosis. This is sent to the national office.

Searching the registry – Your tissue type is entered into the Stem Cell Donors Australia database. A computer program compares it with all donors on the Australian registry. It may take a few hours to get a list of potentially matched donors.

Expanding the search – If no suitable match is found in Australia, the search expands to international stem cell and cord blood registries, including the World Marrow Donor Association.

Confirming potential matches – Potential donors are asked to confirm their tissue type. If needed, high-resolution DNA sub-typing is done. Samples are sent to Stem Cell Donors Australia's tissue-typing laboratories for testing. Your own tissue type is also re-checked with high-resolution DNA sub-typing.

It's important to know that donors can change their mind about donating at any time, up until you're admitted for the transplant.

How long it takes to identify a donor?

The time it takes to find a donor varies.

Family member – A donor can usually be confirmed within 2–4 weeks of testing, but this may take longer if your sibling lives far away or overseas.

Local registry searches – This can be quicker if the donor has already had high-resolution DNA typing.

International registry donor – It may take 2–4 weeks to confirm if an international donor is a match.

All donors need to repeat their testing to confirm the results. This is called verification testing. They are also tested for infectious diseases. If more than one donor is identified, factors such as CMV status (see page 45), blood group, age and availability are considered.

Next steps after a donor is found

Once a matching donor is found, the transplant team will decide how urgently you need the transplant based on your disease and health.

If the transplant is urgent, the donor will have medical tests (called a workup) to check they're healthy enough to donate.

If a transplant is not needed straight away, an unrelated donor can be reserved for 90 days. You can ask for an extension of another 3 months. If you still don't need the transplant, the donor is put back on the registry, but their details stay linked to your file in case you need a transplant later.

Making contact with your donor

Some people want to contact their donor to say thank you. Deciding to make contact is a personal choice, and can have both positives and negatives.

If you want to contact your donor – Speak with your transplant or collection coordinators first. You can write a letter or email without personal details (e.g. name, date of birth, address). The transplant or collection centre will pass it on to the donor.

If your donor wants to make contact – The donor cannot make contact within the first 2 years. All contact is anonymous and goes through the registry. After 2 years, direct contact is possible if both sides consent.

For more information, contact Stem Cell Donors Australia at stemcelldonors.org.au or speak with your transplant coordinator.

Key points

- HLA (tissue) typing measures how closely a potential donor's cells match your own.
- The closer the HLA match between you and your donor, the better the chance of a successful transplant.
- About 1 in 3 people have a fully matched donor in their immediate family, which is the preferred source of donor stem cells.
- HLA matching is not related to similar physical appearance, blood group, sex or personality between family members.
- Family members considering becoming a stem cell donor should contact your doctor or transplant coordinator.
- Unrelated donors are now more common than siblings as donors.
- If no match is found on national and international stem cell and cord blood donor registries, an extended family search may be considered.
- Half-matched (haploidentical) donors are now being used routinely in Australia and overseas.
- If a fully matched donor cannot be found, a mismatched donor may be considered. There are now medicines that make half-matched and mismatched transplants much safer.
- The search for a donor should begin as soon as possible, even if a transplant is not required immediately, as it can take weeks or months to find a suitably matched donor.
- Once a suitable donor is found, the transplant team will work out how urgent the transplant is based on your disease and overall health.

For the donor: How stem cells are donated

This is a short description of what to expect before, during and after the donation process.

Before donation

Donors will have a medical check-up and tests to confirm suitability. These include:

- blood tests and screening for infectious diseases (e.g. hepatitis, HIV)
- review of health history, current medicines and allergies
- kidney and liver function tests
- chest x-ray or heart test (electrocardiogram or ECG), if necessary.

A doctor will explain the process and possible side effects, and answer any questions. Donors then sign a consent form before proceeding.

How stem cells are collected

Stem cells can be collected in 2 ways. The choice depends on what's best for the patient and what the donor prefers.

Peripheral blood stem cell (PBSC) donation – The most common method. Donors receive injections of a medicine called granulocyte-colony stimulating factor (G-CSF) for a few days. This helps the bone marrow make more white blood cells, specifically a type called granulocytes, and helps release stem cells into the bloodstream. On the day of donation, blood is taken from one arm, stem cells are separated using a machine (called apheresis), and the remaining blood is returned through the other arm. This process takes a few hours.

Bone marrow donation – Less common. Under general anaesthetic, up to 1.5 litres of marrow is collected from the pelvis using a special needle. After the procedure, the donor receives pain relief and spends a short time in recovery before going home, usually the same day.

Side effects

Most donors recover quickly. Common side effects include:

- tiredness, soreness or bruising, which improve within 1–2 weeks
- bone pain or fatigue from G-CSF, which improves within 2 days after the last injection
- mild pain at the collection site for a few days, which is managed with paracetamol.

Infection is rare. Contact the haematologist at the hospital if the collection site becomes red, warm or painful, or if a fever develops. Most donors return to normal activities within a week.

After donation

Stem cells are usually given to the patient the same day, but can also be frozen for later use. If not enough cells are collected, the donor may have another dose of G-CSF and return the next day for a second donation. A follow-up visit or blood test may be needed the week after donation. A donor support coordinator will contact donors after donation to make sure they are recovering well.

For more information: visit stemcelldonors.org.au.

CHAPTER 6

Preparing for a transplant

Before your transplant, you'll have check-ups to make sure your body is fit enough to cope with the treatment. This process is called a workup. It may include tests, placing a central access venous device (CVAD), a dental check-up and a discussion about fertility. The timing of your transplant can also depend on how your disease is progressing, what type it is, and when a suitable donor becomes available.

How you may feel

It's normal to feel nervous, uncertain or even relieved that treatment is starting. Everyone reacts differently. For more support, see Chapter 4, *Emotional and practical concerns*, which covers common emotional challenges and ways to cope.

The workup

Most of the tests for the workup are done before you're admitted to hospital (see table on next page). Your transplant team will explain what each one is for and what to expect. You may not need every test – it depends on your health and the type of disease you have. After the transplant, some tests will be repeated to check your overall health and how the disease has responded to the transplant.

Central venous access device (CVAD)

A CVAD is a thin, flexible tube placed into a large vein, usually in your chest or neck, with the tip sitting near your heart.

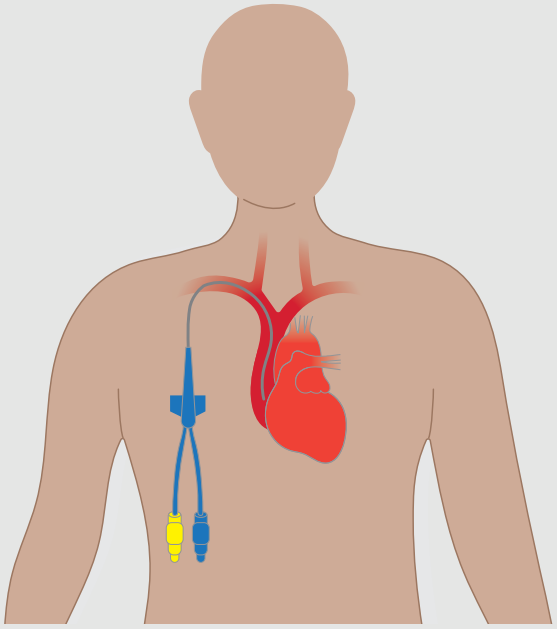
The part that stays outside your body may have 2–3 small tubes (called lumens). These let you receive more than one type of treatment at the same time.

There are different types of CVADs, such as a central line or Hickman catheter.

You may need a CVAD to:

- collect blood
- give you medicines and fluids
- give you your new stem cells.

An example of a central line in place – a Hickman catheter



It will stay in place during the transplant and reduce the need for repeated needles or injections.

The CVAD is inserted under local anaesthetic, so you'll be awake but should not feel pain. It may be placed in the operating theatre, during an x-ray or on the hospital ward. A small clamp keeps the line closed when it's not in use.

Common tests you may have during workup

TEST	WHY IT'S DONE	WHAT TO EXPECT
Gated heart pool scan (GHPS)	Checks your heart health	• You'll have a small injection of a radioactive tracer • You lie under a camera while images are taken of your heart as it beats
Cardiac echocardiogram (ECHO)	Checks your heart health	• Gel is placed on your chest • A handheld probe moves over your skin to take pictures of your heart
Glomerular filtration rate (GFR)	Checks your kidney health Results may affect how much fluid you receive during treatment or your medicine dose	• You'll have a small injection of a tracer • Several blood samples are taken over a few hours to see how well your kidneys filter it • Often done on a different day to GHPS
Lumbar puncture	Looks for disease in spinal fluid. May also be used to give chemotherapy	• A needle is carefully inserted between the bones in your back to collect spinal fluid (cerebrospinal fluid or CSF)
Chest x-ray	Checks your lung health	• Scan is quick and painless
Sinus x-ray	Checks your sinus health	• Images are taken of your sinuses to look for infection
CT (computerised tomography) scan	Assess disease or check for infection	• You'll lie on a table that moves through a scanner
PET (positron emission tomography) scan	Checks disease status before and after the transplant	• Involves a small injection of radioactive glucose
Blood tests	Check blood counts, and kidney and liver function to see how your body is working before treatment	• Blood is taken from a vein in your arm • You may have many blood tests before a transplant
Bone marrow biopsy	Checks disease before and after the transplant	• A needle is used to take a small sample of bone marrow, usually from the hip

Dental check-up

The mouth (oral cavity) is a major source of bacteria, which can cause infections during an allogeneic stem cell transplant.

A dental check-up can help identify and treat any problems before your transplant. If your dentist needs more information about the transplant, they can contact your doctor.

If you're worried about the cost of having dental treatment, talk to your doctor, transplant coordinator or social worker. They may be able to arrange a dental check-up through a hospital or community dental service.

Checklist for preparing for your transplant

Preparing for an allogeneic stem cell transplant involves planning. Thinking ahead about practical issues can make things easier for you and the people around you.

Transport and accommodation

- Plan how you'll travel to and from the hospital.
- Find out about parking or public transport for visitors.
- Ask whether you can get help with travel or accommodation costs.

Health and wellbeing

- Eat nourishing food, get enough sleep and keep as active as possible.
- If you smoke, quitting will improve your recovery. Ask your doctor for advice or call the Quitline on 13 7848.
- Limit how much alcohol you drink.
- Talk to a counsellor, psychologist or social worker about how you're feeling.
- Try relaxation techniques such as meditation or gentle yoga to reduce stress.
- Connect with what gives you strength – this may be faith, nature, music or personal reflection. You can also speak with a spiritual care practitioner or religious leader.

Practical matters

- Sort out finances, work or study leave, insurance, superannuation or Centrelink payments.
- Arrange childcare, pet care and help with household tasks.
- Make or update a will or set up an enduring power of attorney.
- Talk to a hospital social worker about financial and practical support.

Support network

- Talk to family or friends about how they can help.
- Choose one main contact person to keep others updated, by phone, email or social media.
- Accept offers of help with meals, transport, shopping or other tasks.

Hospital stay

- Pack items to help you feel comfortable and pass the time (e.g. phone or tablet, books, movies, music or podcasts, photos, journal).
- Download relaxation or mindfulness apps to use while in hospital.
- Plan how you'll stay connected with family and friends through calls, messages or online games.

For more information on coping with the emotional and relationship challenges of a transplant, see Chapter 4, *Emotional and practical concerns*.

Fertility

The conditioning therapy (see Chapter 7) given before your allogeneic stem cell transplant can damage the cells needed for reproduction (eggs or sperm).

For most people, this damage is permanent and causes infertility. For others, it may be temporary.

Factors that affect fertility include:

- age – the most important factor
- gender
- type of conditioning therapy used (e.g. total body irradiation or chemotherapy)
- previous treatment with chemotherapy and radiation therapy.

Learning that a transplant can affect your fertility can be devastating, especially if you haven't had children or would like to have more in the future. There are ways to freeze eggs, sperm, embryo, or ovarian or testicular tissue for later use. Whether this is possible depends on your disease and how quickly treatment needs to begin.

Talk to your transplant team about fertility as early as you can. If you're considering storing eggs, sperm or embryos, ask for a referral to a fertility clinic or an oncofertility specialist. You can also ask about the costs and any ongoing fees for storing eggs, sperm or embryos.

Key points

- Before the stem cell transplant, you'll have routine medical tests, called a workup, to check your body is ready for the transplant.
- The timing and planning of your transplant depends on your health, your type of disease and when a donor is available.
- A central venous access device (CVAD) may be placed to give medicines and collect blood during treatment. This reduces the number of needles you need.
- A dental check-up before the transplant helps find and treat any infections that could cause problems during the transplant.
- Conditioning therapy can affect fertility. Before you start, talk to your transplant team about options for storing eggs, sperm, embryos or reproductive tissue with your transplant team.
- Plan ahead for your hospital stay and pack things that help you feel comfortable and connected.
- Organise travel, accommodation and anything you'll need for hospital.
- Sort out practical matters such as finances, leave from work or study, childcare and who will make medical decisions if you can't.
- Look after your wellbeing with rest, nourishing food, gentle activity and relaxation.
- Talk to your social worker about emotional, financial and practical support.
- Plan how to stay in touch with family, friends or chosen family during your hospital stay.

CHAPTER 7

Conditioning therapy

Conditioning, or preparative, therapy is given a few days before the transplant to prepare your body to receive the donor's stem cells. It usually involves high-dose chemotherapy, and sometimes, it also includes total body irradiation (TBI), a type of radiation that targets your whole body.

The aim of conditioning therapy is to kill any remaining cancer cells and improve the chance of cure, while also weakening your immune system so it doesn't reject the donor's stem cells.

Side effects are common with conditioning therapy. Your transplant team will explain what to expect and how to manage them (see page 35).

Types of conditioning therapy

There are 2 types of conditioning therapy used before a transplant:

Myeloablative (full intensity) – This uses very high doses of chemotherapy and TBI. It destroys all bone marrow, making space for the donor's stem cells.

Reduced intensity conditioning or RIC – This uses lower doses of chemotherapy. It weakens but doesn't fully remove your bone marrow. RIC relies more on the donor's immune cells to fight the disease (graft-versus-tumour effect — see page 51).

What to expect during conditioning therapy

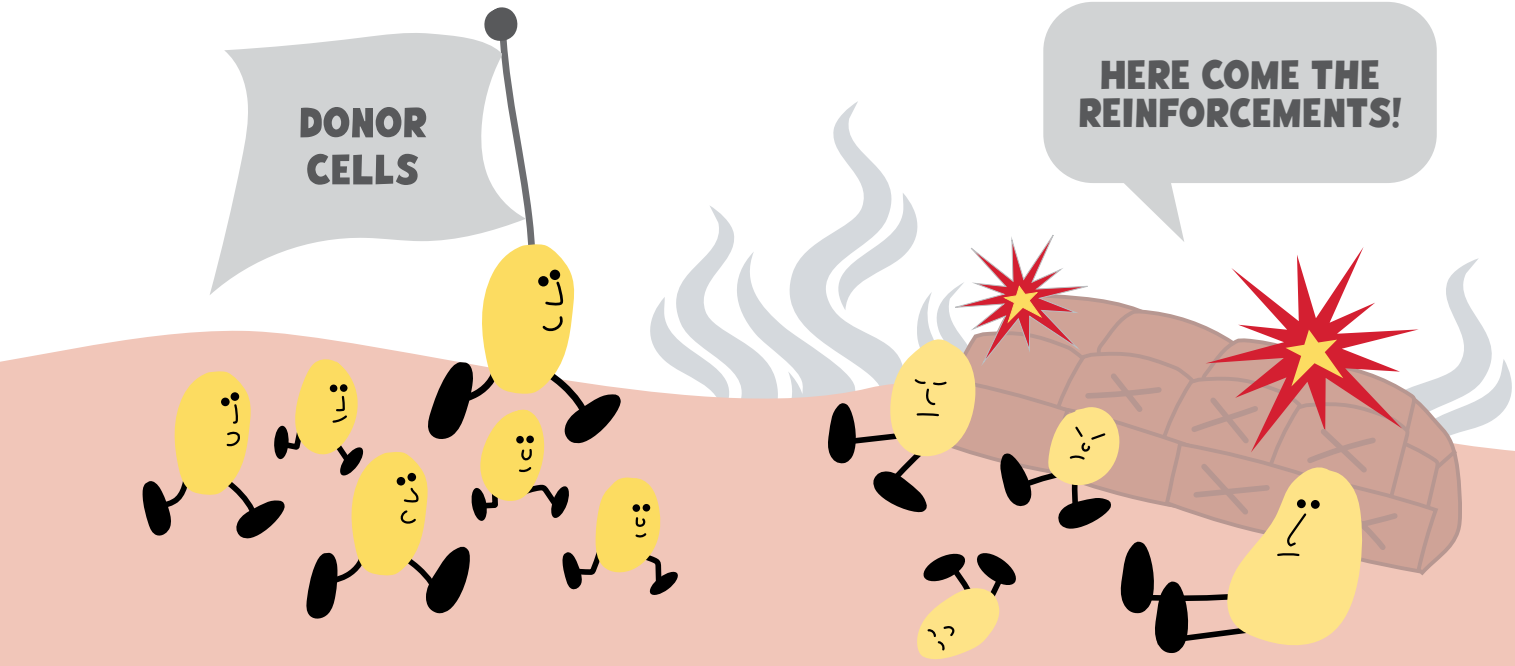
Chemotherapy

This uses strong medicines to kill cancer cells or slow their growth. For conditioning therapy, chemotherapy is given at high doses often into a vein (intravenously).

See page 35 for a list of chemotherapy medicines you may receive.

Total body irradiation (TBI)

TBI is a type of radiation therapy sometimes used with chemotherapy before a transplant. It works by killing cancer cells and suppressing your immune system so the donor's cells can engraft.



TBI is delivered using a machine called a linear accelerator. To protect organs, such as the lungs, from radiation, shields may be used during treatment. Some centres use volumetric modulated arc therapy (VMAT), which can shape the radiation more precisely and avoid unnecessary exposure to radiation.

During TBI, you may be asked to sit, stand or lie down. A brace helps you stay still so the radiation is delivered to the same place each time.

You'll be alone in the treatment room, but the radiation therapist will watch you on a monitor and talk to you through a speaker.

TBI is usually given twice daily for 3 days, but this may vary depending on your treatment protocol. Each session takes about 30–60 minutes. You may be given medicine to help you relax and to prevent and reduce nausea.

Common side effects of TBI include nausea and vomiting, dry mouth and mouth ulcers, skin redness, dry eyes, and low blood counts. Some people may also have lung damage.

How you may feel

Conditioning therapy is one of the most intense parts of the transplant process. It's natural to feel anxious, tired or uncertain about what's ahead. You may also feel frustrated by the change in your usual routines and independence, or worried about how you'll cope with side effects.

Many people say this stage feels like life is on hold. It can help to focus on what you can control, such as how you structure your day or small things that make you feel more like yourself.

You may find talking with your social worker, psychologist or another member of your transplant team about how you're feeling useful. They can connect you with support services or peer groups. See Chapter 4, *Emotional and practical concerns* for more information.

Common conditioning protocols in Australia

In Australia, most allogeneic stem cell transplants follow well-established protocols. The table opposite lists the medicines you may have and their side effects. Understanding how these medicines work and what to expect can help you feel more prepared.

Your conditioning protocol

You'll be given a copy of the treatment protocol your hospital will follow, a day-to-day schedule of your medicines, and a sheet to record your blood counts.

The type of conditioning treatment and the number of days it takes vary depending on your disease, the treatment protocol chosen, and the hospital's preferred approach.

To find out more about conditioning medicines used for an allogeneic stem cell transplant, visit eviq.org.au.

"It was hard to see very far into the future, so in hospital I focused on achieving small steps. Each meal break became a milestone, and when I heard the electric meal cart, I knew I was a step closer. Some days were really hard, but every day eventually ended, just like the ones before it." **David**

MEDICINE	HOW IT'S GIVEN	COMMON SIDE EFFECTS	LESS COMMON SIDE EFFECTS
cyclophosphamide	Through a drip (IV)	• Nausea and vomiting • Metallic taste • Low blood count • Hair loss • Infertility	• Bladder irritation (haemorrhagic cystitis) • Second cancers • Damage to the heart (cardiotoxicity) • Too much fluid in the body (SIADH – Syndrome of Inappropriate Anti-Diuretic Hormone)
busulfan	Through a drip (IV)	• Nausea and vomiting • Hair loss • Drop in blood count • Seizures • Infertility	• Lung damage (pulmonary fibrosis) • Skin darkening • Second cancers
melphalan	Through a drip (IV)	• Nausea and vomiting • Increased risk of infection • Infertility	• Second cancers
fludarabine	Through a drip (IV)	• Mild nausea • Low blood count (very low CD4 immune cells) • Increased risk of infection	• Confusion and drowsiness (rare at standard doses) • Second cancers
anti-thymocyte globulin (ATG)	Through a drip (IV)	• Fever • Chills • Low blood pressure • Increased risk of infection	• Serum sickness
treosulfan	Through a drip (IV)	• Nausea • Low blood count • Increased risk of infection	• Skin redness • Liver irritation • Fertility effects
thiotepa	Through a drip (IV)	• Skin redness or peeling • Nausea • Low blood count • Increased risk of infection	• Liver irritation • Bladder irritation • Fertility effects

Key points

- Conditioning therapy is given in the week before the transplant.
- It usually involves high-dose chemotherapy, which uses strong medicines to kill cancer cells or stop them from growing. Sometimes, you may also have total body irradiation (TBI), a type of radiation that targets your whole body.
- The goals are to kill cancer cells and to suppress your immune system so the donor's cells can grow (engraft) in your body.
- There are 2 types of conditioning therapy: myeloablative conditioning and reduced intensity conditioning (RIC).
- Myeloablative conditioning uses high doses of chemotherapy, and sometimes TBI, to kill cancer cells and bone marrow.
- RIC uses lower doses of chemotherapy that weaken your immune system, but it doesn't completely destroy your bone marrow. It relies more on the donor's immune cells to attack the cancer cells (the graft-versus-tumour effect).

CHAPTER 8

The transplant

The transplant is when the stem cells are infused into your bloodstream, usually a day or two after conditioning therapy finishes. It takes place in your hospital room through your central line (see page 29), much like a blood transfusion. The infusion takes 30–60 minutes. During this time, you'll be monitored for fever, chills, hives and chest pain.

What to expect during the transplant

The transplant is tracked using a numbered day system. The day your stem cells are infused is called Day 0.

The days before the transplant are counted as 'minus days'. For example, Day -5 means you are 5 days away from your transplant.

The days after the transplant are counted as 'plus days'. For example, the day after your transplant is day +1, two days is day +2, and so on.

How you may feel

Having the transplant is a major milestone. It's the start of a period of waiting and recovery. Common feelings include relief, hope, gratitude and excitement, but also anxiety, sadness or fear of the unknown.

Although the infusion itself is quick, it can help to mark the day with a special moment, e.g. taking a photo, having someone with you to celebrate. It's a chance to acknowledge the start of your recovery and the hope ahead.

The transplant team understands this is an important day, and that you may feel many emotions. They are there to support and connect you with counselling, a social worker or peer support if you want it.

"I felt hopeful, but also worried, during the transplant." **Lisa**

"The medical team referred to Day 0 from the workup period and beyond. All workup preparation was framed in relation to Day 0: the days leading up to it, the days after while I was in hospital and then receiving treatment in the months that followed. My family still refers to it, and I acknowledge 'Day 0' each year – now approaching Day 0 +14 years."

Eleanor

Key points

- The transplant is when healthy stem cells are infused into your bloodstream, usually 1–2 days after finishing conditioning therapy.
- Stem cells are given through your central line in your hospital room, similar to a blood transfusion. The infusion usually takes 30–60 minutes.
- During the infusion, you will be monitored for fever, chills, hives and chest pain.
- The transplant is tracked using a numbered day system: Day 0 is the day of transplant, minus days are the days before transplant and plus days are the days after transplant.
- Consider ways to make the day you have the infusion a special moment.

Typical allogeneic stem cell transplant timeline

This timeline is a general guide. Your transplant team will talk to you about what to expect for your situation.

TIMEFRAME	MILESTONE	KEY ACTION
Day -7 to -1	Conditioning	• Admission to hospital • Receive high-dose chemotherapy (and sometimes radiation) to destroy diseased bone marrow and prepare for new stem cells
Day 0	Transplant	• Healthy stem cells are infused into your bloodstream (like a blood transfusion)
Day 0 to Day 14	Engraftment	• Infused stem cells travel to the bone marrow, begin to grow and make new blood cells • Monitor for side effects and complications (infection risk highest)
Day 14 to 21	Discharge home	• If recovery is stable, you may leave hospital but still need close follow-up for side effects including GVHD
Day +30	Early recovery phase	• Monitor blood counts, manage side effects • Regular clinic visits continue
Day +60	Immunosuppressant taper begins	• Monitor for GVHD flare • Tests are done to check the success of the transplant and look for signs of disease
Day 100	First 100 days review	• Transplant team assess transplant success, complications and long-term care plan
6 months	Revaccinations start	• Begin routine re-immunisation schedule • Coordinate with GP or transplant clinic • Gradually increase daily activities based on your energy levels
6 to 12 months	Ongoing recovery	• Monitor immune recovery • Manage GVHD or late side effects • Get support for returning to work, study or usual life activities
After 12 months	Long-term survivorship	• Continue follow-up with transplant team

CHAPTER 9

Engraftment

After your allogeneic transplant, the donated cells start making new, healthy blood cells. This process is called engraftment. It's an important milestone and means your body is beginning to rebuild its immune system. Engraftment usually happens in the first 2–4 weeks after transplant, but the timing can vary from person to person.

What to expect during engraftment

Daily monitoring – You'll have blood tests every day to check white blood cells, platelets and red blood cells. The transplant team will also ask how you're eating and drinking. The blood tests help them track your progress and manage any complications.

Chimerism testing – This shows how much of your immune system is now made of donor cells. It helps your team see how well the transplant is working.

Signs of engraftment – As a general guide, engraftment happens when:

- absolute neutrophil count is above 0.5 × 10^9/L for 3 days
- platelet count is above 20 × 10^9/L for 7 days without transfusion.

During this time, your body rebuilds its ability to make healthy blood cells.

Isolation – To protect you from infection while your immune system is very weak, you'll be cared for in a single hospital room, where possible, with limited visitors. This can feel lonely, but it helps keep you safe. See page 40 for more.

Medicines to support recovery – You'll be given medicines to prevent infections and manage complications such as graft-versus-host disease (GVHD). See pages 48–52 for more information.

Side effects – Feeling unwell during engraftment is common. You may have mouth sores, fatigue and changes in appetite and mood. See the *Infection*, *GVHD* and *Other complications* chapters for tips.

Nutrition and exercise – Eating well and doing light exercise can help your recovery. Some foods may increase infection risk (see page 62). Ask the physiotherapist what exercise is safe for you (see pages 64–66).

Length of hospital stay – Most people stay in hospital for 4–5 weeks, including the conditioning week. You may be able to go home once your bone marrow is making enough healthy blood cells and there are no major complications.

Your DNA after a transplant

After an allogeneic transplant, your blood and immune cells will gradually be replaced by cells containing your donor's DNA. This means you will have two sets of DNA in your body — your own in most of your cells, and your donor's in your blood and immune cells. This is called chimerism and is a normal part of the transplant process.

Your transplant team will monitor your chimerism with regular blood tests. The goal is usually 100% donor chimerism, meaning your immune system is fully made up of donor cells, though this can take months to achieve.

Because your new immune system works to a different set of instructions, you may notice some unexpected changes, such as new allergies or losing allergies you had before. Your donor's DNA in your blood cells is not passed on to any children you may have in the future.

How you may feel

Waiting for your blood counts to recover can be physically and emotionally challenging. You may feel anxious, especially when you're alone in a hospital room and visitors are limited for safety reasons (see page 40). Your transplant team, social worker and psychologist can support you during this time.

Living with uncertainty

Uncertainty is a normal part of the transplant process. Recovery is often slow – some days you'll feel better, other days you may feel the same or worse. Even if your team says you're recovering well, it may not feel that way when you're exhausted after a shower, find sitting up in bed hard or talking on the phone may take more energy than usual.

Isolation

Infection precautions to protect your immune system can mean long hospital stays and, after going home, limiting how often you go out.

Sadness

It's common to feel anxious or sad during the transplant process. Some medicines used to manage side effects can also affect your mood. You may also grieve changes to your daily life, appearance, sex life or fertility.

> "I was surprised how quickly the actual transplant took place, and then the slow process of engraftment began. It felt like groundhog day – every day in the hospital was just a repeat of the day before." **JulieAnne**

If sadness lasts for more than 2 weeks, makes it hard to get out of bed or takes away your motivation to do things you usually enjoy, it could be a sign of depression. Talk to your transplant team or social worker for support. They may suggest counselling or medicine. You can call Beyond Blue on 1300 22 4636 or at beyondblue.org.au for confidential support and information. For urgent help, call Lifeline on 13 11 14 or visit lifeline.org.au.

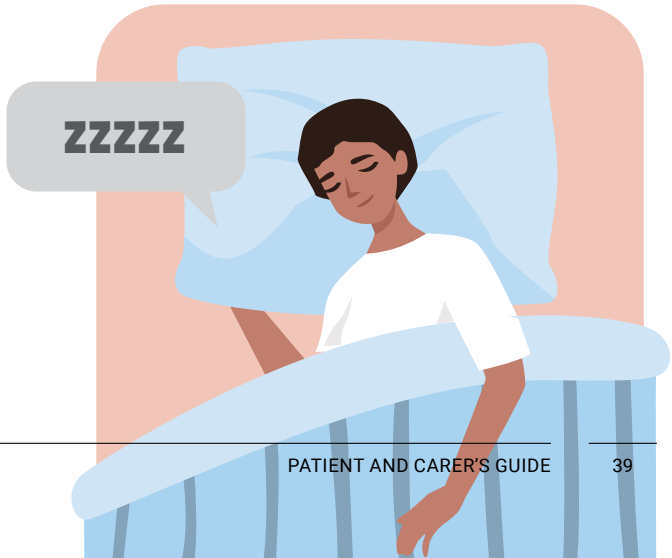
Sleep issues

Trouble sleeping is common after a transplant. Medicines such as steroids can also affect sleep. Not getting enough sleep can leave you tired, irritable and make it harder to cope.

Tips for better sleep

- Go to bed and get up at the same time every day.
- Avoid screens and caffeine before bed.
- Create a relaxing bedtime routine.
- Ask your transplant team if sleep medicines may help.

For more information, download the *Can-Sleep: making night-time sleep problems go away* booklet from petermac.org.



Tips for coping with your hospital stay

Creating privacy

- Hospital days can feel slow and lonely, especially at night. Frequent interruptions and little privacy can be tiring. On difficult days, having quiet time and personal space may be especially important. Let the nurse know if you'd like some quiet or uninterrupted time each day.
- Put a 'do not disturb' sign on your door during that time.
- Set your phone to silent or 'do not disturb' or ask to have your calls diverted to the front desk so the ward clerk can take messages.
- Let family and friends know when you need time alone, with no visitors or phone calls.

Managing your space

- Make your room feel more familiar and comforting. Bring photos, books or a favourite blanket. These small touches can make the space feel more like home and help ease anxiety, especially at night.
- Ask the Nursing Unit Manager if you can use a laptop to access the internet.
- Use social media, messaging apps, emails or online games to stay in touch with family and friends when it feels right for you.

Passing the time

- Plan a daily schedule with regular activities (e.g. reading, puzzles, journaling or watching a favourite show) to give structure to your day, while staying flexible around hospital routines.
- Spread out visitors to break up the day and give yourself something to look forward to.
- Ask family, friends or staff for ideas – they may have suggestions you haven't thought of.

"I found it a stark contrast going from being on a ward with other patients and speaking to them, seeing their visitors, and walking around the ward each evening before bed, to not being able to leave my room. I heard stories from my visitors about other people on the ward who had spoken to their visitors in the tearoom, but you never actually see anyone. You have no contact with anyone going through the same things you are at the same time and that can be hard at times." **Eleanor**

Side effects after engraftment

It's common for side effects that started during conditioning therapy to continue into the engraftment phase. Your transplant team will help with pain, nutrition and daily care.

After conditioning therapy finishes, your white blood cell levels, including neutrophils, drop very low. This increases your risk of infection (see Chapter 10, *Infection* for more information).

Nausea and vomiting

Feeling sick (nausea) is common during conditioning therapy, when strong chemotherapy and radiation therapy are given. Antibiotics, damage to the lining of the intestines, or graft-versus-host disease (GVHD) can also cause nausea and vomiting.

Chemotherapy-related nausea is usually well controlled with medicines called anti-emetics. These may be given as injections or tablets. If you feel sick, tell the nurses immediately, as nausea is easier to treat before vomiting starts.

Mouth and throat problems

Mucositis is inflammation of the lining of your mouth and digestive tract. It can be caused by chemotherapy, total body irradiation (TBI, see page 33), low white cell counts or infections. Mucositis can lead to mouth ulcers, which cause pain and discomfort when swallowing, eating and drinking, along with dryness and changes in taste.

Tell your transplant team if your mouth feels sore, you have painful ulcers, or your saliva becomes thick and difficult to swallow. They can give you medicines to reduce pain and discomfort.

Ways to manage mucositis

- Use mouthwash regularly to help ease mouth pain.
- Ask your treatment team which mouthwash to use and how often.
- Ask a nurse about using a suction device to gently remove saliva that's too thick to swallow.
- Suck on ice chips during the infusion to reduce the chance of severe mouth sores.

Diarrhoea

Some types of conditioning therapy can cause diarrhoea. It can also happen if GVHD (see page 49) affects the gut.

Diarrhoea can be uncomfortable and cause stomach pains and cramps. If you develop diarrhoea, the transplant team will track how often you're going to the toilet each day. They'll also ask you about how you're eating and drinking.

Key points

- New blood cells start to grow 2–4 weeks after transplant. This is called engraftment. Daily blood tests check your white blood cells, red blood cells and platelets.
- You'll be cared for in a single room, where possible, to reduce risk of infection. This can feel lonely, but it is an important part of your recovery.
- Most people stay in hospital for 4–5 weeks, including the day of conditioning therapy. You can go home once your blood counts have improved and are stable, and there are no major complications.
- Some side effects begin during conditioning therapy, and continue into the engraftment phase.
- Nausea and vomiting are usually well-controlled with anti-nausea (anti-emetic) medicines, but it may take time to find the combination that works for you. Tell the nurses as soon as you feel sick, because it's easier to treat before vomiting starts.
- Mouth and throat problems (mucositis) can cause ulcers, pain, dryness and changes in taste. Use mouthwashes, ice chips and suction devices to relieve discomfort.
- Diarrhoea can occur from conditioning therapy and GVHD of the gut. Let your nurses know how severe it is. Once the diarrhoea improves, your medicine may need to be reduced to avoid constipation.
- On hard days, remind yourself why you chose to have the transplant. This can help you stay focused on your recovery.
- Notice and celebrate progress in your recovery, whether it's big or small. From an improvement in mouth ulcers to reaching engraftment day, recognising progress can help you get through the day.
- Ask your nurse about setting aside quiet time each day. A sign on your door can signal when you don't want to be disturbed.

CHAPTER 10

Managing infection

An allogeneic stem cell transplant affects how your immune system works. Infections are one of the most common complications after a transplant. They may be bacterial, fungal or viral. Not everyone will get an infection, and the type and severity will depend on your age, health, donor match and treatments you receive.

How a stem cell transplant affects your immune system

Conditioning therapy destroys cancerous cells, but it also damages healthy, fast-growing cells in the mouth, gut, bone marrow and hair. It lowers the number of white blood cells, especially neutrophils, which help your body fight infection. When neutrophils are very low, called neutropenia, it's easier to get infections.

Normally, your skin and the lining of your mouth, nose and gut protect you from harmful germs. When these areas are damaged, germs can enter the body more easily.

After a stem cell transplant, your immune system is weaker, which is called being immunocompromised. This means your body cannot fight infections as well, or make antibodies. Some of the antibodies you had before treatment may also be destroyed or reduced during the transplant. This puts you at risk of infections such as cytomegalovirus (CMV), herpes viruses such as cold sores or chicken pox, even if you've had them before. (See Chapter 8 for information on white blood cells and the immune system.)

Where infections come from

Infection after a transplant can come from:

- other people, e.g. colds, flu, COVID-19
- viruses already in your body that 'wake-up' (reactivate)
- bacteria or fungi that normally lives on your skin or in your gut
- fungal spores in the environment, such as mould.

How long the risk of infection lasts

The risk of infection is highest in the first 100 days after transplant, but it can continue for many months. How long the risk last depends on how quickly your immune system recovers and if you have graft-versus-host disease (GVHD) or are taking immunosuppressive medicines.

First 2–4 weeks after transplant – This is the most critical period. Your new bone marrow is starting to make blood cells, but as your immune system isn't working properly yet, your risk of infection is high.

Up to 6–12 months – Your immune system can remain low during this period, and you'll need to keep taking steps to prevent infection.

Longer if you develop GVHD – GVHD and medicines used to treat it can slow immune recovery, so your risk of infection may last beyond the first year.

How to prevent infections

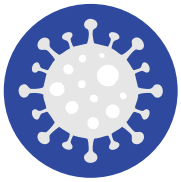
While your immune system recovers, you'll need to take extra care to avoid infections.

Practice good hygiene

- Ask visitors, including staff, to wear a mask and wash their hands thoroughly with antiseptic soap before touching you. If you're not sure if they have washed, ask.
- Wash or shower every day, including your hair or scalp, using antibacterial skin wash or liquid soap. Do not use cake soap.
- Use a clean or disposable washcloth every day.
- Check your body daily for unusual changes and tell staff if something looks or feels different.

Be gentle with skin and gums

- Use an electric shaver to avoid cuts and clean it well after each use. If using a razor, change the blade after each shave.
- Rinse with mouthwash at least 4 times a day. Regular mouth care doesn't always prevent ulcers, but it helps reduce the risk of infection. It doesn't matter which mouthwash you use, as long as you use it regularly.
- Brush your teeth with a soft toothbrush and avoid pressing hard on your gums so you don't irritate or damage them.
- Try to avoid becoming constipated. If your bowel movements are hard, dry or difficult to pass, let the transplant team know.
- Report any burning, stinging or blood in the urine when passing urine.



Limit visitors and exposure

- Limit visitors to 2 people at a time to reduce the risk of infection and save your energy. Visitor rules can vary between hospitals, so check with your transplant team about what applies to you.
- Ask family and friends not to visit if they have a cold, flu, diarrhoea or any other infectious disease. If they've recently had a vaccination, ask them to check with staff before visiting.
- Do not have fresh flowers and plants in your hospital room as they can carry bacteria or fungi.

Choose food carefully

- Avoid foods that may be a potential source of infection.
- Ask the dietitian about what to eat and what to avoid until your immune system recovers. (See page 62 for more information about food safety).

Types of infections after a transplant

TYPE	WHEN IT HAPPENS	COMMON SIGNS	PREVENTION	TREATMENT
Bacterial Tiny germs that grow quickly and release toxins that damage your body. **Common examples** sepsis, pneumonia	Early stages of stem cell transplant when white cell count is low.	• Fever • Fast heartbeat • Low blood pressure • Mucus or phlegm (spit) that looks green or discoloured • Pale skin that feels sweaty or clammy	• Keep central lines clean • Tell your team if you feel unwell • Take antibiotics • Have regular temperature checks	• Antibiotics • Close monitoring in hospital if serious
Fungal Yeast or mould that grows when good bacteria are wiped out by antibiotics. **Common examples** candida, aspergillus	Common in the first 3 months, especially if you have GVHD.	• Mouth pain or white patches (thrush) • Gut: stomach pain or cramps • Lungs: cough, shortness of breath	• Take medicines if prescribed • Avoid mouldy environments (e.g. compost heaps, decaying leaves, air conditioning) • Have filtered air in hospital room • Manage GVHD and use antibiotics	• Antifungal medicines (e.g. fluconazole) • IV treatment for serious infections
Viral Tiny parasites that live inside your cells; can come back later. **Common examples** cytomegalovirus (CMV), herpes simplex virus (HSV), colds and influenza, varicella zoster virus (VZV), BK virus	Most common in the first year; can occur up to 2 years.	• Cold sores • Shingles • Fever • Tiredness	• Have regular blood tests • Avoid people with infections • Take medicines if prescribed	• Antiviral medicines (e.g. acyclovir, ganciclovir) • Regular blood tests to check if viruses come back

Types of serious bacterial infections

Some bacterial infections can quickly become serious and need urgent treatment.

Sepsis – A bacterial infection that has spread into the blood. You'll need treatment straight away and close monitoring.

Pneumonia – A serious lung infection that can make it hard to breathe. You may need support from a breathing machine, either on the ward or in intensive care. Sometimes support is started early to prevent breathing from becoming too difficult or tiring.

Septic shock – A severe form of sepsis where blood pressure drops very low and organs don't get enough oxygen. You'll be given fluids and medicines to raise blood pressure, and may need intensive care. The team will act quickly to keep you safe. It's important to discuss your wishes and any concerns with your transplant team in advance.

Viral infections

Viruses are tiny germs that need human cells to grow. They take over the cell and make it produce more viruses, which can spread to other cells.

After conditioning therapy, your immune system is weaker, so you're more at risk of viral infections and they can be more difficult to treat because they often come back.

You may get a viral infection from a new virus or from a virus already in your body becoming active again (reactivated). Viral infections are most common in the first year after a stem cell transplant but may occur up to 2 years later.

Common viral infections are listed below. See page 47 for less common types.

Cytomegalovirus (CMV)

CMV is a common virus that usually causes mild, flu-like symptoms in healthy people. After a transplant, CMV can reactive if your immune system is weak.

When it happens: Usually in the second or third month after the transplant. Risk is higher if you and the donor have different CMV status, or if you're taking immunosuppressing medicines for GVHD.

Prevention: Before the transplant, you and your donor will have a blood test to check if either of you have been exposed to CMV.

- CMV-negative: extra care is taken to avoid exposure to CMV such as selecting a CMV-negative donor if possible, using only CMV-negative blood products, and filtering blood during transfusions to stop blood-borne transmission.
- CMV-positive: you may be given antiviral medicines to prevent infection and have regular blood tests to check for CMV.

Treatment: Your transplant team will give you antiviral medicines if CMV reactivates. Finding and treating CMV early usually prevents serious complications.

Herpes simplex virus (HSV)

There are two types of herpes simplex virus:

- HSV 1: causes cold sores around the mouth. Most people (about 70%) are exposed to the virus during childhood.
- HSV 2: causes blisters in the genital area.

When it happens: First month after transplant, usually from a virus already in your body.

Prevention: If you've had herpes before (or blood tests show you have), you'll be given antiviral medicines (e.g. valaciclovir) to prevent it from coming back. If you can't swallow tablets, you'll have the medicine through a drip.

Treatment: Higher dose of acyclovir.

Varicella zoster virus (VZV)

VZV causes shingles, the same virus that causes chickenpox. Shingles occur only in people who have had chickenpox.

When it happens: Usually after day +100 and within the first year; especially if you have GVHD.

Symptoms: A blister-like rash on one side of the body along a nerve path. If it is near the eye, the rash can appear on the forehead and eyelids, and may damage the eye if not treated quickly.

Prevention: Avoid contact with anyone who has chickenpox or shingles. Antiviral medicines (e.g. valaciclovir) may be given, and starting from about 6 months after the transplant, you'll have a non-live shingles vaccine.

Treatment: Antiviral medicines for shingles.

BK virus

BK virus is common and usually harmless, but can reactivate after a transplant when the immune system is suppressed.

When it happens: Most commonly in the first few months after transplant.

Symptoms: Haemorrhagic cystitis – pain or burning when urinating and blood in the urine. In severe cases it can affect the kidneys. See page 58.

Prevention: No standard preventive medicine, but your team will monitor for early signs.

Treatment: No specific antiviral is approved for BK virus. Treatment focuses on managing symptoms, staying well hydrated, and reducing immunosuppression where possible.

Medicines used to treat infections

There are many medicines used to prevent and treat infections. This table gives examples of common medicines, how they are given and possible side effects. The medicines you are offered may change as new treatments become available.

ANTIBIOTICS	HOW GIVEN	COMMON SIDE EFFECTS	LESS COMMON SIDE EFFECTS
cephalosporins	IV	• Rash • Allergy • Bowel changes (nausea, diarrhoea)	• Kidney problems
penicillin	IV	• Rash • Pain at infusion site	• Anaphylaxis • Nausea and vomiting • Kidney or liver problems
aminoglycoside	IV	• Kidney damage • Ringing in ears or hearing loss	• Rash • Allergy • Diarrhoea
vancomycin	IV	• Kidney damage • Ringing in the ears	• Redness of upper body (vancomycin flushing reaction), usually if infused too quickly • Low blood pressure • Nausea, vomiting and diarrhoea
ANTIFUNGALS	**HOW GIVEN**	**COMMON SIDE EFFECTS**	**LESS COMMON SIDE EFFECTS**
fluconazole	IV or by mouth	• Headache • Stomach pain • Diarrhoea • Nausea and vomiting	• Rash • Liver problems • Changes to electrolyte levels • Low blood pressure
ANTIVIRALS	**HOW GIVEN**	**COMMON SIDE EFFECTS**	**LESS COMMON SIDE EFFECTS**
Brand name: Ganciclovir	IV (timing depends on dose)	• Diarrhoea • Low platelets • Anaemia	• Rash • Infertility • Fits, decreased level of consciousness
Brand name: Acyclovir	By mouth or IV	• Rash • Sensitive to sun • Kidney issues • Nausea and vomiting	• Confusion • Hallucinations • Changes in how the liver works • Allergy
ANTI-PROTOZOAL	**HOW GIVEN**	**COMMON SIDE EFFECTS**	**LESS COMMON SIDE EFFECTS**
Brand name: Cotrimoxazole	By mouth or IV	• Nausea and vomiting • Lack of appetite • Rash • Increased risk of sunburn	• Kidney problems • Dizziness • Headache • Ringing in the ears • Low blood sugar levels

Other viruses

While these viruses are less common, they can still cause serious illness in some people.

Adenovirus – Can cause pneumonia and gastrointestinal infections.

Respiratory syncytial virus (RSV) – Can cause respiratory illnesses, including pneumonia. You may be offered a vaccine. The cost of this vaccine is not covered by Medicare, so you will need to pay for it.

Epstein-Barr virus (EBV) – Rarely, can cause a condition similar to lymphoma.

Human papillomavirus (HPV) – Monitored as part of your post-transplant care.

COVID-19 and influenza

COVID-19 is a risk for people who have a weak immune system. It is treated with antivirals. You'll have vaccines for flu and COVID-19 after the transplant.

Protozoa infections

Protozoa are single-cell parasites that can cause serious infections, especially for people with weakened immune system and low T-cell counts.

Pneumocystis jirovecii (formerly known as Pneumocystis carinii pneumonia or PCP) can cause a serious lung infection when the immune system is suppressed.

Prevention: You may take antibiotics for at least 6 months after the transplant, and sometimes longer.

Toxoplasmosis

This infection is caused by the protozoan Toxoplasma gondii, which is commonly found in the faeces of cats.

Prevention: Limit contact with pets, especially cats. Always wash your hands thoroughly after handling animals. Avoid emptying litter trays.

Treatment: If you're at higher risk, you may be given medicine to prevent infection.

Key points

- Conditioning therapy lowers white blood cells and can damage skin and mucous membranes, increasing infection risk.
- Your body is less able to fight infections and past infections (e.g. measles, CMV, chickenpox) may reactivate.
- Infection risk is highest in the first 2–4 weeks, remains elevated for 6–12 months, and may stay higher if you have GVHD or take immunosuppressive medicines.
- To prevent infections, practice good hygiene, gentle skin and mouth care, limit visitors, and choose food carefully.
- Bacterial infections can become serious quickly. Watch for fever, fast heartbeat, low blood pressure or changes in skin or mouth.
- Fungal infections are common in the first 3 months, especially with GVHD. Signs include mouth pain, gut pain, cough or shortness of breath.
- Some viral infections such as CMV, HSV and VZV can reactivate after transplant, often in the first year. Early treatment with antivirals is important.
- Some infections are rare but serious, such as Pneumocystis jirovecii and toxoplasmosis. Taking preventive medicines reduces the risk.
- Antibiotics, antifungals, antivirals and anti-protozoal medicines are tailored to your needs and monitored for side effects.

CHAPTER 11

Graft-versus-host disease (GVHD)

GVHD is a common complication after an allogeneic stem cell transplant. It happens when the donor's immune cells (the graft) see your body (the host) as foreign and attack your tissues and organs. Improvements in treatment to prevent GVHD means it's less common than it used to be, but it can be a serious complication and requires close monitoring.

Who develops GVHD

The transplant team will assess your risk of developing GVHD. One of the factors is how closely matched you are with your donor. About half (50%) of people who have a transplant from a matched related donor develop some degree of GVHD.

Other factors that can increase your risk, include:

- having a donor who is not related to you or mismatched (newer medicines are making half-matched or mismatched donors safer)
- you or your donor are over 30 years old
- having a female donor who has been pregnant.

Having more than one risk factor increases the risk of developing GVHD.

Types of GVHD

There are 2 types of GVHD:

- acute – usually develops within the 100 days of transplant
- chronic – develops after 100 days; may last for months or years.

You may not develop GVHD at all, or you may develop one or both types.

Acute GVHD

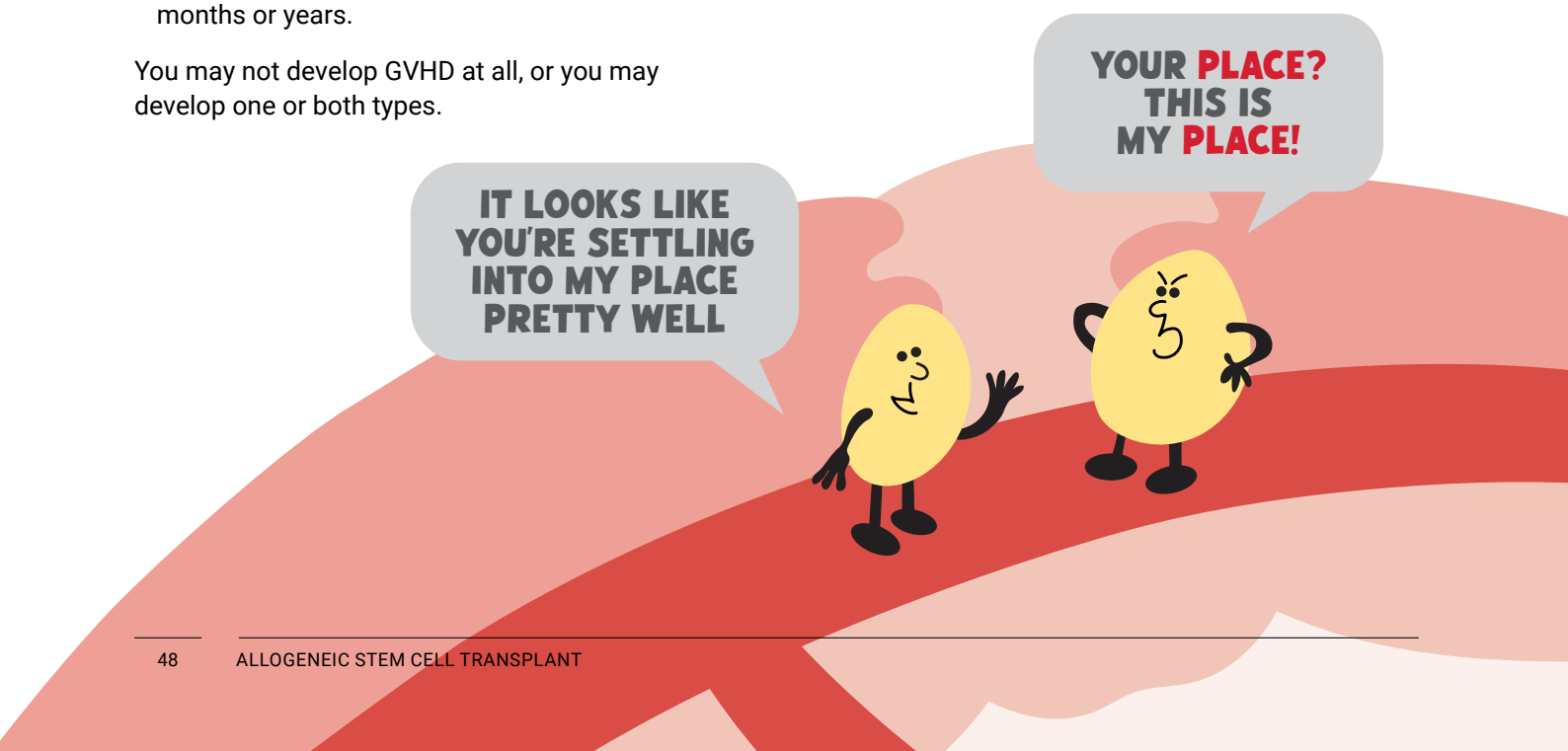
Acute GVHD mainly affects the skin, liver and gastrointestinal tract (gut).

Your transplant team will ask about symptoms and how long it's been since your transplant to help diagnose GVHD. They'll also check for infections or other possible causes. To confirm the diagnosis, they may take a small tissue sample (biopsy) from your skin or gut.

Grades of acute GVHD

Acute GVHD is classified into 4 grades, depending on how much of the body is affected:

- Grade 1 (mild) – rash on less than 25% of the body
- Grade 2 (moderate) – rash on 25–50% of the body, mild liver or gut problems
- Grade 3 (severe) – red skin with moderate liver or gut problems
- Grade 4 (life-threatening) – peeling skin, and severe liver or gut problems.



Symptoms

Acute GVHD can affect different parts of the body. Symptoms vary from person to person and may include:

Skin – rash on the palms of the hands or soles of the feet; burning and redness (like sunburn) that may spread to the whole body; blistering and peeling.

Gut (gastrointestinal tract) – nausea, vomiting, stomach cramps, loss of appetite, or watery diarrhoea, which may become bloody.

Liver – yellowing of the eyes and skin (jaundice); tummy pain; swelling of the liver; changes in liver blood tests results.

Prevention

You'll be given several medicines at the time of the transplant to help prevent acute GVHD (see page 51). These medicines reduce the ability of donor T cells to attack your tissues and organs. Your team will adjust the medicines, depending on the grade and how long acute GVHD lasts.

Treatment

Treatment depends on symptoms.

Mild to moderate symptoms – Skin symptoms may be treated with steroid creams (e.g. cortisone). Mouth symptoms may be treated with a steroid mouthwash.

Moderate to severe symptoms – High-dose intravenous or oral steroids (e.g. prednisone) are usually given daily. If symptoms don't improve, you may be given other medicines (e.g. anti-thymocyte globulin).

Gut symptoms – Pain, cramps, diarrhoea, nausea and vomiting are managed with medicines to relieve discomfort. For more severe symptoms, you may need to stop eating or drinking for a while and have nutrition through a drip called total parenteral nutrition (TPN) – see page 61.

Chronic GVHD

Chronic GVHD starts more than 100 days after BMT. It happens when donor immune cells attack your body's tissues. It is more common in older people or when the donor is unrelated or not a perfect match. About three in four people with chronic GVHD have previously had acute GVHD.

Types of chronic GVHD include:

- Progressive – continues directly from acute GVHD
- Quiescent – comes back after a period of improvement
- De novo – develops even if you haven't had acute GVHD before.

Grades of chronic GVHD

Chronic GVHD can affect many parts of the body, including the skin, eyes, mouth, liver, lungs, joints and genitals. Doctors describe chronic GVHD as mild, moderate or severe based on which organs are affected and how severely.

Symptoms

If you notice new or changing symptoms, such as a rash, dry eyes or mouth, yellow skin or shortness of breath, contact your transplant team immediately. Do not wait for your next appointment. GVHD symptoms can get worse quickly, and early treatment can make a big difference.

Treatment

The main treatment for chronic GVHD is steroids (such as prednisone), often combined with immunosuppressive drugs (such as cyclosporin). Other options include:

- Immunosuppressive medicines – tacrolimus, mycophenolate, sirolimus
- Ruxolitinib – reduces inflammation and may allow prednisolone dose to be lowered
- Extracorporeal photopheresis (ECP) – a specialised treatment where your white blood cells are treated with ultraviolet (UV) light. Available at some hospitals by referral only
- PUVA therapy – a type of UV light treatment used for skin and mouth symptoms.

Common symptoms of chronic GVHD

BODY AREA	SYMPTOMS	HOW TO MANAGE
Skin	• Dry, itchy red rash • Changes in skin colour • Tight or hardened skin	• Use gentle, perfume-free moisturiser daily • Wear sunscreen • May be given steroid cream, tablets or immunosuppressants
Liver	• Yellowing of eyes or skin (jaundice) • Abnormal liver test results	• Need regular blood tests • Take prescribed steroids or immunosuppressants
Mouth	• Dry mouth • Burning taste with toothpaste or acidic foods	• Take frequent sips of water • Add gravies and sauces to food • Use artificial saliva products
Eyes	• Dryness or stinging eyes	• Use eye drops regularly • Wear sunglasses • Avoid wind and dry air
Vagina	• Vaginal dryness or discomfort	• Use lubricants • Ask for a referral to a gynaecologist
Immune system	• Frequent infections	• Take prescribed antibiotics • Keep vaccinations up to date

Less common symptoms of chronic GVHD

BODY AREA	SYMPTOMS	HOW TO MANAGE
Hair	• Hair loss • Early greying	• Use gentle hair care products
Digestive tract	• Difficulty swallowing • Diarrhoea • Gut problems such as cramps, bloating or poor nutrient absorption	• See a dietitian • Ask about nutritional support or TPN, if needed • See chapter 13, *Nutrition and transplant*
Joints	• Tight tendons • Stiffness	• Do gentle exercises • Ask for a referral to see a physiotherapist
Lungs	• Wheezing • Bronchitis • Pneumonia	• Have regular lung function tests • See a lung specialist • Treat infections promptly
Penis	• Pain, sensitivity or scarring	• Ask for a referral to a urologist

Medicines used to prevent and treat GVHD

You'll be given medicines to lower the chance of GVHD, and to treat it if it develops. These medicines work by reducing how strongly the donor's immune cells react to your tissues.

Preventing infections

Because GVHD medicines weaken your immune system, you may also be given antibiotics and antiviral medicines to prevent infections.

Vaccinations

Talk to your transplant team about when to start vaccinations after your transplant. Do not have any vaccines without checking first. Live viruses, such as German measles and polio, aren't given until at least 2 years after a transplant, and sometimes longer if you're still taking immunosuppressive medicines or have active GVHD.

Graft-versus-tumour effect

Sometimes GVHD can be a good sign. Mild GVHD may mean the donor's white blood cells are attacking any remaining cancer cells. This is called graft-versus-tumour effect.

This effect is strongest in some types of leukaemia and lymphoma. If cancer returns after a BMT, your team may infuse a small amount of donor cells, called donor lymphocyte infusion (DLI), to help bring the cancer back into remission.

Your transplant team can explain what GVHD means for you and help you understand the potential benefits and risks.

Medicines to prevent GVHD

MEDICINE	HOW IT WORKS	HOW AND WHEN GIVEN	SIDE EFFECTS
cyclosporin (CSA)	Stops donor T cells from attacking the body	• IV drip at first, then capsules • Starts day before transplant • If no GVHD, dose is slowly reduced and stopped about 6 months after a transplant – for some people this may be earlier or later	• Kidney problems • Tremors • High blood pressure • Nausea • Diarrhoea • Swollen gums • Extra hair growth (goes away when medicine is stopped) • Swelling of eyelids, hands, feet • Higher risk of infection
tacrolimus	Stops donor T cells from attacking the body	• IV drip at first, then capsules • Starts day before transplant	• Tremors • Headache • Diarrhoea • Nausea • Kidney problems • Blood pressure • Risk of infection
methotrexate (MTX)	Weakens donor T cells so they don't attack the body	• Injection into a vein • Days +1, +3, +6, +11	• Mouth and throat ulcers • Skin more sensitive to light • Liver problems
mycophenolate mofetil (MMF)	Reduces new immune cells development	• Tablets, capsules or liquid taken by mouth, sometimes IV • Used for acute and chronic GVHD	• Nausea and vomiting • Diarrhoea • Increased risk of infection • Lower blood counts

Medicines for after transplant

MEDICINE	HOW IT WORKS	HOW AND WHEN GIVEN	SIDE EFFECTS
cyclophosphamide	Kills donor T cells and suppresses immune response	• IV drip • Given a few days after transplant	• Nausea • Hair loss • Low blood count • Bladder irritation

Medicines to treat GVHD

MEDICINE	HOW IT WORKS	HOW AND WHEN GIVEN	SIDE EFFECTS
methylprednisolone (steroid)	Suppresses immune response of donor cells attacking your body	• IV drip or tablets • Treatment for acute and chronic GVHD	• Potential high blood sugar levels • Trouble sleeping • Feeling hungrier
ruxolitinib	Reduces immune signals that cause donor cells to attack the body	• Tablets • Used in acute and chronic GVHD	• Low blood counts • Increased infection risk

Key points

- GVHD happens when donor immune cells attack parts of your body after an allogeneic transplant.
- Risk is higher with unrelated or mismatched donors, older age, or female donors who have been pregnant.
- Mild GVHD can help prevent cancer returning, as donor cells may attack cancer cells. This is called graft-versus-tumour effect.
- There are two main types of GVHD: acute (within 100 days) and chronic (after 100 days, may last months or years).
- Acute GVHD usually affects the skin, liver and gut. It is graded from 1 (mild) to 4 (life-threatening) based on severity.
- Symptoms of acute GVHD include rash, blistering, yellowing skin (jaundice), nausea, vomiting, diarrhea and stomach pain.
- Medicines such as cyclosporin, tacrolimus, methotrexate, or cyclophosphamide are used to prevent acute GVHD.
- Mild acute GVHD may be treated with creams or mouthwash; moderate to severe cases may need high-dose steroids or other immunosuppressive medicines.
- Chronic GVHD can follow acute GVHD or appear later. It may affect the skin, mouth, eyes, liver, lungs or other organs, and be mild, moderate or severe.
- Symptoms of chronic GVHD include dry or itchy skin, abnormal liver function, dry mouth, eye irritation, vaginal dryness, lung or joint problems and increased infections.
- Treatment of chronic GVHD may include steroids and immunosuppressive medicines. Other options include ruxolitinib, extracorporeal photopheresis (ECP) and PUVA therapy.
- Because GVHD treatment weakens immunity, antibiotics, antivirals and vaccines given at the right time are important.
- For more information, watch the Agency for Clinical Innovation video on understanding graft vs host disease at aci.health.nsw.gov.au/networks/bmtct/resoures/patient-information.

CHAPTER 12

Other complications

An allogeneic stem cell transplant can affect different parts of the body. This chapter explains common complications that may happen in the liver, lungs, kidneys and other areas. It covers who is at risk, how problems are detected, and what treatments are available to prevent or manage them. This information can help you understand and monitor your recovery.

Liver complications

Liver complications are common after a BMT. This section explains the main types of liver problems, who's at risk, how they're diagnosed, and what treatments are available.

How the liver works

The liver sits under the ribs on the right side of the abdomen (belly). It helps clean the blood, make protein for clotting, produce bile for digestion and store energy.

During a transplant, the liver may be affected. Damage to liver cells or to the small tubes called bile ducts may stop it from working properly, causing a build-up of toxins or other substances such as bilirubin.

Types of liver disorders

There are 3 types of liver disorders:

- those affecting the liver cells directly
- those affecting the blood vessels that transport blood through the liver
- those affecting bile ducts carrying bile to the gall bladder and intestines.

Sometimes, more than one liver complication happens at the same time. Most complications are temporary and treatable, but some can be serious or life-threatening. Many liver problems look similar, so it can take time to find the exact cause.

Who is at risk

You may be more likely to develop severe liver complications if:

- your liver wasn't working well before the transplant
- you have hepatitis (inflammation of the liver usually caused by a virus), fungal infections, gallstones or bile duct blockages.

Checking your liver health

You may have several tests to check your liver before, during and after a transplant:

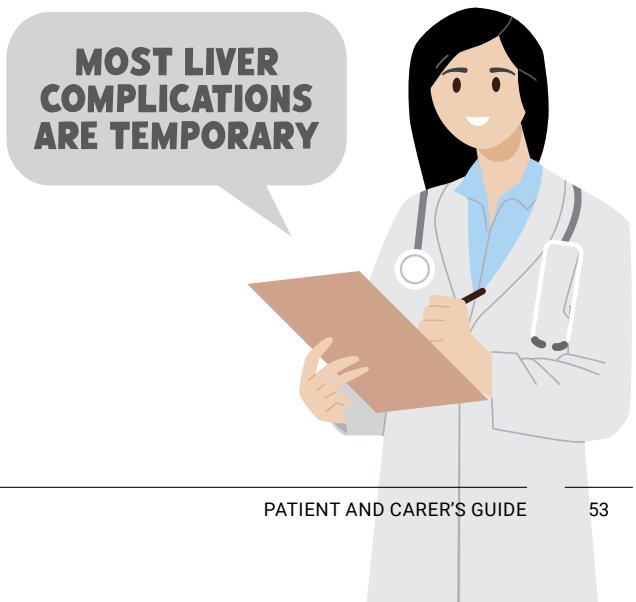
- blood tests to check bilirubin and enzyme levels
- physical exams of the abdomen to feel the size of the liver
- ultrasound or CT scan
- measurement of your belly size
- daily or twice-daily weight checks
- liver biopsy (if needed for a clear diagnosis).

Treating any issues early helps reduce the risk of serious liver complications and gives you time to recover before admission. The tests also give the transplant team important information that may help prevent serious liver problems.

Signs of liver problems

If you notice any of following signs, let your transplant team know straightaway:

- yellowing of the skin or eyes (jaundice)
- swelling or tenderness in the liver area
- sudden weight gain from fluid build-up
- swelling of the arms, legs or abdomen
- high bilirubin and liver enzymes levels in blood tests
- confusion (can also be caused by medicines).



Liver problems in the first 100 days

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Acute GVHD of the liver	Donor immune cells attack small bile ducts, causing bile build-up. This can range from mild to severe. More likely with unrelated or mismatched donor.	• Yellow skin or eye (jaundice) • Mild tenderness in the liver area	**Prevention:** GVHD prevention medicines before and after transplant (see pages 51–52). **Treatment:** Steroid medicines to reduce inflammation; other immunosuppressive medicines if symptoms persist.
Sinusoidal obstruction syndrome (SOS), previously known as veno-occlusive disease	Blockage of tiny blood vessels in the liver. This stops the liver from filtering blood properly, which causes waste products to build up in the body. Usually in the first few weeks after conditioning therapy. Higher risk if you have had busulfan; previous transplant, liver disease or hepatitis, radiation to the abdomen, or a mismatched or unrelated donor.	• Swelling in legs or abdomen • Sudden weight gain • Yellow skin or eyes (jaundice) • Enlarged, tender liver • Nausea • Confusion in severe cases	**Prevention:** • Low risk – Ursodeoxycholic acid • High risk – defibrotide (available through special access programs). **Treatment:** Defibrotide to protect blood vessels in the liver and reduce clots. Other care may include: • reducing or stopping medicines that strain the liver • diuretics to remove extra fluid • reducing salt intake and managing fluids • blood products if needed.
Infections affecting the liver	Infection in other parts of the body can affect how the liver works. Can occur at any time.	• Abnormal blood test results • Yellow skin or eye (jaundice)	**Treatment:** Antibiotics to treat the underlying infection.
Fungal infections of the liver	Fungal infection (usually Candida or Aspergillus) that grows when the immune system is weak and antibiotics have reduced the body's 'good' bacteria. Can occur while white cell count is low, if you are taking steroids (e.g. prednisone) for GVHD, or if you have a fungal infection in the gut or bloodstream.	• Fever that doesn't improve with antibiotics • Swollen or tender liver • Abnormal liver blood tests	**Prevention:** Antifungal medicine (e.g. fluconazole); filtered air in hospital room; avoid fresh plants, fruit and vegetables. **Treatment:** Long-term antifungal medicine (e.g. amphotericin).
Medicine-related liver problems	Some medicines used during or after transplant can temporarily affect liver function. Can occur at any time after transplant.	• Yellow skin or eyes (jaundice) • Abnormal liver blood tests	**Treatment:** Usually improves when the medicine is adjusted or stopped. Liver function is monitored regularly.

Liver problems in the first 100 days

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Viral infections See page 45 for more information about viral infections after a transplant.	Certain viruses can cause swelling of the liver. Common viruses include hepatitis B and C, adenovirus, herpes simplex, varicella zoster, cytomegalovirus (CMV) and Epstein-Barr virus (EBV). Can occur at any time after transplant; CMV is most common and can cause serious problems if not diagnosed early.	• Abnormal liver blood tests • Tiredness • Yellow skin or eyes (jaundice)	**Prevention and treatment:** Regular blood tests to detect viruses early. Antiviral medicines are used to treat or prevent infection.
Biliary disease	Bile may become thick when you're not eating normally. Most common during recovery when appetite is poor.	• Pain when eating • Fever • Gallstones • Swelling of gall bladder	Symptoms usually improve once you're eating normally again. Antibiotics if infection develops. Adjusting intravenous feeding (type or amount) can help if liver tenderness occurs.

Liver problems after day +100

Liver problems are less common after the first 100 days. However, if you had acute GVHD or a viral infection before day +100, your risk may be higher. Most liver issues that occur after +100 days are mild to moderate and not life-threatening.

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Chronic GVHD of the liver	Chronic GVHD affects the small bile ducts inside the liver, blocking or slowing the flow of bile from the gall bladder into the intestines. It can occur with or without acute GVHD (see pages 48–49). After day +100; more likely if you had acute GVHD before.	• Yellow skin or eyes (jaundice) • Abnormal liver blood tests	**Treatment:** Steroid tablets (e.g. prednisone) and other medicines (e.g. cyclosporin or tacrolimus) to reduce immune-related inflammation. Regular blood tests to monitor liver function.
Chronic viral hepatitis	Viruses such as hepatitis B or C can stay dormant for years and reactivate when immune system is weak. Can occur months or years after transplant, especially if you've had hepatitis B or C before.	• Often mild; may cause tiredness, jaundice or abnormal liver blood tests	**Treatment:** Managed by your transplant and liver specialists. Hepatitis C can be difficult to treat because some medicines (e.g. interferon) can lower white cell counts and increase infection risk.

Lung complications

The lungs can be affected because of infections, bleeding, side effects of chemotherapy or radiation therapy, GVHD or problems with the immune system. Lung problems are common after a BMT, especially while your immune system is weak. This table summarises the main types of lung problems, who's at risk, how they are diagnosed, and what treatments are available.

Lung problems in the first 100 days

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Bacterial pneumonia	Infection of the lungs caused by bacteria. After transplant, bacteria are often harder to treat than in healthy people. Often 2–3 weeks after transplant, when white cell count is low.	• Fever • Chills • Chest pain • Cough • Yellow or green phlegm • Difficulty breathing	**Diagnosis:** Chest x-ray or CT scan, blood and sputum tests. **Treatment:** IV antibiotics, oxygen, ventilator if severe.
Fungal infections	Fungal spores inhaled into the lungs can cause infection when immunity is low. Any time while white cells are low or if taking strong immuno-suppressing drugs or steroids, or have GVHD.	• Similar to bacterial pneumonia (fever, cough, shortness of breath)	**Prevention:** Filtered air room, antifungal medicine (e.g. fluconazole). **Treatment:** IV antifungal medicine (e.g. amphotericin).
Pneumocystis jirovecii pneumonia (PJP/PCP)	Pneumonia caused by a small parasite that normally lives harmlessly in the lungs but grows when immunity is weak. Usually during periods of very low white cells or while on immunosuppressants.	• Fever • Dry cough • Shortness of breath	**Prevention:** Antibiotic (Bactrim/cotrimoxazole) until immune recovers. **Treatment:** High-dose antibiotics if infection develops.
Pulmonary haemorrhage	Bleeding into the lungs, usually caused by low platelets or damage from conditioning therapy. Rare but serious. Usually in the first month after transplant.	• Coughing up blood • Difficulty breathing	**Treatment:** Platelet or plasma transfusions, high-dose steroids, ventilator support if needed.
Interstitial pneumonia	Inflammation and scarring of lung tissue, sometimes due to virus, parasite, radiation, medicine, or unknown causes. Usually 2–3 months after transplant.	• Fever • Dry cough • Difficulty breathing	**Diagnosis:** Chest x-ray or CT scan, virus testing (e.g. CMV), bronchoscopy. **Treatment:** Treat infection if found, steroids, oxygen or breathing support.

Lung complications after day +100

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Lung fibrosis	Scar tissue forms in the lungs, making them stiff and harder to expand. Can result from medicines (e.g. busulfan), radiation or unknown causes. Gradually develops months or years after a transplant.	• Dry cough • Shortness of breath	**Diagnosis:** Chest x-rays, CT scan, breathing tests, lung biopsy if needed. **Treatment:** Steroids; may not always reverse damage.
Chronic GVHD of the lungs	Chronic GVHD damages the small airways (bronchioles), narrowing them and reducing airflow. Occurs after day +100; risk higher if you had GVHD earlier.	• Wheezing • Difficulty breathing out • Recurrent bronchitis or pneumonia	**Diagnosis:** CT scan, breathing tests, biopsy if needed. **Treatment:** Increased dose of immunosuppressive medicines, though not always effective.
Recurring infections due to immune deficiency	Ongoing GVHD or immunosuppressive medicines weaken the immune system, increasing risk of repeated lung infections. Can occur any time after transplant while on long-term immunosuppressants.	• Frequent chest infections such as bronchitis or pneumonia	**Treatment:** Antibiotics to treat and prevent infections and intravenous immunoglobulin (IVIg) to boost immunity.

Kidney complications

The kidneys filter waste products, such as creatinine, and remove excess water. Kidney problems are common after a transplant. They are often side effects of medicines, infection or other complications.

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Kidney disease	Reduced kidney function caused by medicines, infection, low blood pressure, or other complications such as sinusoidal obstruction syndrome (SOS) of the liver. Kidney disease can occur at any time after the transplant.	Often no early symptoms. Kidney problems are often found by blood tests that show raised creatinine levels. In severe cases: swelling, tiredness or passing less urine.	**Prevention:** Regular blood tests to check kidney function. **Treatment:** Adjust or stop medicines that affect the kidneys (e.g. cyclosporin, gentamicin or amphotericin); may need IV fluids or medicines to help raise low blood pressure. In rare cases, dialysis is needed but is usually temporary.

Other complications

CONDITION	WHAT IT IS AND WHEN IT HAPPENS	SYMPTOMS	PREVENTION AND TREATMENT
Haemorrhagic cystitis	Inflammation and bleeding of the bladder lining, often caused by cyclophosphamide (chemotherapy) or viral infections (e.g. CMV, BK virus, parvovirus). Haemorrhagic cystitis occurs weeks to months after a transplant.	• Pain or burning when passing urine • Frequent urination • Blood or clots in urine	**Treatment:** Often mild and settles on its own. In severe cases, bladder irrigation through a catheter, blood transfusion, and fluids may be needed. A catheter may also help remove clots.
Microangiopathic disease (thrombotic thrombocytopenic purpura/TTP)	Rare condition where small blood vessels become blocked, reducing blood flow and causing clotting problems. May affect kidneys, brain or other organs. Can occur any time after a transplant, sometimes linked to cyclosporin use, CMV infection or previous radiation therapy.	• Anaemia • Bleeding • Confusion • Fever • Seizures • Coma	**Treatment:** Reduce or stop cyclosporin, blood transfusions, plasma exchange (plasmapheresis), dialysis if kidney failure occurs. In some cases, medicine such as eculizumab may be used.

Key points

- An allogeneic stem cell transplant can affect different parts of the body, including the liver, lungs, kidneys and other organs.
- Liver complications can occur from chemotherapy, radiation therapy, infection or medicines. The complications can range from mild and temporary to severe, but most can be treated if found early.
- You'll have regular liver checks. Blood tests, scans and weight checks help find changes early.
- Common early liver problems include acute GVHD and sinusoidal obstruction syndrome (SOS), which is when blood can't flow properly through the liver.
- Lung complications may be caused by infection, bleeding or side effects of treatment.
- Kidney and bladder problems are often caused by medicines. Infections can also cause swelling or blood in the urine.
- Various medicines are used to manage these complications.

CHAPTER 13

Nutrition and transplant

Eating well before, during and after an allogeneic stem cell transplant plays an important part in helping your body recover. Food gives you energy, builds and repairs tissues, and keeps the immune system working properly. Good nutrition also helps you cope with side effects and fight infections.

During a transplant, eating well can be difficult. Conditioning therapy, medicines, infections or graft-versus-host disease (GVHD) may affect your mouth, stomach and bowels. Side effects such as loss of appetite, taste changes, nausea and vomiting, diarrhoea and sore mouth or throat (mucositis) can last for weeks or months after the transplant, increasing the risk of malnutrition.

Food can carry bacteria or fungi, so it's important to follow food safety guidelines until your immune system has recovered (see page 62).

The transplant team, including a dietitian, will work with you to get the best nutrition possible, even if your eating patterns have changed.

Seeing a dietitian

You'll probably see the transplant dietitian the week before the transplant or when you're admitted to hospital. They will help you with what you can eat and offer advice. This is an important part of keeping you strong and healthy before and after the stem cell transplant.

The dietitian will make a nutrition care plan for you. While you're in hospital, they'll keep a record of what you eat and how much, and you may be asked to fill in daily food charts.

The dietitian will look at:

- your height and weight
- any recent changes in your weight
- symptoms such as feeling sick (nausea) or diarrhoea, which can affect how much food you can eat and how well your body uses it
- how much energy and protein your body needs to recover and fight infections
- your usual eating habits, which may be affected by illness, medicines, and also by your religious or cultural beliefs.

Nutrition before transplant

- Eating well prepares your body for treatment.
- You'll meet with a dietitian, usually the week before your transplant or when you're admitted to hospital.
- They'll assess your weight, appetite, eating habits, and any symptoms like nausea or diarrhoea.
- They'll make a personalised nutrition plan.

Nutrition during transplant

- Conditioning therapy often changes what you can eat.
- Common side effects include loss of appetite, taste changes, nausea, diarrhoea and mucositis. These usually appear within 3–10 days and can last weeks.
- It's important to follow food safety guidelines to avoid infections.
- If you can't get enough nutrition from food, you may need tube feeding.
- Your dietitian and transplant team will work closely with you to maintain your strength.

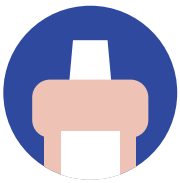
Nutrition after transplant

- Side effects can continue for weeks or months after a transplant.
- Graft-versus-host disease (GVHD), especially if it affects your gut, can make it harder to absorb nutrients.
- Food safety is important as your immune system will still be weak. Follow all food safety guidelines until your transplant team says your immune system has recovered.
- As you regain strength, your dietitian will adjust your plan to help you return to normal eating and rebuild your body.

Managing common nutrition concerns during transplant

Changes to appetite and weight

- Eat small meals every 2–3 hours.
- Choose foods you like, even if they are high in fat and sugar.
- Use nutritional supplements (e.g. Sustagen, Ensure, Resource). These are high in energy and protein, which can help maintain your strength. A dietitian can recommend the right nutritional supplements.



Sore mouth and trouble swallowing

- Avoid spicy, salty, sour or very hot or cold foods.
- Eat soft or pureed foods.
- Have fluids such as soups, milk drinks or commercial supplements.
- Use a mouthwash to keep your mouth clean.

Nausea and vomiting

- Eat 6 small meals a day instead of 3 main meals.
- Include high-carbohydrate foods and fluids, such as bread, rice, pasta, fruit and fruit juice.
- Have cold foods and clear fluids.
- Limit high-fat foods.
- Avoid strong odours and cooking smells.
- Take anti-nausea medicine as prescribed.

Diarrhoea

- Drink lots of fluids to prevent dehydration.
- Limit caffeine and spicy foods.
- Try a low-lactose diet as you may be temporarily lactose intolerant.
- Limit high-fibre foods such as legumes, whole grains and seeds.
- Take anti-diarrhoea medicine as prescribed.

Taste changes

- Add flavour to food with salt, garlic, cooked herbs and spices.
- Marinate meat, fish, poultry or tofu to add flavour.
- Add sugar or honey to food if it tastes metallic or salty.
- Use salt, lemon juice or vinegar if food tastes too sweet.

Nutrition during transplant

Conditioning treatment can affect your digestive tract (gastrointestinal or GI system), which runs from the mouth to the bowel. This is why you may need nutrition support during a stem cell transplant.

Most people develop a sore mouth or throat (called mucositis), including mouth ulcers or sores, or have changes in appetite, digestion or taste about 3–10 days after starting chemotherapy. These side effects can make eating more difficult. How long they last varies from person to person.

GVHD, especially when it affects the gut, can make it harder for your body to absorb nutrients. This increases the risk of malnutrition and can slow recovery. Your dietitian will work with you to help you maintain your strength and prevent weight loss.

If you're not able to eat enough, you may need nutritional support for a while, such as:

- nasogastric (NG) tube – a tube that goes through your nose into your stomach
- total parenteral nutrition (TPN) – a drip into your vein that gives nutrition directly into your blood.

If a feeding tube is needed, your transplant team will explain the options and help you decide what's best.

Nutrition after transplant

When you leave hospital, you may only just be starting to eat more normally again. Side effects such as taste changes and poor appetite may last for a while and make it harder to put weight back on.

Eating well will help you rebuild strength, regain weight and recover faster. After you go home, weigh yourself once a week to track your progress. It may take time, but your appetite and energy will return. You may need to keep seeing a dietitian until you are eating normally again. Ask for their contact details before you leave hospital.

"I'd been really nervous about getting the NG tube, but it ended up making everything so much easier." **David**

Electrolytes

After a transplant, the levels of some electrolytes such as potassium and magnesium can drop because of medicines, illness or not eating well. Electrolytes help your body work properly, especially your heart and muscles.

Your doctor may prescribe supplements. Eating foods high in potassium and magnesium can also help.

Foods high in potassium

- **Fruits –** bananas, mangoes, peaches, nectarines, plums, kiwifruits, rockmelon, honey dew
- **Dried fruits –** prunes, dates, raisins
- **Vegetables –** potatoes, spinach, silverbeet, mushrooms
- **Legumes –** dried peas and beans
- **Grains –** wholemeal bread and cereals
- **Protein foods –** meat, chicken, fish, eggs
- **Other –** chocolate (including cakes and biscuits), licorice
- **Drinks –** fruit and vegetable juices; vegetable soups; meat or yeast-based drinks or broths (e.g. Vegemite); chocolate drinks (e.g. cocoa, Milo, drinking chocolate); beer and wine (check with your doctor)

Foods high in magnesium

- **Wholegrain breads and cereals –** especially wheat germ, bran, oats
- **Nuts and seeds –** almonds, pumpkin seeds, chia seeds
- **Green leafy vegetables –** spinach, kale, silverbeet, bok choy
- **Legumes –** dried peas and beans
- **Dried fruits –** prunes, dates, raisins
- **Fruits –** bananas, avocados, citrus fruits
- **Other –** dark chocolate

Eating safely with a transplant

After your transplant, your immune system will be weaker making you more at risk of infections from food. For the first 3–12 months, you'll need to take extra care preparing and storing food. These steps can help protect you from foodborne infections.

Tips for food safety

Clean

- Wash your hands, utensils, cutting boards and kitchen surfaces often with hot soapy water.
- Wash fruit and vegetables well.
- Keep your fridge clean and below 5ºC.

Separate

- Use separate chopping boards for raw and cooked foods.
- Keep raw and cooked foods apart to prevent cross-contamination.
- Store raw foods on a plate or in a container on the bottom shelf of the fridge to avoid dripping.
- Keep pets and pests out of the kitchen.

Cook

- Cook food thoroughly and reheat until piping hot (make sure microwaved food is hot all the way through).
- Never reheat food more than once.
- Don't refreeze defrosted food.
- Keep hot foods hot and cold foods cold.
- Refrigerate leftovers promptly; don't leave food sitting out.
- Defrost food in the fridge or microwave, not on the bench.

Check

- Don't eat foods past their use-by date or foods that have been in the fridge too long.
- Avoid damaged or dented food cans.

Low-bacteria diets

Some hospitals recommend a low-bacteria or neutropenic diets to reduce exposure to germs.

Talk to your hospital dietitian for advice, or visit aci.health.nsw.gov.au and search for 'low microbial diet' to find more information online.

High-risk foods to avoid

- Raw fruit and vegetables with rough surfaces (e.g. strawberries, raspberries, cauliflower, broccoli)
- Unwashed raw fruit and vegetables
- Salad bars, smorgasbords and self-serve restaurants
- Pre-prepared takeaway foods
- Soft, semi-soft and surface-ripened cheeses (e.g. brie, camembert, ricotta, feta)
- Soft serve ice-cream, yoghurt with live cultures
- Raw or undercooked meats, chicken, fish, shellfish, eggs, tofu, salami, deli meats, pates and dips
- Sprouted seeds, fresh herbs and raw mushrooms
- Unpasteurised milk, cheese and other dairy products
- Food containing raw eggs (e.g. homemade mayonnaise, raw cake mix, biscuit dough)

Special diets that may not be safe

Some people want to change what they eat during or after a transplant. However, there is no evidence that special foods, diets or vitamin and mineral supplements can help. Some unproven diets may:

- cut out entire food groups, such as meat and dairy, which can make it hard to get enough protein, vitamins and minerals and energy
- encourage large amounts of specific foods, juices or supplements
- promote high doses of vitamins, antioxidants or herbal products.

These types of diets can cause unwanted weight loss and fatigue, which can make it harder for your body to recover.

Before making changes to what you eat, consider if the diet:

- provides enough energy to maintain your weight
- is well-balanced in vitamins, minerals and fibre
- is expensive or takes time to prepare
- has proven health benefits.

Always talk to your doctor or dietitian before changing what you eat. They can explain the benefits and risk, and make sure any changes are safe during and after your transplant. It's also important to check with them before taking alternative products, such as herbs, high-dose vitamins or antioxidants, as these can interfere with your treatment or harm your liver or kidneys.

If you have GVHD

If you're being treated for GVHD, it's important to keep following the food safety advice you were given in hospital (see page 62). This is because your risk of infection remains high while your immune system is weak.

GVHD that affects the gut can cause tummy pain, diarrhoea and nausea. To manage these symptoms, you may need to follow a low-lactose and low-fibre diet.

Tell your doctor or dietitian if you have:

- a dry or sore mouth
- difficulty swallowing
- losing weight without trying
- ongoing nausea or vomiting
- frequent loose bowel movements (diarrhoea).

They can suggest ways to manage these symptoms.

Key points

- Eating well before, during and after a transplant helps your body stay strong and supports recovery. Good nutrition gives you energy, repairs tissue, supports your immune system, and helps you cope with treatment and fight infections.
- Side effects from conditioning therapy (e.g. nausea, diarrhoea, taste changes, mouth sores) can make eating difficult. These usually improve over time but may last for weeks or months after the transplant, increasing the risk of malnutrition.
- If you're not able to eat enough, you may need nutrition support such as a feeding tube (nasogastric or NG tube) or nutrition given through a drip into your vein (total parenteral nutrition or TPN).
- Food safety is essential while your immune system is weak. Take extra care when preparing and storing food for 3–12 months. Follow all food safety guidelines on cleaning, separating and cooking food, and avoid high-risk foods.
- Special diets or high-dose supplements may be unsafe or interfere with your treatment. Always check with your doctor or dietitian before making changes to your diet or taking supplements.

CHAPTER 14

Exercise and transplant

Exercise is important before, during and after a transplant. Staying active helps keep your bones and muscles strong, especially after long periods in hospital. It also reduces tiredness, lifts your mood, improves sleep, and eases stress and anxiety.

Exercise is structured physical activity that aims to improve health and fitness. It can include guided movements (e.g. yoga, exercise class) or other physical activity (e.g. bike ride, walk).

Exercise before transplant

- Stay as active as possible to prepare your body for treatment.
- Try gentle walking, stretching or strength exercises.
- See a physiotherapist to improve movement, flexibility and muscle strength.

Exercise during transplant

- Start moving as soon as you feel well enough. The sooner you start the better.
- Try short walks around the ward, standing up regularly or do light stretches in bed.
- Your physiotherapist can suggest safe activities based on your blood counts and energy levels (see page 66).
- Avoid exercise if you have a fever or an infection.

Exercise after transplant

- Build up activity slowly. Walking is a good way to rebuild strength.
- Keep moving, even when tired.
- See a physiotherapist to review your progress and adjust your exercise plan as you recover.

Seeing a physiotherapist

You'll usually see a hospital physiotherapist before, during and after your transplant. They'll help improve your mobility, strength and energy levels to make daily tasks easier. They'll also suggest safe exercises and adjust them as you recover.

If you live in a rural or remote area, ask about telehealth physiotherapy or tele-rehabilitation services, which can provide support and guidance from home.

Types of exercise

Different types of exercises help your body in different ways. Doing a mix of exercises can build strength and make everyday tasks easier.

Try to include exercises from each of the 4 types:

Aerobic – Strengthens your heart and lungs. For example: walking indoors or outdoors (if your immune system is strong enough), cycling, dancing.

Resistance (strength) – Builds and maintains muscle. For example: using light weights or resistance bands, or doing body weight exercises such as repeated standing from a chair, wall push-ups or lifting light objects.

Flexibility – Keeps joints moving and reduces stiffness. For example: stretching, yoga or Tai Chi.

Balance – Helps prevent falls. For example: standing on one leg, using wobble cushions or doing simple balance poses.

Many exercises can be adapted to suit your ability, including using a chair or bed, arm circles and sit-to-stand movements. Always check with a physiotherapist before starting any new activities.

Exercising safely with a transplant

Fatigue, nausea or sore muscles can make movement harder, but gentle exercise can help you feel better. Recovery may take 6–9 months or longer.

Even small amounts of activity such as walking around your room or stretching in bed, can help. When you stop moving completely, your body quickly loses strength and fitness, making everyday tasks harder. Doing small amounts of movement will help you stay independent and recover more quickly once you're home.

Tips for exercising with side effects

- Start with short walks or light stretches. Even 5–10 minutes at a time can help.
- Break up activity into small sessions throughout the day.
- Rest when needed but avoid staying in bed all day.
- Move a little every hour.
- Stop if you feel dizzy, become very short of breath, or feel pain.
- Avoid gyms, public swimming pools and crowded places until your immune system is stronger.
- Clean shared exercise equipment before use.
- Ask your transplant team or hospital physiotherapist which exercises are safe and suitable for you.
- Take care with any tubes or lines still in place.

Monitoring your blood count

Your transplant team will monitor your blood counts during recovery (see page 66). The results guide safe activity levels and help your physiotherapist choose the right exercises for you.

Getting support

Many transplant centres offer exercise or physiotherapy programs designed for people recovering from a transplant. Talk to a hospital physiotherapist about what type and amount of exercise is best for you.

How much exercise to do

The Clinical Oncology Society of Australia (COSA) recommends exercise as a standard part of cancer care. Exercise & Sports Science Australia (ESSA) also encourages people with cancer to stay active.

- Start with 5–10 minutes of walking several times a day.
- Slowly increase to 20–30 minutes on most days if you can. You can split this into shorter sessions of 5–10 minutes.
- Over time, aim for 2½ hours of activity a week.
- Focus on being consistent, rather than on pushing yourself too hard.

> "I walked a lot in hospital and kept track of how many laps of the ward I did each day on the whiteboard. I also followed an exercise program in my room. When I got home, even though I was tired, I found it helpful to keep going for walks and do some seated exercises with light weights."
>
> **JulieAnne**

Key points

- Staying active before, during and after a transplant helps your body stay strong and recover faster.
- Exercise can reduce fatigue, improve sleep and mood, and help manage stress and anxiety.
- Include a mix of aerobic, strength, flexibility and balance activities.
- Start gently and build up slowly. Even short sessions make a difference.
- Side effects such as nausea or tiredness may make it harder to be active, but small amounts of movement still help.
- Always check with your transplant team or physiotherapist before starting or changing your exercise plan.
- Avoid gyms and crowded places until your immune system has recovered.

Exercise suggestions based on your blood counts

PLATELET COUNT (X109/L)	WHAT YOU CAN DO	WATCH FOR
Below 10	• Only do light daily activities (e.g. sitting out of bed, gentle self-care). • Your team may give you a platelet transfusion before any exercise.	Dizziness and falls, standing up too quickly
11–20	• Gentle movement only. • No resistance or straining. • Keep blood pressure below 170/100.	Bleeding or bruising – tell your team if this happens
21–50	• Light exercise. • Use resistance bands not weights. • Cycle gently if your physiotherapist says its safe.	Minor bleeding or bruising
Over 50	• Exercise as usual, following advice from your physiotherapist. • Avoid vigorous or high-impact activity.	Watch for unusual bleeding or bruising
HAEMOGLOBIN (G/L)	**WHAT YOU CAN DO**	**WATCH FOR**
Below 70	• Usually wait for a transfusion before physiotherapy. • If not having a transfusion, your physiotherapist will check with your doctor first.	Dizziness, chest pain, shortness of breath
70–80	• Gentle, low to moderate activity only.	Feeling light-headed, pale skin, breathlessness, chest pain, dizziness when standing up
Over 80	• Continue with usual activities.	
NEUTROPENIA	**WHAT YOU CAN DO**	**WATCH FOR**
Neutropenic but feeling well	• Exercise is usually fine. • Wash your hands before and after each session. • Clean shared equipment before and after use. • Wear a mask outside your room. • Exercise in your own room if possible.	Infection, fever, sudden illness
Neutropenic and unwell (fever, infection, unstable heart or breathing)	• Only essential daily activities. • No resistance or straining. • Walking around the room, sit-to-stand. • Keep blood pressure below 170/100. • The physiotherapist may pause treatment until you're stable.	Fever, worsening infection, dizziness, shortness of breath

CHAPTER 15

Life after transplant

Life after a transplant can feel different. It takes time to adjust physically and emotionally. How you feel and the challenges you face will depend on your personal situation such as how you respond to the transplant, your original disease and its stage, your overall health, your past treatments, and how closely your donor matches you. Your transplant doctor can tell you what to expect and discuss your possible transplant outcome.

Going home

Leaving hospital after your transplant can bring up many different feelings. You may feel excited and relieved, but also anxious or worried about managing without constant medical care.

Before you leave the hospital, ask your doctor or nurse for the following:

- contact numbers for your transplant centre
- instructions for caring for your central venous catheter (CVC), if you still have one
- advice on eating well, staying active and avoiding infections
- list of your medicines and how to take them
- your schedule for outpatient appointments and tests.

Having this information can help you feel more comfortable and supported as you transition to outpatient care.

Settling back in – Recovery continues for several months after you're home. The first few weeks often include good days and bad days. You may feel very weak and only manage to sleep, sit up and walk short distances around the house.

Support from others – Family, friends and carers can help you adjust to life at home. You may need help with everyday activities and getting to medical appointments until your strength improves. Let the team know about any changes or difficulties you experience at home.

Tips

- Take things slowly – don't expect too much from yourself too soon.
- Contact the transplant clinic if you notice new or concerning symptoms.
- Accept help from family, friends or carers for daily tasks and appointments.

Staying near the hospital

For the first 100 days after your transplant, you'll need to visit the hospital or clinic regularly, usually about twice a week, so your transplant team can monitor your progress and give you any medicines or blood products you need.

Staying close to the transplant centre during this time makes it easier to attend appointments. It also means your team can respond quickly to complications such as GVHD or infection.

"There is life after a bone marrow transplant. I now live a normal life, and people who don't know my history have no idea what I went through. We are so lucky in Australia to have the medical, financial and emotional support that helps us recover."

Susanna

As well as seeing the transplant team, you may need blood or platelet transfusions or IV medicines, which are usually given in the outpatient clinic.

Readmission to hospital

It's common to be readmitted to hospital after you've been discharged. This is often to manage complications such as GVHD or infections. While being readmitted can feel like a setback, it doesn't mean your transplant has failed.

Your treatment centre will have a protocol to make sure you're seen quickly if you need urgent care. If you feel unwell or develop a fever, go straight to the emergency department and tell staff you've had a stem cell transplant and need to be seen immediately.

Follow-up care

Regular check-ups at the transplant clinic are an important part of your recovery. These visits are a chance to:

- ask questions
- adjust medicines
- review your progress and raise any concerns.

How often you need check-ups will vary from person to person, and they'll become less frequent as you start to feel better. It can help to keep a record of any side effects, symptoms, changes in how you're feeling or questions you want to ask. Bring these to your appointments so nothing gets missed.

It's common to feel nervous before follow-up appointments, even months or years after your transplant. If you're worried, talk to your doctor.

Medicines

When you leave hospital, you'll still need to take medicines to help your recovery. It's important to keep taking them as prescribed, as they help your body heal, avoid infections and make sure the transplant is successful.

Your transplant team will adjust your medicines during your follow-up appointments. As you recover, the number and dose of medicines will gradually decrease. Some people will need to keep taking medicines for several years after the transplant.

The transplant team will give you a written medicine schedule. It's helpful to bring this to each clinic visit.

Common medicines you may take at home

To prevent GVHD

- Cyclosporin
- Mycophenolate mofetil (MMF)
- Sometimes a combination of both

To manage nausea and vomiting (antiemetics)

- Ondansetron
- Olanzapine
- Cyclizine
- Metoclopramide
- Sometimes a combination of these

To prevent infections (antimicrobials)

- Bactrim
- Antifungals (e.g. posaconazole, fluconazole – depending on risk)
- Sometimes antivirals (e.g. valaciclovir, letermovir)

To protect your liver (SOS prevention)

- Ursodeoxycholic acid

Preventing infections

Your immune system may take 3–6 months or longer to recover after the transplant, making you more likely to get infections, especially if your white cell count is low.

This can feel frustrating after spending so long in hospital, but these precautions are temporary.

Ways to reduce infection risk

- Wash your hands often, especially before eating and after using the bathroom.
- Wear a mask in crowded places or when advised by your transplant team.
- Avoid public transport, shopping centres and cinemas, especially at peak times.
- Limit contact with people who are unwell or who've recently been exposed to illnesses. Stay away from children with chickenpox, measles or who've been recently vaccinated.
- Don't swim with a Hickman catheter or central line. Keep the bath water below the exit site.
- Avoid gardening and handling soil or potting mix, as they may contain live bacteria and fungi.
- Wash your hands after touching animals. Patting dogs or cats is okay, but don't let them lick you.
- Clean makeup brushes and applicators regularly, and choose lip balm, moisturiser and soap in pump dispensers. Avoid sharing products.
- Don't wear contact lenses until you've checked with your transplant team.
- Follow food safety advice (see page 62).
- Eat outdoors where possible.

Revaccination after transplant

Your transplant weakens your immune system. It can wipe out the protection you built up from vaccines you had earlier in life. This means you'll need to be vaccinated again for diseases you were already protected from, and for some new ones too.

Revaccination usually starts about 6 months after your transplant. The exact timing depends on factors such as whether you're still taking immunosuppressive medicines or have active GVHD. Your transplant doctor will work out the right vaccination schedule for you and help coordinate this with your GP.

Vaccination schedule after an allogeneic transplant

Revaccination happens in stages. The timing depends on how quickly your immune system recovers and when each vaccine can be safely given.

Stage 1 – Early vaccines (from about 6 months)

Most people start their revaccination around this time. These are non-live vaccines, usually given as a series of doses spread out over weeks or months. They commonly include vaccines against:

- pneumococcal disease
- Hib (Haemophilus influenzae type b)
- diphtheria, tetanus, pertussis (whooping cough)
- polio
- meningococcal disease
- hepatitis B (if you're at risk).

You'll also usually start influenza (flu) and COVID-19 vaccination around this time. These continue every year.

Stage 2 – Extra vaccines and booster doses (from about 12 months)

You'll usually be finishing the vaccine courses from Stage 1. New vaccines may be added, such as:

- human papillomavirus (HPV)
- shingles.

Stage 3 – Live vaccines (from about 2 years, only if you're ready)

Some vaccines, such as measles-mumps-rubella (MMR), contain a live but weakened virus. These are only safe when:

- you are no longer taking medicines that suppress your immune system
- you do not have chronic GVHD
- your immune system has recovered enough.

The timing will vary. For some people, this may be 2 years after transplant.

Ongoing

Some vaccines need booster doses throughout your life. Recommendations for flu, COVID-19 and other vaccines can change. Your transplant team or GP can tell you about any vaccines or booster you need in the future.

For more information, visit aci.health.nsw.gov.au/networks/bmtct/resources and the Australian Immunisation Handbook at immunisationhandbook.health.gov.au.

Returning to work or study

Deciding when to return to work or study will depend on your recovery and the type of work you do. Most people go back about 6–12 months after their transplant, but the timing can vary. Your transplant specialist can tell you when they think you're ready to take on your usual tasks.

It's natural to feel uncertain about returning. You may be eager to get back to normal, or nervous about whether you're ready.

Tips

- Talk to your employer about a return-to-work plan.
- Consider returning to work or study part time or reducing your workload.
- Gradually increase hours as your energy improves.
- Talk to your social worker if you're not able to return to your previous job. They can help you find financial support and options for job retraining.

Emotional concerns

How you may feel

Many people expect life to return to normal after an allogeneic stem cell transplant, but surviving a life-threatening illness often changes your priorities, relationships and outlook. It takes time to adjust to your 'new normal'. It's common to have mixed feelings, including:

- relief and joy for surviving and for the support of family and friends
- confusion or uncertainty about how to move forward after treatment
- fear and anxiety about relapse and ongoing side effects
- sadness or depression because of changes to how you look or what you can do, or if recovery is slow
- guilt if others you know didn't survive the transplant.

Support is available from family and friends, others who've had similar experiences, your hospital social worker or psychologist, and your transplant team.

Fear of recurrence

Worrying about the cancer coming back (recurrence) is common. Many people say they feel differently about their body – a sense that it has let them down or can't be trusted, particularly if they had few or no symptoms before diagnosis.

You may feel more anxious before follow-up appointments or when you feel unwell, and worry this means the disease has returned. Talking about how you feel with your team, family and friends can help.

Changes in body image and identity

Physical changes after a transplant, such as hair loss, weight changes, muscle loss, having a Hickman catheter or nasogastric tube, skin changes from GVHD, chemotherapy or radiation therapy, and the effects of medicines, can affect how you see yourself.

Give yourself time to adjust to the changes. If you've experienced hair loss, it may grow back differently in colour, texture or thickness. In some cases, hair doesn't grow back. You may want to consider borrowing a wig from the hospital's wig library.

You may also have long-term changes to your body. These vary from person to person, so it's best to talk to your transplant team about what to expect and how to manage them.

Fertility issues

Current evidence does not show an increased risk of genetic problems or cancer in children conceived naturally after an allogeneic transplant. However, research is ongoing. It's recommended that you use barrier contraception for the first 6 months after your transplant. If you have any concerns, talk to your transplant team. See page 72 for more information.

If the transplant affects your ability to conceive a child, you may feel devastated. Even if your family is complete or you weren't planning to have children, you may still experience a sense of loss.

These feelings can be difficult to process. Your transplant team can refer you to counselling or fertility specialists for support.

Changes in relationships

A stem cell transplant affects not just you, but also the people close to you. Partners and family often take on new roles or more household responsibilities, which can strain relationships, disrupt routines and cause money worries.

Partners go through the experience of treatment too. They may find parts of it frightening and face the fear of losing you. It can take time for both of you to adjust and reconnect. With patience and understanding, many relationships adapt over time.

Speaking with a social worker or psychologist, together or separately, may help.

Sex and intimacy

It's common to experience changes in sex and intimacy after a stem cell transplant. These may include:

- less interest in sex (low libido)
- difficulties with sexual function (e.g. erections, orgasms, vaginal dryness).

A transplant can also affect how you feel about your body and your confidence. These changes can be caused by fatigue, stress, treatment side effects or GVHD.

Despite these physical and emotional challenges, sex and intimacy are still possible. There are many ways to stay close and connected, including touch, affection, humour and spending time together.

For more information about sex and intimacy, talk to your transplant team or visit cancer.org.au to read Cancer Council's *Sex and Intimacy* booklet.

Tiredness and fatigue

Feeling tired after the transplant is very common. How long it lasts varies from person to person. For some people, fatigue may continue for months or even years.

Fatigue usually improves gradually, which can be frustrating. Factors such as GVHD (see page 48) can affect how long it takes for energy levels to improve. Eating well, staying active and getting enough sleep can help reduce fatigue and rebuild your strength.

Possible late side effects

Some effects of a transplant may appear months or even years after treatment. These are called late effects. Your transplant team will continue to monitor your health closely to help manage or prevent complications.

Bone density changes

Problems with bones are fairly common after a transplant. This may be from taking steroid medicines such as prednisone, though other factors can also play a role. The main conditions that affect the bones are osteopenia, osteoporosis and avascular necrosis.

Osteopenia and osteoporosis

These conditions mean thinning bones. They're common as people get older, but they can also happen if you're given steroid drugs during the transplant. Women who go through early menopause after a transplant also have a higher risk because of lower oestrogen levels.

Your bone strength may be checked with a bone density scan before and after the transplant. If you have low bone density, you may be given calcium and vitamin D supplements, hormone therapy, or medicine to protect your bones.

Avascular necrosis

This uncommon condition happens when blood flow to a bone is reduced or blocked, usually due to steroid medicines such as prednisone. It can cause joint pain in the hips, knees and shoulders. You may have an x-ray, MRI or bone scan to check for this.

Treatment may include reducing the dose of prednisone, pain relief and having physiotherapy. Some people may need surgery to replace the damaged joint.

Heart problems

Heart problems can develop months or even years after a transplant. These are often due to the conditioning treatment, especially if you had high-dose chemotherapy or total body irradiation (TBI). Some types of chemotherapy used before the transplant can increase heart issues after the transplant.

Damage to the heart muscle (cardiomyopathy) causes shortness of breath and fatigue. Treatment usually involves heart medicines such as beta blockers.

Your heart health will be monitored for changes over time.

Cataracts

Cataracts happen when the lens at the front of the eye becomes cloudy. This makes your vision blurry, especially at night or in bright lights.

If you've had steroid treatment or total body irradiation (TBI), you're more likely to develop cataracts 1–2 years after a transplant. You may have surgery to replace the cloudy lens with an artificial lens, which usually improves your vision.

Fertility

Conditioning treatment before a transplant often affects fertility. In myeloablative conditioning, high-dose treatment usually stops periods and reduces or stops sperm production. Before the transplant, your team will talk to you about fertility and may refer you to a specialist to discuss ways to preserve fertility. See page 70 for more information.

Sperm production

A transplant can permanently lower sperm count. Testosterone levels may also drop and may need to be replaced with injections, tablets, creams or patches. Depending on your age and what treatment you've had, sperm levels may improve over time. If you're sexually active and not planning a pregnancy, it's important to use a condom.

Ovaries

Chemotherapy and TBI often affect the ovaries, causing infertility and premature menopause. Symptoms may include hot flushes, vaginal dryness, no periods and mood changes. Your transplant team will talk to you more about this, check your hormone levels and symptoms, and arrange an appointment with a gynaecologist to discuss hormone replacement and ways to manage any symptoms.

Even though infertility is common after a transplant, it's still important to use contraception in case your fertility returns.

If your fertility is affected, you may want to explore other ways to become a parent. Your transplant team can discuss these options and refer you to a specialist.

Second cancers

After an allogeneic stem cell transplant, your risk of developing another cancer may be higher than for people who haven't had a transplant. This is mainly due to the high-dose chemotherapy (cyclophosphamide) and total body irradiation (TBI) used in conditioning treatment, and the long-term effects of a weakened immune system. Some types of GVHD can also increase risk of second cancers.

You may have a higher risk of several types of cancer, including:

- skin cancers
- oral cancers, which are more common in people with chronic GVHD
- blood cancers such as myelodysplastic syndrome (MDS) and acute myeloid leukaemia (AML)
- solid cancers, including breast and thyroid cancers.

Cancer screening and follow-up

Regular cancer screening is important throughout your life, and these checks help find any problems early, when they are easier to treat. Your transplant team and GP will let you know what screening you need. This may include:

- regular dental check-ups and oral cancer screening, especially if you have chronic GVHD
- routine cancer screening for bowel, cervical, breast and skin checks
- ongoing follow-up tests as recommended by your transplant team.

Protect your skin from the sun

Skin cancer is the most common second cancer after transplant, so you'll need to protect your skin for the rest of your life. This means:

- applying SPF 50+ broad-spectrum sunscreen
- wearing clothing that covers your shoulders, neck, arms, legs and body
- wearing a broad-brimmed hat
- looking for shade where possible
- using the free SunSmart app to check the recommended sun protection times in your local area
- checking your skin regularly for new or changing spots, moles or sores that don't heal.

Key points

- Recovery takes time. Don't expect too much too soon.
- Your immune system may take 3–6 months to recover. During this time, take care to avoid infections.
- When you leave hospital, your transplant team will give you information about caring for yourself at home, including hygiene, diet, physical activity and medicines.
- You'll need to visit the hospital transplant clinic regularly for check-ups. Report any symptoms and call the clinic if you have any concerns between visits.
- Feeling anxious before follow-up appointments is normal. Talk about your worries with your doctor.
- You'll need to repeat many vaccinations you had as a child or adult. Your transplant team will give you a schedule and help organise them with your GP.
- Most people return to work or study 6–12 months after the transplant. You may prefer to go back part time at first.
- Worrying about the disease coming back after the transplant is common. This concern is natural, and talking about it can help.
- A transplant can affect your appearance, emotions, relationships and sex life. It takes time to find your 'new normal'.
- Long-term side effects can include bone problems, infertility, cataracts, heart problems and second cancers.
- If a transplant is not successful, you may be offered more treatment. In some cases, treatment may shift to palliative care. See next page.

When a transplant doesn’t work

Most people who have a stem cell transplant do see some benefit, but sometimes the transplant may not work as expected. This can happen if the new stem cells don’t grow (engraft), if the original disease comes back, or if serious complications develop.

If this happens, your transplant team will discuss the next steps with you. They may suggest further treatment or treatment may shift from trying to cure the disease to controlling symptoms and improving quality of life. This is called palliative care.

Hearing the words palliative care can be frightening because you might think it’s for people who are dying. Palliative care includes a range of services that can help with managing pain or getting around more easily. The team may include doctors, nurses, social workers and counsellors, who work together to keep you as comfortable and supported as possible.

Sometimes, when a person has a serious illness that can’t be cured, they may decide to end their life with help from a doctor. This is known as voluntary assisted dying (VAD). The word ‘voluntary’ means it is the person’s own decision.

VAD is not part of palliative care. It is now legal in every Australian state, but access to VAD in the territories is still under review. The rules, eligibility and timing are different in each state. You must meet very specific criteria and go through a series of steps set out by the laws in your state or territory. These rules make sure the decision is truly voluntary. Your doctor or social worker can help you understand the laws and options where you live.

CHAPTER 16

Information and support

Having the right information and support can make a real difference during and after your transplant. This chapter lists organisations, services and resources that can help you and your family.

Cancer and blood cancer information and support

Cancer Council
13 11 20 / cancer.org.au
Free, confidential support and information for people with cancer and their carers.

Canteen
1800 226 833 / canteen.org.au
Support and information for young people aged 12–24 who have cancer or have a sibling or parent with cancer.

Leukaemia Foundation
1800 620 420 / leukaemia.org.au
Support and information for people with leukaemia and their families and carers, including help with transport, accommodation and treatment costs. Aboriginal specific resource available at leukaemia.org.au/education/support-for-first-nations-peoples.

Lymphoma Australia
lymphoma.org.au
Information, nurse support and resources for people affected by lymphoma.

Myeloma Australia
myeloma.org.au
Specialist nurse support and resources for people living with myeloma and their carers.

Our Mob and Cancer
ourmobandcancer.gov.au
Information and support for Aboriginal and Torres Strait Islander people, developed by Aboriginal and Torres Strait Islander people. Covers cancer types, prevention, diagnosis, treatment, living with cancer, finding support and clinical trials.

Rare Cancers Australia
rarecancers.org.au
Support, advocacy and resources for people diagnosed with rare and less common cancers.

Maddie Riewoldt's Vision
mrv.org.au
Funds research and support for patients with bone marrow failure syndromes.

Fight Cancer Foundation
fightcancer.org.au
Provides accommodation, education support and funding for cancer research.

Snowdome Foundation
snowdome.org.au
Helps accelerate access to new treatments for Australians with blood cancers.

Clinical trials and registries

Australia and New Zealand Transplant and Cellular Therapies (ANZTCT)
anztct.org.au
Tracks stem cell transplants and cellular therapies across Australia and New Zealand. Used by hospitals, researchers and government bodies to improve care and plan services.

Australasian Leukaemia and Lymphoma Group (ALLG)
allg.org.au
Conducts clinical trials and research to improve treatment for leukaemia and lymphoma.

Australian Cancer Trials
australiancancertrials.gov.au
Searchable database of cancer clinical trials in Australia with consumer-friendly summaries.

Australian New Zealand Clinical Trials Registry (ANZCTR)
anzctr.org.au
Official registry of clinical trials in Australia and New Zealand across all health conditions.

Education and clinical information

Agency for Clinical Innovation
aci.health.nsw.gov.au
Works together with clinicians, consumers and system leaders to design and implement new ways to deliver health care in NSW. Includes resources and videos on stem cell transplant and cellular therapy.

eviQ
eviq.org.au
Provides evidence-based cancer treatment protocols and education for health professionals and patients.

Practical and financial assistance

Carer Gateway
1800 422 737 / carergateway.gov.au
Free services and support for carers, including counselling, coaching and help accessing respite care.

Look Good Feel Better
1800 650 960 / lgfb.org.au
Free workshops and kits to help manage appearance-related side effects of cancer treatment and boost self-image. Offered online and in-person across Australia.

NDIS
1800 800 110 / ndis.gov.au
Funding and support for Australians with permanent and significant disability. Contact your transplant social worker to discuss eligibility.

Services Australia
servicesaustralia.gov.au
Delivers government payments and services including Centrelink, Medicare and Child Support.
- Centrelink multilingual: 13 12 02
- Disability, sickness and carers: 13 27 17
- Family Assistance Office: 13 61 50
- Youth and student services: 13 24 90

Stem cell and transplant support

Arrow Foundation
arrow.org.au
Supports stem cell transplant and cellular therapy patients and their carers through financial support, education and research funding. Services include:
- help with treatment-related costs
- information resources and support groups for patients and families
- scholarships for nurses and allied health professionals
- investment in research to improve transplant outcomes.

Stem Cell Donors Australia
stemcelldonors.org.au
Australia's national blood stem cell donor registry. Connects volunteer donors with patients needing life-saving transplants for blood cancers and other serious conditions.

Transplant Australia
transplant.org.au
Supports transplant recipients and their families, people on the waiting list, donor families, living donors, healthcare professionals and anyone affected by organ and tissue donation. Transplant Australia runs programs that encourage physical activity to help transplant recipients live longer and healthier lives, including the Australian Transplant Games and Fit for Life.

Telephone support and counselling

Beyond Blue
1300 22 4636 / beyondblue.org.au
Confidential support and information for anxiety, depression and mental health. Available 24 hours.

Headspace
1800 650 890 / headspace.org.au
Free mental health support for young people aged 12–25, including online and phone counselling.

Lifeline
13 11 14 / lifeline.org.au
24-hour crisis support and suicide prevention.

QLife (LGBTQI peer support and referral)
1800 184 527 / qlife.org.au
Free, confidential peer support and referral for LGBTQI+ people. Available 3pm–midnight daily.

TIS (Translating and Interpreting Service)
13 14 50 / tisnational.gov.au
Free interpreting service for people who speak a language other than English.

Find a health professional

The following national peak bodies represent key allied health professionals. Visit their websites to search for an accredited practitioner in your local area.

Australian Association of Social Workers
aasw.asn.au

Australian Physiotherapy Association
australian.physio

Dietitians Australia
dietitiansaustralia.org.au

Exercise & Sports Science Australia
essa.org.au

Occupational Therapy Australia
otaus.com.au

International

Anthony Nolan (UK)
anthonynolan.org
Supports people with blood cancer and blood disorders by providing information and support for patients and families.

BMT InfoNet (US)
bmtinfonet.org
Provides information and support to bone marrow, stem cell and cord blood transplant patients and their families.

Blood Cancer United (US)
bloodcancerunited.org
Provides education programs, support services and access to telephone and online information specialists.

National Bone Marrow Transplant Link (US)
nbmtlink.org
Offers education, emotional support and resources for people having bone marrow or stem cell transplants.

National Marrow Donor Program
nmdp.org
Connects patients with volunteer stem cell donors worldwide.

CHAPTER 17

Glossary

allogeneic stem cell transplant
A type of transplant that uses stem cells donated by another person.

anaemia
A condition where the number of red blood cells is too low.

apheresis
A procedure that separates certain parts of the blood, such as stem cells, and returns them to the body.

aspergillus
A common fungus found in decaying vegetation, such as compost heaps and fallen leaves, air-conditioning systems or construction sites.

autologous stem cell transplant
A transplant that uses blood stem cells from a person's own body.

avascular necrosis
Death of bone tissue caused by loss of blood supply to the bones. It usually affects the joints and hips, and sometimes knees and shoulders.

bacteria
Microscopic organisms that can invade the body and cause infection.

bile
A fluid made by the liver and stored in the gall bladder. It helps breakdown fats during digestion.

bilirubin
A substance made when red blood cells breakdown. Measuring bilirubin helps check how the liver is working.

biopsy
A procedure that takes a small piece of tissue to help diagnose a disease.

bone marrow
The soft, spongy material found inside bones. It makes stem cells that develop into blood cells.

bone marrow harvest
A procedure to collect bone marrow from the hip bone while the donor is under general anaesthetic.

bone marrow transplant (BMT)
A treatment that replaces unhealthy bone marrow with healthy stem cells from a donor. It is used for some life-threatening blood or immune system diseases.

bronchoscopy
A procedure using a flexible tube (bronchoscope) passed through the nose or mouth into the lungs to look inside and, if needed, take samples.

candida
A common fungus that normally lives in the mouth, vagina or gut. It can cause thrush if it overgrows.

CAR-T cell therapy
This uses the patient's immune cells, which are changed in a lab to help recognise and attack cancer cells.

cataracts
A clouding of the lens in the eye that can affect vision.

central line
A type of central venous access device. Also known as Hickman catheter. It is a thin long, hollow tube placed in the chest, with 2–3 passages (called lumens). It is used to collect blood samples and give medicines and fluids.

central venous access device (CVAD)
A type of thin plastic tube inserted into a vein, usually in the chest, neck or arm, and threaded toward the heart.

chemotherapy
A cancer treatment that uses drugs to kill cancer cells or slow their growth.

chimerism
When donor cells and your own cells are present in your body after a transplant.

conditioning (preparative) therapy
High-dose chemotherapy, sometimes with total body irradiation, given before a stem cell transplant. It kills cancer cells and suppresses the immune system so donor cells can engraft.

creatinine
A waste product from muscle breakdown. A blood test for creatinine helps check how the kidney is working.

CT (computerised tomography) scan
A scan that uses x-rays to take detailed pictures of the inside of the body.

cytomegalovirus (CMV)
A common virus in the herpes family. It usually causes mild illness but can be serious after a transplant.

dialysis
A procedure that removes waste products from the blood when the kidneys are not working.

dietitian
A health professional who specialises in nutrition and diet.

donor lymphocyte infusion (DLI)
An infusion of extra donor cells given after a transplant to treat relapse and help restore remission.

electrolytes
Salts in blood and body fluids that help balance fluid, move nutrients into cells and remove waste from cells.

engraftment
When transplanted stem cells begin to grow and make new blood cells.

Epstein-Barr virus
A common virus in the herpes family. It can increase the risk of developing some cancers.

extracorporeal photopheresis (ECP)
A treatment for chronic GVHD. White blood cells are removed, treated with ultraviolet light and returned to the body.

gated heart pool scan (GHPS)
A scan that shows how well the heart is pumping.

glomerular filtration rate (GFR)
A test that measures how well the kidneys are working.

graft-versus-host disease (GVHD)
A common complication of allogeneic transplant, when donor immune cells attack healthy cells. Acute GVHD occurs in the first 100 days; chronic GVHD develops 100 days after a transplant.

graft-versus-tumour effect
When donor immune cells help cure disease by killing cancer cells after a transplant.

granulocyte-colony stimulating factor (G-CSF)
A man-made version of a natural hormone that helps the body make more stem cells so they can move into the blood.

haematopoietic stem cell transplant (HSCT)
When damaged or diseased bone marrow is replaced with healthy stem cells. These stem cells can grow into new blood cells, helping your body make red cells, white cells and platelets again.

haemoglobin
A protein in red blood cells that carries oxygen from the lungs around the body and gives blood its red colour.

hepatitis
Inflammation of the liver, usually caused by a virus.

Hickman catheter
A type of central line inserted into a vein in the chest. Used for giving medicines and taking blood samples.

human leukocyte antigen (HLA)
Proteins on most cells that help the immune system tell the difference between the body's own cells and foreign cells, such as bacteria. A close match between donor and patient increases the chance of a successful transplant.

immune system
The body's defence network of cells and organs that protect against foreign invaders, such as bacteria and viruses.

immunocompromised
When the immune system is weakened, making the body more vulnerable to infection.

immunosuppressive treatment
Medicines that weaken the immune system so donor cells can engraft after a transplant.

infertility
The inability to conceive a child.

intravenous (IV) injection
An injection of medicine or fluid directly into a vein.

jaundice
Yellowing of the skin or the eyes caused by a build-up of bilirubin in the blood.

lactose
A sugar found in milk and some dairy products.

liver
A large organ found on the upper right side of the abdomen that lies under the ribs. It filters toxins from the blood, makes a fluid called bile to aid digestion, and helps remove bilirubin, a by-product of red blood cell breakdown.

lumbar puncture
A test that collects fluid from around the brain and spinal cord (cerebrospinal fluid) using a needle inserted into the lower back.

lung
An organ used for breathing that supplies oxygen to the blood and removes carbon dioxide.

lymphocytes
A type of white blood cell that helps fight viruses, bacteria, fungi and parasites.

monocytes
A type of white blood cell that destroys bacteria and fungi, and cleans up after infection.

mucositis
Sores and ulcers in the mouth. A common side effect of chemotherapy and transplant.

mucous membranes
The moist linings of the eyes, nose, mouth and gut.

myeloablative therapy
A strong conditioning treatment that destroys the patient's bone marrow and cancer cells before a transplant.

nasogastric (NG) tube
A plastic feeding tube that is passed through a nostril, down the throat and into the stomach to give nutrition.

neutropenia
A low level of neutrophils, a type of white blood cell. It increases the risk of infection.

neutrophil
A white blood cell that kills bacteria.

non-myeloablative
A lower-dose conditioning treatment that suppresses rather than completely destroys the immune system before transplant.

nutrition
The process of eating and using food for health and energy.

nutritional supplement
A food or drink that provides extra energy, protein or vitamins.

osteopenia
Low bone density. This can be a risk factor for osteoporosis.

osteoporosis
Thinning and weakening of the bones, which increases the risk of fractures.

patient controlled analgesia (PCA)
A method of pain control where the patient presses a button to give themselves a set dose of medicine intravenously.

peripheral blood stem cell harvest
A procedure to collect donor stem cells from circulating blood.

peripheral blood stem cell transplant (PBSCT)
A transplant using stem cells collected from blood (the peripheral blood).

platelets
Blood cells that help blood to clot and stop bleeding. Also called thrombocytes.

pluripotent stem cell
An early-stage cell that can copy itself and make lymphoid and myeloid stem cells, which develop into all types of blood cells.

precursor cells
Cells that are partly developed and will soon become mature cells.

protein
A nutrient that helps the body build and repair tissues, muscles and cells.

protocol
A planned course of treatment.

protozoa
Single-cell parasites that live in humans and need human cells to multiply.

PUVA
A treatment using a medicine called psoralens (P) plus long wavelength ultraviolet light (UVA). It may help with skin and mouth problems.

red blood cells (RBCs)
Blood cells that contain haemoglobin and carry oxygen around the body. Also called erythrocytes.

reduced intensity conditioning (RIC) therapy
A transplant that uses lower doses of chemotherapy and/or radiation therapy than a standard (myeloablative) transplant.

relapse
When a disease comes back after it has improved (remission). Also known as recurrence.

remission
When the signs and symptoms of a disease get better or disappear.

septic shock
A life-threatening condition where severe infection leads to low blood pressure and poor blood flow. This causes the brain, heart, kidneys and liver to not work properly or to stop working.

sinusoidal obstruction syndrome
A potentially serious condition that affects the liver. It happens when the vessels inside the liver (called sinusoids) become swollen and blocked, making it harder for blood to flow through the liver. Previously called veno-occlusive disease.

spleen
An organ on the left side of the abdomen. It filters blood, stores immune cells and removes old blood cells.

stage
How far the cancer has grown and whether it has spread from an original site to other parts of the body.

stem cells
Early-stage cells that make all types of blood cells, including red cells, white cells and platelets.

stem cell transplant
A treatment that replaces unhealthy stem cells with healthy ones, taken either from the patient or from a donor.

steroid
A medicine that reduces inflammation and may help relieve nausea and fatigue. Also called corticosteroids.

T cell
A type of lymphocyte (white blood cell) that helps regulate the immune system and kill infected or cancerous cells.

thrombotic thrombocytopenic purpura (TTP)
A rare complication where small blood vessels form clots, blocking blood flow and damaging organs.

tissue typing
A test to check how closely the donor's human leukocyte antigen (HLA) proteins match the patients. Also known as HLA typing.

total body irradiation (TBI)
Radiation therapy that treats the whole body. It is sometimes used with chemotherapy before a transplant.

total parenteral nutrition (TPN)
Liquid nutrition given through a vein when eating or digestion is not possible.

virus
A tiny infectious agent that needs living cells to survive and multiply.

white blood cells (WBCs)
Blood cells that help fight infection and protect the body against foreign organisms. Types of white blood cells include neutrophils, lymphocytes and monocytes. Also called leukocytes.

x-ray
A test that uses radiation to take pictures of the inside of the body.

Notes

Notes

Message from a patient

Dear Reader,

I remember when I was 16 and facing a bone marrow transplant for acute lymphoblastic leukaemia in February 1985. I was given a booklet about what was ahead – small in size and in content, because transplant was still a very new treatment at that time. There hadn't been many patients before me.

And here I still am, over 40 years later, so happy to be alive and very much kicking (sometimes also screaming!) and so pleased to see this patient information guide come to fruition. I commend Arrow on developing this invaluable resource.

I was once asked in a radio interview what my secret to survival was. I said it certainly wasn't eating cancer fighting carrots – because I hate them. It's about living each day with passion, practising resilience and enjoying some fine bubbles along the way.

There is no single secret to survival in my humble opinion. But being in Australia, with access to some of the best doctors, nurses and research in the world, is a lucky start. Not to mention the generosity of donors and foundations such as Arrow.

Let's hope a long life is ahead for you too: it's possible. Arm yourself with all the information you can, ask the hard questions and face the answers with as much courage as you can muster. Try not to dwell on "why me?" or spend today worrying about tomorrow. Let yourself be sad and fearful, and then try and get back up to face the battle of, and for, your life.

Because it can be won.

Lisa

PS I still don't eat carrots.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