

OVERVIEW OF AN ALLOGENEIC STEM CELL TRANSPLANT

An information sheet for patients, families and whānau



WHAT IS AN ALLOGENEIC STEM CELL TRANSPLANT?

A stem cell transplant is a treatment option for some people who have a blood cancer or blood condition.

In a typical stem cell transplant, a person first gets high doses of chemotherapy, and sometimes radiotherapy, to try and kill all the cancer cells. This treatment also kills the stem cells in the bone marrow. The bone marrow becomes empty of blood stem cells in preparation for the healthy transplanted stem cells.

Healthy blood stem cells, that are donated from another person, are given to replace those that were destroyed. These new stem cells are infused via an intravenous (IV) drip (much like a blood transfusion). The goal is that the new stem cells will travel to the bone marrow, where they will begin to grow and make healthy blood cells.

Depending on where the stem cells come from, the transplant procedure may be called different names:

- Haematopoietic stem cell transplant (HSCT)
- Bone marrow transplant (BMT)
- Peripheral blood stem cell transplant (PBSCT)
- Umbilical cord blood (UCB) transplant (paediatrics only).

An allogeneic stem cell transplant is a complex procedure that carries significant risks, so every patient is reviewed by a team of health care professionals to ensure it is the best treatment option.

Referral to the transplant team

Once your haematologist has referred you for transplant, you will be booked in for an appointment with a haematologist and nurse who specialise in stem cell transplants. If you are an adult living in New Zealand the transplant centres are in Auckland, Wellington and Christchurch. Starship hospital in Auckland is where children and adolescents go if they need an allogeneic stem cell transplant.

This appointment will include discussion on your:

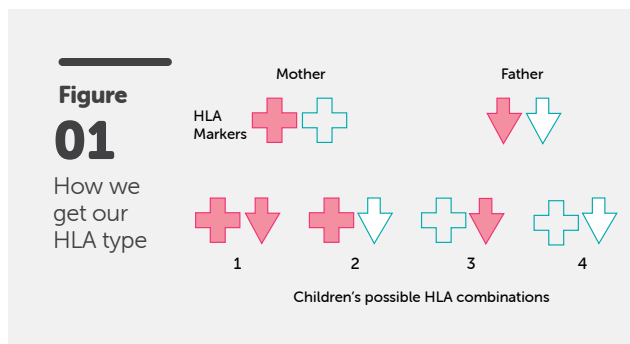
- Medical history
- Blood cancer or blood condition diagnosis
- Treatment to date
- Information about your family and potential donor search
- General overview of the stem cell transplant process
- What tests and procedures are potentially needed in preparation for a stem cell transplant
- The expected time to transplant.

This appointment is an opportunity for you to meet the transplant specialists and for you to ask questions and gather information. It is important to note that a stem cell transplant won't necessarily be confirmed or booked at this appointment. A lot of planning needs to be done to ensure you will benefit from having an allogeneic stem cell transplant. This preparation period is often called the 'work up'.

How is a donor found?

You will be asked to have a specific blood test called tissue typing or human leukocyte antigen (HLA) typing. Everyone has different HLA markers which are found on almost all cells in your body.

Everyone has two sets of HLA markers (also called haplotypes) which are inherited from each parent. There are four possible combinations of your parents' HLA marker sets, which means you have a one in four chance of having the same HLA markers as a sibling.



A donor search will be conducted by your medical team. This may be a:

- Related donor
- Unrelated donor.

Related donor

With your consent, your siblings will be contacted to see if they are willing to have the HLA typing blood test. Your health care team will discuss the process of tissue typing, arrange for their blood to be taken and provide information about stem cell donation, should they be a match. If you have a sibling, it is still not guaranteed that their HLA markers match yours, it is a one in four chance. This type of transplant is called a matched related donor (MRD) stem cell transplant.

A haploidentical stem cell transplant is another option your doctor may consider. A haploidentical donor may also be called a half-match donor. Usually, parents and their children are haploidentical to one another, sometimes siblings are as well.

Unrelated donor

Unrelated bone marrow donor registries have been developed to help the 60-70% of patients who don't have a suitable related donor. Bone marrow donor registries around the world list volunteers willing to anonymously donate blood stem cells for people needing a stem cell transplant. Donors have all had initial tissue typing which are recorded on the database.

Cord blood registries may be helpful in finding a donor for some children. Cord blood is collected from the placenta and the umbilical cord and stored on a database.

Harvesting donor stem cells

There are three ways to collect or harvest the donor's stem cells:

- **Peripheral blood stem cells:** This is when stem cells are collected from the donor's bloodstream through a process called apheresis (a-feh-ree-sis) after receiving medications to stimulate the bone marrow to produce blood stem cells.
- **Bone marrow stem cells:** This is when stem cells are collected from the donor's bone marrow through a process called bone marrow harvesting.
- **Umbilical cord blood stem cells:** Stem cells are frozen and stored in a cord blood bank.

The donor's stem cells must adequately match the genetic makeup of your own cells. Specialised blood tests (called tissue typing) are done to work out if the donor's cells match yours.

Transplant 'work up'

Your transplant team will book you in to get a variety of health checks and tests done to ensure you are physiologically fit for transplant.

Health checks and tests may include:

- Blood tests (including virology)
- Dental review
- Echocardiogram (ultrasound of your heart, also known as ECHO)
- Lung (pulmonary) function test
- Gynaecology review for adult female patients
- Restaging (bone marrow biopsy, PET, CT)
- Psychosocial assessment
- Transplant education with your nurse specialist
- Other – as directed by your haematologist.

You will meet the transplant doctor again to provide informed consent to proceed to SCT. You will have the contact details of your nurse specialist who you can liaise with regarding specific questions you may have along the way. If you reside far from the transplant centre, your eligibility for accommodation and travel assistance may be assessed according to specific criteria.

Your transplant team will put together a schedule, often with a calendar, so you know what to expect on each day when you're in hospital.

Your emotional and mental health is very important. You may experience a range of feelings while preparing for a stem cell transplant. You may be overwhelmed, confused, sad or eager to get started. All of these feelings are normal. You can talk to your transplant team if you have any questions or feel like you're not coping and need extra support.

What is conditioning treatment?

As part of your stem cell transplant you will receive treatment to get your body ready, even if your disease is in remission. This is called conditioning treatment and involves IV chemotherapy, and potentially radiotherapy.

The goal of conditioning treatment is to:

- Get rid of the dysfunctional cells remaining in your body.
- Make room for the donor stem cells in your bone marrow.
- Suppress (weaken) your immune system so you can accept the donor stem cells.

You may hear the phrase 'countdown to transplant' which is how your treatment team documents the number of days until your transplant. For example, day -5 (minus 5) means that you are five days away from transplant day, which is called day 0.

What happens on transplant day?

On day 0 you will receive the new donor cells.

The stem cell return is not a surgical procedure, it will take place in your hospital room. The donated stem cells are infused through your central venous catheter into your bloodstream (like a blood transfusion). Your transplant team will monitor you closely while you get your new cells. On the transplant day they will also explain to you what to expect, how long it will take and how you might feel.

The process of receiving the new stem cells can range from 30 minutes to 4 hours or more. The length of time can depend on the number (volume)

of cells you receive and how your body responds.

The infused stem cells make their way to your bone marrow where they set up home and begin to repopulate the bone marrow with immature blood cells that grow into healthy cells, such as white blood cells, platelets and red blood cells.

Neutropenic phase

After conditioning treatment (chemotherapy +/- radiotherapy) your blood counts drop. During this time, you will be more at risk of infections (due to low white blood cells). You will likely hear the word, 'neutropenic' which means you have a low number of neutrophils which are a type of white blood cell. You will be monitored closely for signs of infections, such as a fever and will likely require antibiotics to help prevent or treat infections.

At the same time, your blood counts will be low and at higher risk of bleeding (due to low platelets) and anaemia (due to low red blood cells). Blood and platelet transfusions are given regularly throughout your transplant to sustain your platelet and red blood cell levels.

Leaving the hospital

Once your blood counts have recovered with your new stem cells (engrafted) and you are feeling well enough, discharge planning may start.

Your transplant team will want you to stay close to the hospital as you will still have regular appointments and blood tests. Generally, this is for the first 3 months after your transplant. It's not uncommon for patients to be readmitted to hospital during their recovery with infections and other complications that require close monitoring.

Depending on how far you live from the hospital, you and your support person may be required to stay in accommodation close to the hospital before being discharged back home.

You will be given discharge instructions such as advice around taking your temperature, and what medications to take. Your transplant team will let you know who to contact if you have any questions or concerns. You will be provided with contact details for 24/7 advice.



Recovery and monitoring

Although your blood counts appear recovered, your new immune system is still vulnerable. Your body will take some time to recover to a normal level of functioning. This will differ from person to person but usually takes at least 12 months.

Many of the side effects of a stem cell transplant are temporary, however some can last longer and need ongoing monitoring.

As part of your follow-up care, your treatment team will discuss with you the following:

- **Vaccinations after transplant:** After your transplant, you will lose immunity to many of the diseases you were vaccinated against as a child. These include measles, mumps, rubella and polio. Your doctor will assess when your immune system has recovered enough to be re-vaccinated after your transplant.
- **Monitoring for graft versus host disease (GVHD):** GVHD is a common complication of allogeneic stem cell transplants. GVHD develops when the donor's T-lymphocytes, which are a type of white blood cell, recognises your body as foreign and begins to fight it. There are two main types of GVHD; acute GVHD and chronic

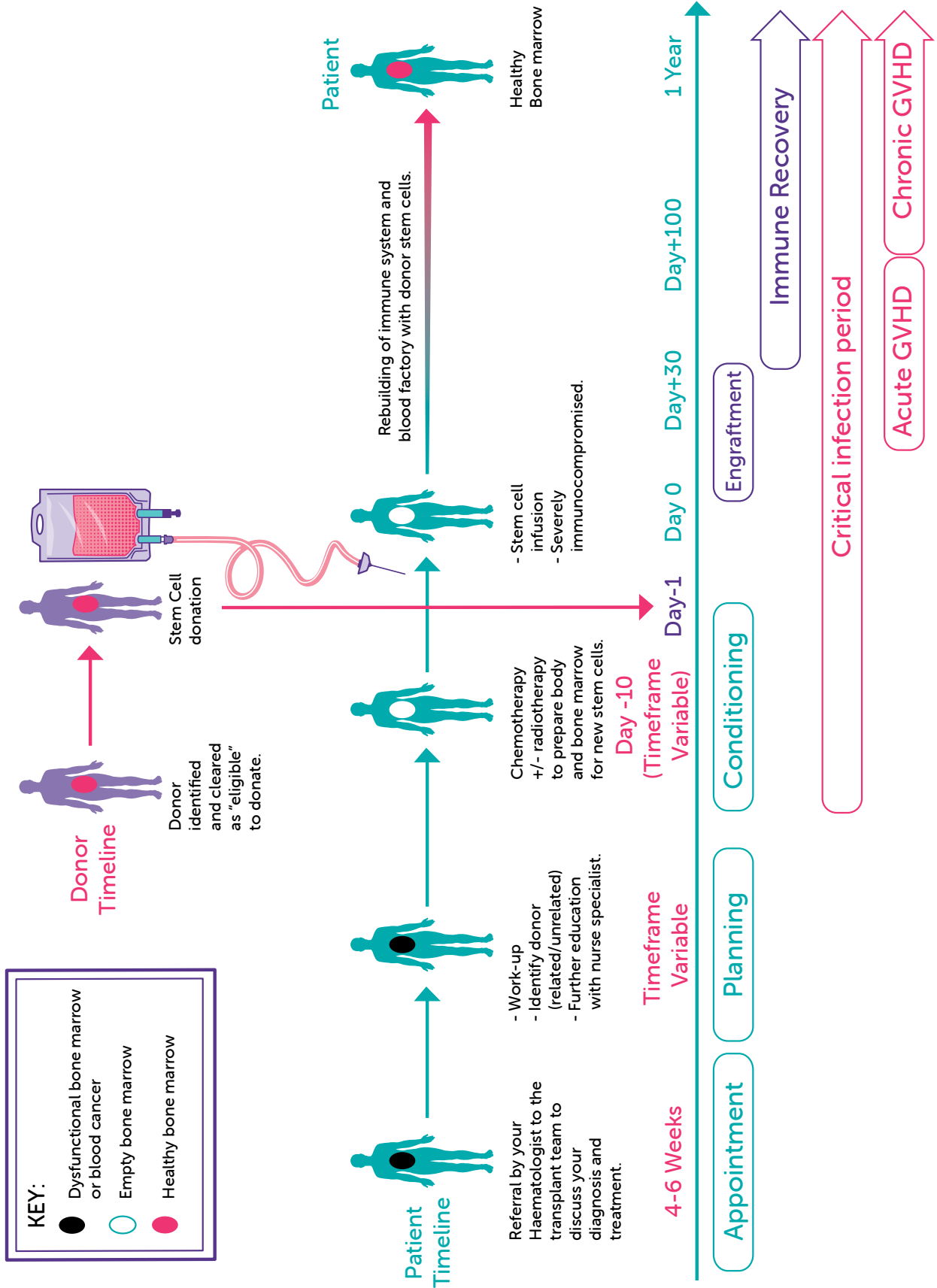
GVHD. Each type affects different organs and tissues and has different signs and symptoms. Everyone who has an allogeneic stem cell transplant takes prescribed immunosuppressant medications (anti-rejection medications) to reduce the chance of GVHD. It is important to report any untoward symptoms to your transplant team. There are medications available to treat GVHD. However, this can be a potentially life threatening complication of SCT if it doesn't respond to treatment.

- **Supportive care:** It is important to report if you are feeling post SCT symptoms, such as fatigue, increased weight loss, pain or change in mental and emotional wellbeing. You may be referred to another specialist team for symptom management.

Everyone's recovery from a stem cell transplant looks different. No two people are the same. It's important to contact your transplant team if you have any questions or concerns.

This information sheet is a brief overview about what an allogeneic stem cell transplant is. Please see page 5 for flowchart. Visit the LBC website for more detailed information. The LBC Support Services Coordinators are also available for support and information for you and your family/whānau.

Overview of an allogeneic stem cell transplant



FREQUENTLY ASKED QUESTIONS

- 1. Is stem cell transplant an operation?** No, it is not a surgical procedure. It takes place in your hospital room, not an operating room.
- 2. How long will I be in hospital for?** Length of stay in hospital is unpredictable and varies from person to person. Generally, people will be in hospital for 4-6 weeks. This includes getting your chemotherapy +/- radiation, the stem cell infusion and short term recovery.
- 3. Will the stem cell donation process impact my donor's health?** The stem cell donation process is a very safe procedure and should have no long-term impact on the donor's health. In rare occasions, donors may be required to donate stem cells through a bone marrow harvest procedure. This procedure is done under general anaesthetic (GA) and the donor may need to stay at the hospital the night following the procedure. Donors may experience bruising, mild discomfort and fatigue for 1-2 weeks following this procedure.
- 4. Is a half match donor enough?** Depending on the type of blood cancer or disorder you have and the potential donors that are available at the time of the search, a haploidentical or half-matched transplant may be recommended for you. In general, half matched donors are a safe and effective alternative to a full matched donor. If you are concerned about your donor options, please discuss this with your haematologist.
- 5. How does my ethnicity affect finding a donor?** A person's best chance of finding a donor may be with someone of the same ethnic background. If you do not have a suitable related donor an unrelated donor search may be conducted. Some ethnic groups are underrepresented on the unrelated donor registry and this may make finding a donor more difficult.
- 6. My friends and relatives want to get tissue typed, can they volunteer?** Generally, only your immediate family members are considered for tissue typing. Friends and extended family/whānau who wish to volunteer as a stem cell donor can find out more information from the New Zealand Bone Marrow Donor Registry (www.bonemarrow.org.nz).
- 7. Can people visit me in hospital when I am having my stem cell transplant?** Yes, although it is best to ask your transplant team about the visitor policy in place as it may differ between transplant centres. Your visitors may be required to complete a health questionnaire before entering the ward. This is to keep sick people away from the ward to minimise the risk of infection to patients. Visiting with children is often limited.
- 8. How can my friends and family support me through my stem cell transplant?** It can be hard for family and friends to know how to support you during your transplant. Your family and friends are your support team so let them know what you need and communicate clearly with them. It can be useful to suggest practical ways they can help and assign one person as the main contact to organise jobs.
- 9. Can I contact my unrelated donor?** Generally, there is no contact between unrelated volunteer donors and patients. If you wish, you may write a letter that your nurse specialist can send to your donor via the New Zealand Bone Marrow Donor Registry on your behalf. No personal details can be disclosed.
- 10. How long will it take for me to recover from my stem cell transplant?** There is no exact timeframe when you will recover from your transplant and everyone's experience will be different. It is a gradual recovery so it's important to be gentle on yourself. For many patients it is possible to start planning their return to work around one year post transplant.



Important information available online

For more information and to download other fact sheets, see our website www.leukaemia.org.nz

If you would like to get in touch:

Call: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

Or visit one of our Support Services offices in Auckland, Hamilton, Wellington, Christchurch or Dunedin