SABMR
SOUTH AFRICAN BONE MARROW REGISTRY

GUIDEBOOK
STEM CELL TRANSPLANT

FOR PATIENTS

1





Preparing for Your Stem Cell Transplant

BLOODSA FOUNDATION

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Welcome!

Your guide to a successful stem cell transplant!

Since joining the SABMR in 2016, it has been my privilege to work alongside dedicated professionals in the life-changing field of stem cell transplantation. Having previously served as Medical Director of the South African National Blood Transfusion Service, I have witnessed firsthand the power of human generosity and medical innovation in saving lives.

This guide is designed to help you understand your journey through stem cell transplantation, offering clarity and hope on every step of the way. Together, with your healthcare team and the support of your loved ones, you will make it through this journey to health. There is hope, healing, and a brighter future ahead.

Dr Charlotte Ingram

CEO and Medical Director
South African Bone Marrow Registry



Best Wishes

Three years ago, I founded BLOODSA with a vision to transform haematology care across Africa through research, quality management, education, and patient support. I've seen the profound impact that knowledge, collaboration, and compassion can have on patients and their families.

Stem cell transplantation is a journey of courage and resilience. This guide is here to equip you with the information and support you need to navigate this path with confidence. Together, through education and empowerment, we can improve outcomes and give hope to every patient and their loved ones.

Estelle Verburgh

CEO, **BLOODS**A | Consultant Haematologist, Groote Schuur Hospital, UCT

ACKNOWLEDGEMENTS

This resource would not have been made possible without the valuable support and input from the following organisations and individuals:

Zaahier Isaacs, Head of Patient Services, SABMR

Veronica Borrill, Past Head of Donor Services, SABMR

Dr Charlotte Ingram, CEO and Medical Director of SABMR

Dr Nicolé Smith, Medical Officer and National Outreach Officer, **BLOOD**SA





INTRODUCTION

If you are preparing to receive a stem cell or bone marrow transplant from a matched unrelated donor (MUD) arranged by the South African Bone Marrow Registry (SABMR) or another registry, you probably have many questions. This guide is designed to:

- Help you understand the details of the process.
- Provide tips on how you can prepare yourself for the transplant.
- Serve as a resource for any questions you may have.

This is the first guidebook in a series:

- **Book 1** – Preparing for Your Stem Cell Transplant
- **Book 2** – Hospital Admission for Your Stem Cell Transplant
- **Book 3** – Post-Transplant Recovery

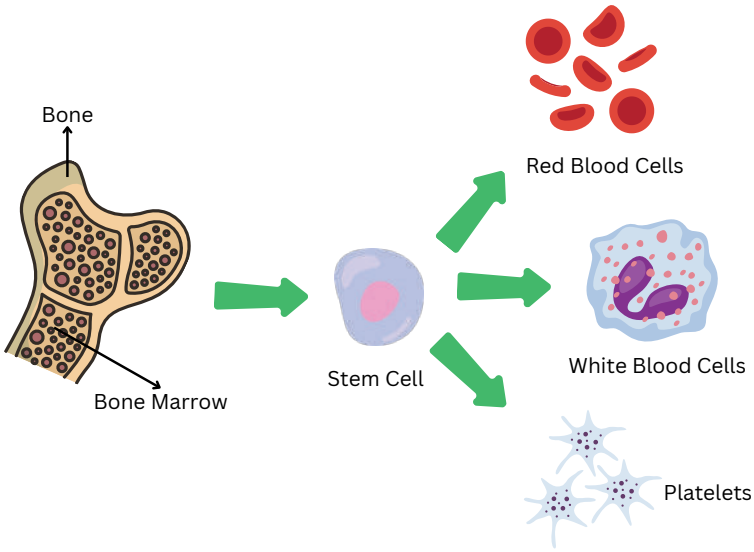
Please remember that this guide does not replace the medical advice given to you by your doctors. Your transplant team knows you best, so always follow their recommendations.





WHAT ARE STEM CELLS?

Stem cells are immature or "baby" cells that have the potential to grow into various types of mature blood cells. Haematopoietic stem cells are the specific type of stem cells found in bone marrow that produce blood cells.



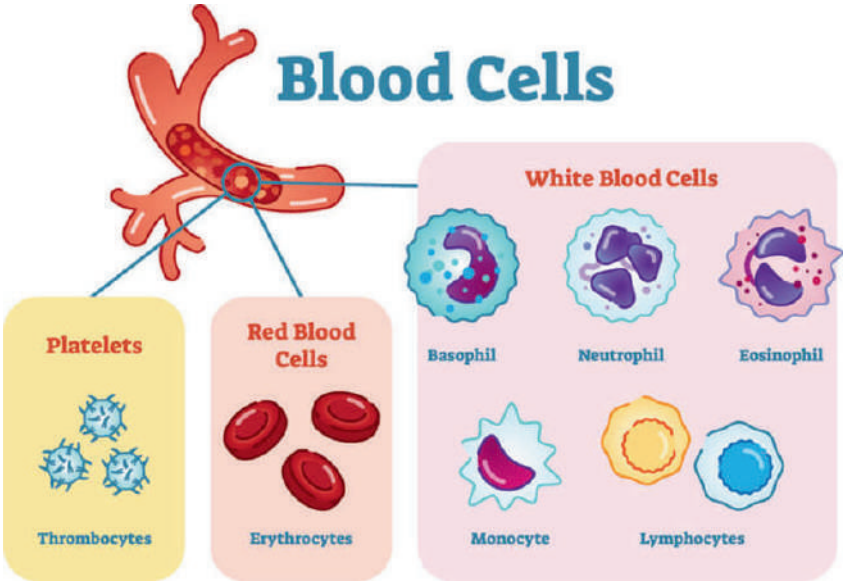
These stem cells form:

White Blood Cells (WBCs): Crucial for fighting infections.
Red Blood Cells (RBCs): Carry oxygen throughout your body.
Platelets: Help your blood to clot and stop bleeding.

White blood cells form a crucial part of your immune system and help your body to fight infections caused by bacteria, viruses and fungi. WBCs are also involved in allergic reactions.

Red blood cells contain haemoglobin (Hb) which carries oxygen to all the cells in the body. If a person's Hb levels are low, we refer to it as anaemia. Symptoms relate to a reduced ability to deliver oxygen to your body and include fatigue, shortness of breath and increased heart rate.

A platelet is a tiny disc-shaped cell that helps to form blood clots. Blood clots work to slow or stop bleeding and allow wounds to heal. Thrombocytopaenia is when the platelet count is low. If the platelet count is very low, there is a risk of spontaneous bleeding, either internally or externally. Platelet transfusions can temporarily improve low platelet levels in patients undergoing stem cell transplantation.



WHAT IS A STEM CELL TRANSPLANT?

A stem cell transplant, also called a bone marrow transplant, is a procedure where healthy stem cells are given to a patient to replace diseased or damaged bone marrow. This procedure is recognized worldwide as an effective treatment for certain types of blood diseases, both cancerous (malignant) and non-cancerous (benign).



In a stem cell transplant:

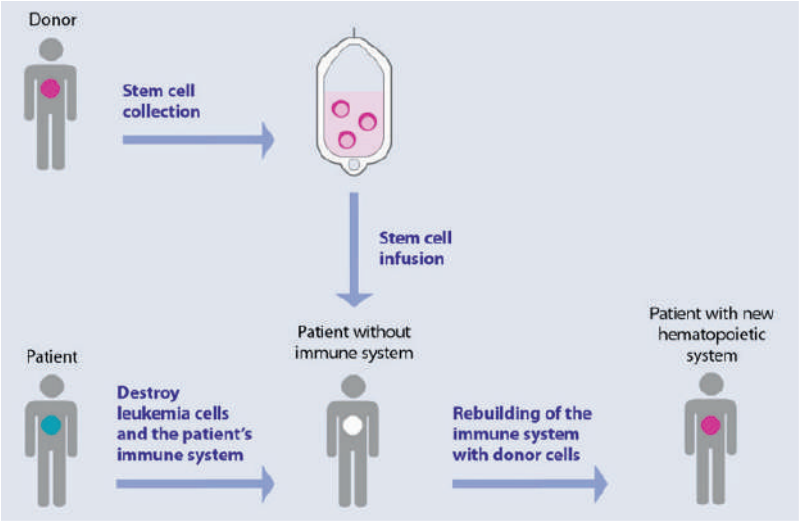
Bone Marrow Transplant (BMT): Stem cells are collected directly from the bone marrow, typically from the hip bones.

Peripheral Blood Stem Cell Transplant (PBSC): Stem cells are collected directly from the bloodstream.

Umbilical Cord Blood: Stem cells can also come from a newborn's umbilical cord, which has a rich supply of these cells.

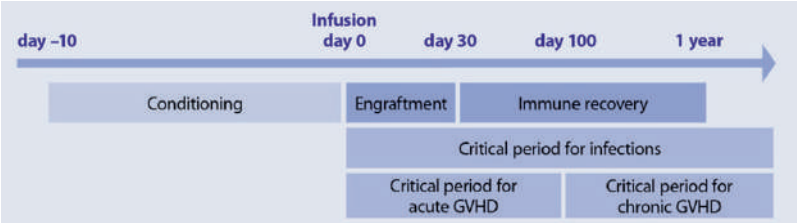
An **allogeneic** stem cell transplant is the process whereby a patient receives stem cells donated by an HLA-matched donor (this will be explained in the pages to come). The donor may be a sibling, an unrelated person or could even come from a baby's umbilical cord blood.

Patients receive **conditioning** which refers to high-dose chemotherapy combined either with or without radiation to destroy the cancer/diseased cells in your body. This is also known as the preparative regimen because it prepares the body to receive the donor cells. This therapy is given over several days, depending on the preparative regimen selected. This treatment also destroys your marrow which may be making the diseased cells. Once the conditioning therapy is complete, the transplant then takes place.



The healthy donated cells are then infused via intravenous (IV) infusion into your bloodstream, like a blood transfusion. The cells travel to the inside of your bones and begin to make healthy red blood cells, white blood cells and platelets.

Recovery may take time and complications may arise. Your transplant team will be available to support you throughout the transplant process and recovery.



Unrelated donor stem cell collections are organised through the Registry and the donated stem cells are delivered to your transplant centre by a trained and dedicated courier.

A hospital stay of between three and six weeks is required after the infusion of the stem cells or “transplant”. During this time, you will be monitored very closely for side effects. The side effects of conditioning therapy may include:

- Low blood counts
- Fever and Infection
- Fatigue
- Bleeding
- Nausea, vomiting and diarrhoea
- Mouth sores
- Decreased appetite
- Skin rash

The healthcare team will manage your side effects with medications, blood transfusions, IV fluids and interventions as appropriate.

Your full blood count (FBC) will be checked daily. After the conditioning therapy, the FBC values will drop below normal. The neutrophil count will fall close to zero and can remain low for several weeks. During that time, a patient is at high risk of infections. That can be the time when you feel the sickest. When the white blood cells start to recover, patients often feel better. This is called **engraftment**. After four to six weeks, you will be discharged and sent home.

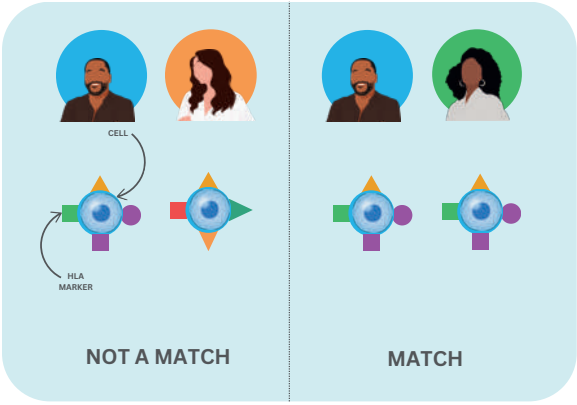
WHAT IS HLA MATCHING?

Human leukocyte antigens (HLA) are proteins present on the surface of nearly all cells in the body, except red blood cells. Your immune system uses these markers to recognize which cells belong in your body and which don't. HLA matching is essential in stem cell transplants to ensure that your body accepts the donor cells.

How HLA Matching Works:

- HLA testing identifies the specific HLA antigens on a patient's and potential donor's cells.
- This matching process is much more complex than simple blood typing.
- Samples, either blood or buccal (cheek) swabs, are taken from you and any potential donors.
- These samples are tested in a lab to determine HLA type, which is then compared for compatibility.

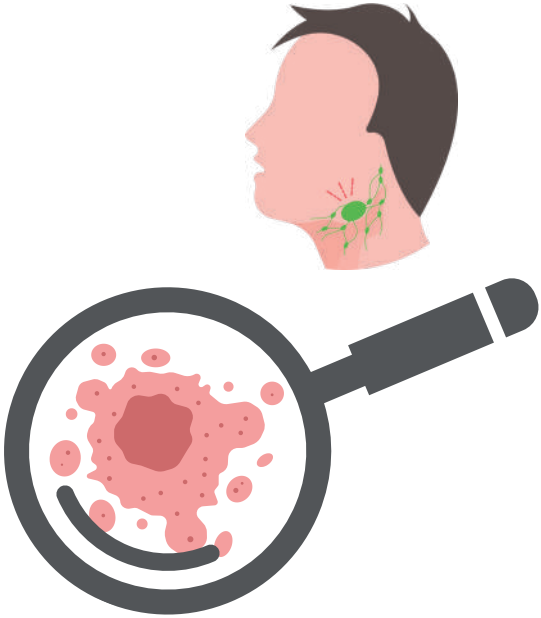
Since HLA types are inherited, you are more likely to match someone from a similar ethnic background. In some cases, it can be challenging to find a match if your HLA type is less common. Once a match is found, the donor will undergo additional tests to ensure they are healthy and can safely donate. If the stem cells come from an umbilical cord, they are also tested to ensure safety.



DISEASES TREATABLE WITH TRANSPLANTATION

Stem cell transplants can treat a range of diseases, including:

- **Leukaemia and lymphoma** (e.g., Myelogenous or Lymphoblastic leukemia, Hodgkin's lymphoma)
- **Bone marrow diseases** (e.g., Aplastic anaemia, Fanconi anaemia)
- **Inherited immune system disorders** (e.g., Severe Combined Immunodeficiency or SCID)
- **Haemoglobinopathies** (e.g., Thalassemia, Sickle Cell Disease)
- **Inherited metabolic disorders**
- **Myelodysplastic syndromes and myeloproliferative disorders**
- **Multiple myeloma and other plasma cell disorders**
- **Certain other malignancies or cancers**



TRANSPLANT ELIGIBILITY

Not every patient is a good candidate for an allogeneic stem cell transplant. There are many factors that must be considered before moving forward, such as:

• Response of the cancer or disorder to chemotherapy/radiation and/or other treatments
• Organ function (heart, lungs, liver, kidneys)
• Overall health and activity level
• Social support and the ability to follow important instructions related to medical care



The transplant team may decide that you do not qualify for a transplant because they believe the risks outweigh the benefits. Other treatment options may be recommendations for you.

The following may be suggested:
• Other types of medical treatments/chemotherapy/radiation.
• A clinical trial: At your transplant centre if one is available, otherwise one might potentially be available at another hospital.
• A second opinion from a hospital that may have different criteria than your current transplant centre. Please feel free to discuss this with your doctor.

PRE-TRANSPLANT TESTING

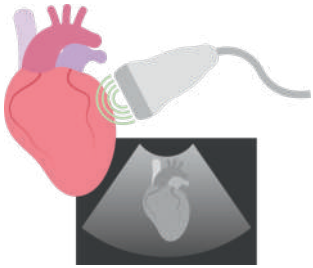
Before you are admitted to the hospital for transplant, the transplant doctor will complete a medical assessment or “pre-transplant work-up.” There are two reasons why this is necessary:

1. The transplant team must be certain that the organs are functioning normally before high-dose chemotherapy is administered.
2. Medical Aid Schemes require these results to authorize payment for the transplant.

Pre-transplant testing may be completed at the transplant centre or through a local doctor.

Heart

Echocardiogram: This is an ultrasound of the heart to show how well it pumps blood to the body.

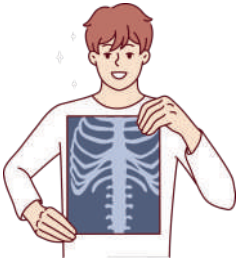


Electrocardiogram (ECG): Measures the electrical activity of the heart.

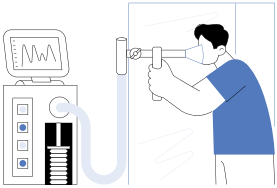


Lungs

Chest X-ray: Evaluates the heart, lungs and chest wall for abnormalities.



Pulmonary function test: Measures the lungs ability to perform effective breathing and oxygen delivery. This test requires you to follow instructions to breathe in, hold your breath and exhale forcefully. Caffeine and smoking are not allowed on the day of testing as they will affect the results.





Lab Tests

Blood and urine tests: Evaluate kidney and liver function. Full blood count. Measuring of disease status.







Infectious disease panel: Screening for a variety of previous virus infections. Please be aware that HIV testing is done on all SCT patients.



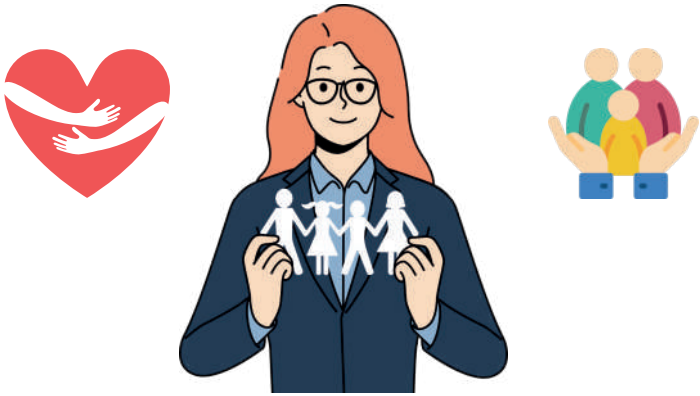


Other

Pregnancy testing and fertility planning: If you are a female and of childbearing age, a pregnancy test will be required before admission. For both men and women, it is important that you discuss fertility concerns and contraception with your doctor prior to transplant.



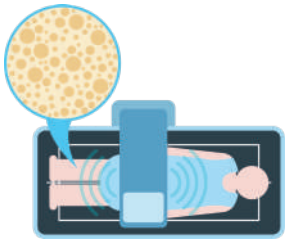
Social worker consult: A social worker will meet with you to assess psychological, social, emotional and practical needs. Your main caregiver should be present at this appointment.



Patients may also need:

Scans

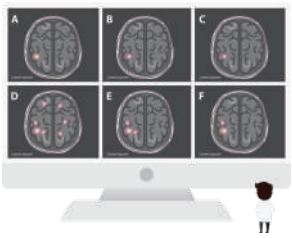
Bone scan: Uses a small amount of radioactive material to create images of bones on a computer screen. This test is useful in finding the spread of cancer to bones.



Computerized tomography (CT) scan: A series of X-ray pictures taken of the body from different angles to search for abnormalities. This is often done at the same time as a PET scan to confirm findings.



Magnetic resonance imaging (MRI) scan: Uses very high-powered magnets to form detailed pictures of the body's soft tissues and identify areas where tumours are present. You may not be able to have an MRI if you have any metal inside your body.



Positron emission tomography (PET) scan: You are injected with a small amount of radioactive sugar that cancer cells quickly consume. This causes them to light up on the scan so that the doctor can easily visualize their location in the body. You need to fast prior to the PET scan to make sure that your own body sugar is not too high.



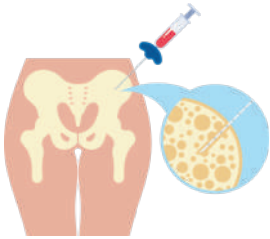
Biopsies

Tissue-specific biopsies: A small sample of tissue (e.g., a lymph node) is removed and examined in the lab. This confirms the presence of disease in a specific location.





Bone marrow biopsy: A sample of bone marrow is examined to confirm disease status and/or remission.

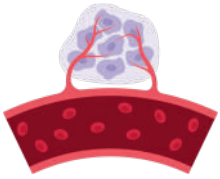


HOSPITAL STAY AND RECOVERY

The timeline to transplant depends on various factors including the availability of a donor. Once conditioning is complete, the transplant will take place. The healthy donor stem cells will be infused into your bloodstream through an intravenous (IV) line, similar to a blood transfusion. These cells travel to your bones and begin producing healthy blood cells, including red and white blood cells and platelets.

The hospital admission lasts on average three to six weeks, but complications may extend this timeframe. Factors affecting length of stay include:

• **Donor source** (sibling, unrelated donor or cord blood)
• **Intensity of conditioning regimen**
• **Age and overall general health** going into transplant
• **Time to engraftment**
• **Individual response:** Recovery after discharge may take several months to even a year or more. Individual cases vary.



After the transplant, you'll likely stay in the hospital for 3–6 weeks, during which your medical team will monitor you closely for side effects. Recovery may take time, and complications can arise. Here's what you might experience:

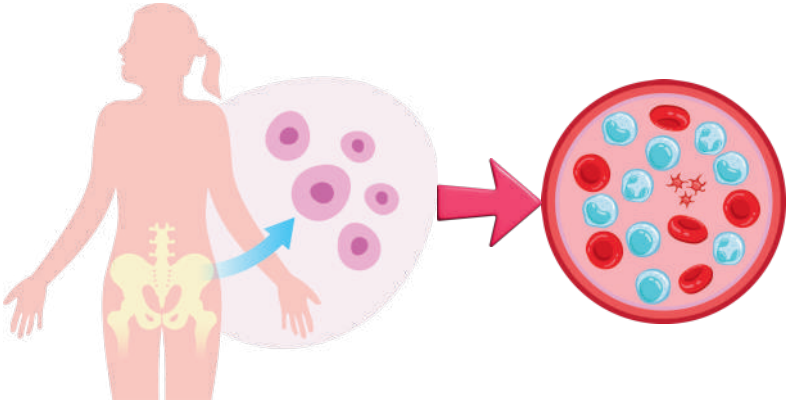
- Low blood counts
- Fever and infection
- Fatigue
- Bleeding
- Nausea, vomiting, and diarrhoea
- Mouth sores
- Decreased appetite
- Skin rash



The healthcare team will manage your side effects with medications, blood transfusions, IV fluids and interventions as appropriate. Your full blood count (FBC) will be checked daily. After the conditioning therapy, your blood cell counts will drop below normal. The neutrophil count (one of your white blood cell types) will fall close to zero and can remain low for several weeks. During that time, a patient is at high risk of infections. That can be the time when you feel the sickest.



When the white blood cells start to recover, patients often feel better. This is called **engraftment**. After four to six weeks, you will be discharged and sent home.



CRITERIA FOR DISCHARGE

Discharge from the hospital is dependent on the following factors:

1. Blood counts returning to a level the doctor feels is safe.
2. No fever present or need for IV antibiotics.
3. Ability to drink fluids; nausea/vomiting/diarrhoea controlled by oral medications.
4. Ability to walk and function safely at home.
5. Discharge medications are available, and the medication schedule is understood. The patient will be required to see their transplant doctor frequently in the first 100 days after transplant.

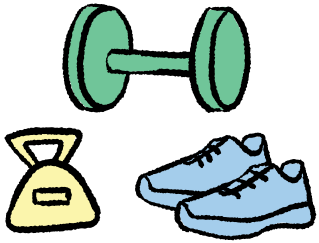


PHYSICAL AND MENTAL PREPARATION

As you prepare for your SCT, talk to your doctor about ways you can help yourself prepare for this treatment. Your doctor may recommend activities and perhaps specific exercises to help get you physically stronger. We realize that the time prior to SCT may create feelings of anxiety as you are going through the medical evaluations.

Exercise, as guided by your doctor, can be a very useful way to reduce anxiety and stress while optimizing your fitness level going into the SCT.





Nutrition is important to help you maintain your weight and strength during the transplant process. The chemotherapy you will receive during your stem cell transplant will affect your nutrition in many ways. You may find that you are not eating the way you normally do because of nausea, mouth and throat soreness, lack of appetite or changes in the way foods taste. You will meet with a registered dietitian to help guide you on the best food choices before, during and after transplant.



Keep faith in the healing journey ahead;
you are braver than you know, and brighter days await.

Emotional readiness is important as well. A blood and marrow transplant is a long, emotionally and physically challenging process for you and your loved ones. Feel free to discuss any concerns you have with your coordinator, nurse, doctor or social worker.



Smoking Cessation
Smoking and transplantation do not go together. Your clinician will discuss options for cessation with you as part of the process prior to transplantation. All patients and visitors coming to the Transplant Unit must be aware that smoking or vaping is not permitted anywhere on site.

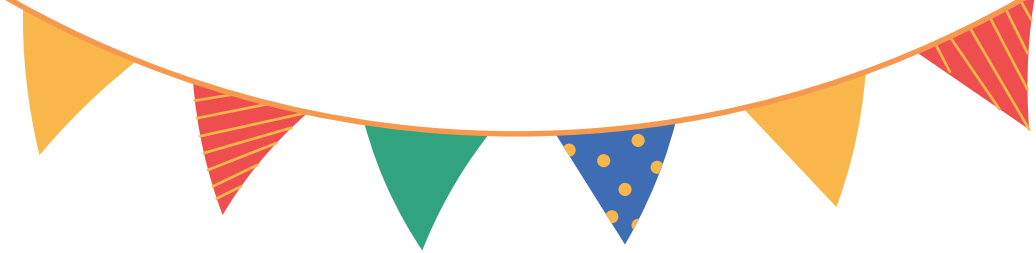
Alcohol and Drug Addiction
Your doctor will advise you not to consume alcohol during this period. Being honest with your transplant team about these issues is very important. Our goal is to get you through the SCT safely. In order to do that, we need to know if you have any alcohol or drug-related problems or concerns. We will then direct you to the right professional and resources to receive help. The transplant team can help you meet the requirements by making appropriate referrals based on your addiction and your commitment to overcoming it.



This guidebook has provided an overview of the stem cell transplant process, from understanding stem cells and HLA matching to the conditioning phase, transplant procedure, and recovery.

Each person experiences the transplant journey differently, and your healthcare team is here to support you every step of the way. Don't hesitate to reach out with questions or concerns. Your health, safety, and comfort are their priorities throughout this process.





THIS GUIDE IS CONTINUED IN BOOK 2: HOSPITAL ADMISSION FOR YOUR STEM CELL TRANSPLANT

Other RESOURCES



In 2020, the SABMR teamed up with 11-year-old transplant recipient Rachel Ancer and her family to produce Rachel's Second Chance, an illustrated children's book and educational booklet on bone marrow transplants. With hope, humour, and insight, including key elements of the transplant process and advice on what to expect during a transplant journey, Rachel's Second Chance is a resource for the whole family.

Buy a Copy Here

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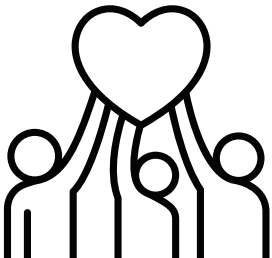

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