SABMR
SOUTH AFRICAN BONE MARROW REGISTRY

GUIDEBOOK

STEM CELL TRANSPLANT

FOR PATIENTS

3





Post-transplant Recovery

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 third 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.





POST-TRANSPLANT RECOVERY

After your transplant, you'll stay in isolation at the hospital to ensure your safety and manage any side effects. Your care team will monitor you closely to prevent complications and make your recovery as comfortable as possible.

Understanding Risks and Complications

Some risks after an allogeneic stem cell transplant include:

- Side effects of high-dose chemotherapy and/or radiation therapy
- Lowered blood cell counts (neutropenia, anaemia, and thrombocytopaenia)
- Organ toxicity (damage to organs from treatment)
- Graft-versus-host disease (GVHD)

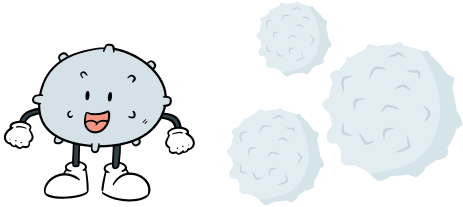


The Basics of Monitoring Your Blood Counts

A full blood count consists of your white blood cell count, haemoglobin and platelet count. This is a blood test which will be performed daily in the initial period after your transplant.

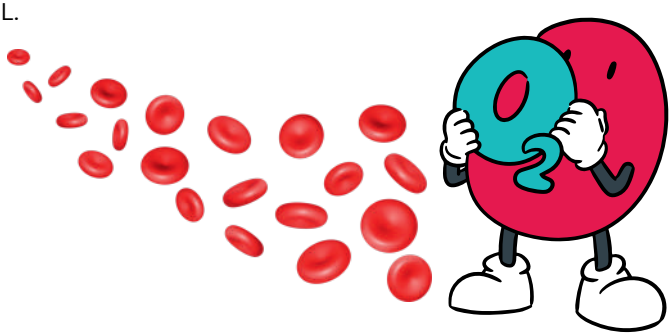
White Blood Cell Count (WBC)

This measures the number of all of the white blood cells in the body that fight and prevent infection. One of these white blood cells, known as a neutrophil, helps to fight bacterial infections. An additional test, known as a differential cell count (diff), can be done to determine the number of neutrophils in the blood.



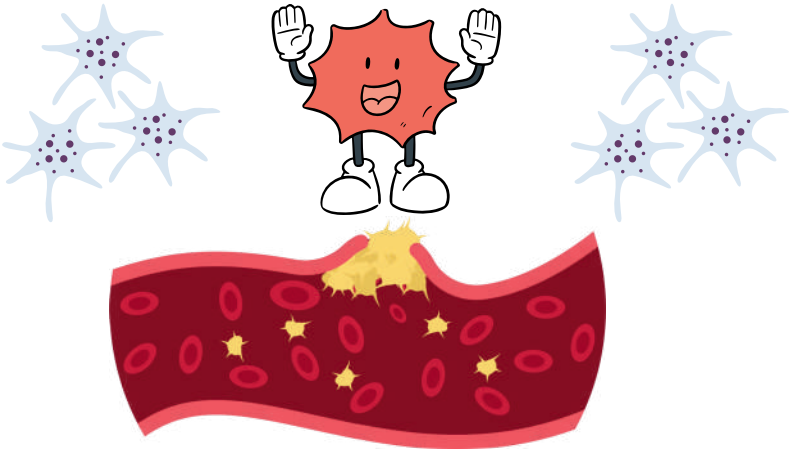
Haemoglobin (Hb)

• The level of haemoglobin determines the red blood cell's ability to carry oxygen.
• Normal values are generally between 13 to 17 g/dL.
• When your Hb is low, it is referred to as "anaemia".
• Packed red blood cells are generally transfused when the Hb is less than 7 g/dL.

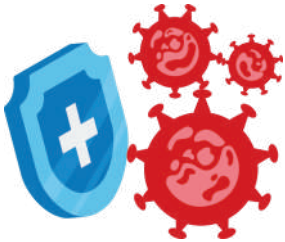


Platelets

• Platelets help prevent bleeding.
• Normal values range between 150 to 450 × 10^9/L.
• When platelets are low, it is referred to as "thrombocytopaenia".
• Platelets are generally transfused when the platelet count falls below 10 × 10^9/L, as there can be dangerous bleeding in the presence of a very low count.



We know that after receiving conditioning, your blood counts will all drop below normal. For each type of blood cell, there are specific risks and safety measures to be aware of.



Neutropaenia
Neutropaenia occurs when your neutrophil count falls below 1×10^9/L, leaving your immune system vulnerable. Think of your immune system as an army protecting you from harmful invaders like bacteria—neutropenia is like that entire army going on holiday at the same time, leaving you defenceless.

To protect yourself, follow these essential precautions:

Personal Hygiene

- **Handwashing**: Wash your hands frequently with soap and water, especially after:
  - Using the bathroom
  - Before and after eating
  - After touching items that others may have handled.

  Ask others to clean their hands before assisting or touching you.



- **Oral Care**: Clean your mouth at least four times a day. If you wear dentures, remove and clean them regularly.



- **Skin Care**:
  - Wash and dry your rectal area after each bowel movement. If you have diarrhoea, inform your nurse so he/she can help you to prevent skin irritation.
  - Avoid using tampons or suppositories.



- **Daily Showering**:
  - Inspect your skin for any rashes, redness, sores, or cuts.
  - Use the antimicrobial and antifungal soap provided (e.g., Sanisoap or Bioscrub) and apply antifungal powder to skin folds after drying. Do not use soap from home.



- **Room Cleanliness**: Keep your room tidy to allow housekeeping to clean effectively.



- **Food Safety**: Do not keep leftover food by your bedside.



Monitoring and Managing Fever

After your transplant, your white blood cell count, including your neutrophil count, may drop to zero for several days. A fever is a common sign of infection, so if your temperature reaches:

- 38.0°C orally or higher
- 38.5°C temporally or higher,



Then your nurse will immediately take blood and urine cultures and start IV antibiotics. Nearly all transplant patients experience fevers, but strict personal hygiene is your **best** defense against infection!

Watch for Symptoms of Infection:

- Shaking chills
- Cough or sore throat
- Redness, swelling, or pain in any area
- Mouth sores or blisters
- Difficulty urinating or cloudy, foul-smelling urine



Anaemia
Anaemia happens when your red blood cell count and haemoglobin is low, reducing your bodys ability to carry oxygen. Symptoms may include:

- Dizziness
- Shortness of breath
- Headache
- Pounding heart
- Fatigue

Let your nurse know if you experience any of these symptoms. A red blood cell transfusion may need to be given if your haemoglobin level drops below 7 g/dL.



Coping with Fatigue
Anaemia-related fatigue can make you feel down or depressed. As your Hb recovers, so will your energy and mood. However, emotional support can be helpful during this time.

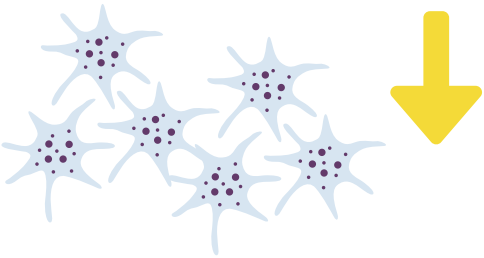
- **Stay Active:** Try light daily exercise, even if it's challenging at first. This can improve sleep and make rest more refreshing.
- **Caution with Hot Showers:** Very hot or long showers may cause dizziness, weakness, or fatigue—be careful!





Thrombocytopenia
Thrombocytopenia occurs when your platelet count drops below normal levels, increasing the risk of bleeding. Platelets are essential for blood clotting, helping to stop bleeding when you get a cut. After your conditioning treatment, your platelet levels will decrease significantly, putting you at risk for both external bleeding (like nosebleeds) and internal bleeding (such as in the brain or stomach).





Platelet transfusions are usually given when your count falls below 10,000 (10×10^9/L), in order to prevent serious bleeding.

Most patients don't experience severe bleeding, but it's essential to follow these precautions:



Safety Tips for Low Platelets

- Call your doctor or nurse immediately if you notice:
  - Any bleeding
  - Headache, confusion, or changes in vision, movement, or coordination
  - Black or bloody stools
  - Bruising or red spots under the skin

- **Oral care:** Use a soft toothbrush and if you normally floss, do so gently.
- **Nose care:** Dab your nose instead of blowing or picking it.
- **Head positioning:** Avoid bending over so that your head is kept above the level of your heart.
- **Personal grooming:** Avoid nail clippers and rather use an electric razor for shaving, if you need to.
- **Menstruation:** If you're menstruating, you may be given medication to stop your period. Use sanitary pads instead of tampons if your period does start.

Fall Risk

Falls can be dangerous when your blood counts are low, as they may cause severe bleeding, bone fractures, and delayed recovery. Your fall risk can change daily, depending on factors like:

- Drowsiness, weakness, or balance issues
- Peripheral neuropathy (numbness or tingling in fingers and toes)
- Postural hypotension (dizziness when standing)
- Anaemia (low red blood cell counts causing fatigue)
- Medications that cause drowsiness, dizziness, or blood pressure changes



Preventing Falls

- **Regular Rounds:** Nurses will check on you regularly to assist with tasks like getting up or using the bathroom.
- **Call Button:** Keep it within reach and use it if you feel dizzy, weak, or unsteady.
- **Fall Risk Alerts:** Wristbands and door signs alert staff and family members to your fall risk.
- **Walking Aids:** Use devices like walkers if needed. Wear non-slip socks or shoes.
- **Physical Therapy:** Muscle strengthening and balance training may be provided.



Safety Tips



- Always ask for help when moving around.
- Inform staff if you feel different or unwell.
- Know the side effects of your medication.
- Keep your room well-lit and free from clutter.
- Get out of bed slowly and sit on the edge of the bed before standing.

Despite the risk of falls, staying active helps combat fatigue and weakness.

Symptoms of Fatigue:



- Weakness
- Drowsiness
- Flu-like tiredness
- Difficulty concentrating
- Trouble performing daily tasks

Exercise is a proven way to reduce fatigue. Even light activity can:



- Maintain physical function
- Combat fatigue
- Strengthen muscles
- Boost mood
- Help prevent lung infections
- Release endorphins which improve feelings of well-being
- Reduce depression and improve the feeling of control over your life

Safe Exercise Tips



- Walk the hallway at least twice a day unless advised otherwise, staying on your ward floor.
- Pace: Walk at a pace where you can speak comfortably.
- Dress: Wear a mask, athletic shoes, and comfortable clothing.
- Hygiene: Wash your hands or use hand sanitiser after walking.
- Support: Ask nursing staff for help if needed.

Try to sit up for meals and activities, even if watching TV, to avoid staying in bed too long. Follow any simple exercises your physiotherapist recommends.

Report Immediately If You Experience:



- Shortness of breath
- Chest pain
- Coughing or wheezing
- Weakness or dizziness

Staying active and cautious can help speed up your recovery. Your healthcare team is dedicated to your safety and well-being, so always communicate any concerns.

LOW MICROBIAL DIET

After a stem cell transplant, your immune system will be weaker, increasing your risk of infections from microbes (usually harmless germs) found in food. Following these safe food practices will help reduce the risk of foodbourne illnesses.

Cooked Foods

- Proper cooking kills harmful bacteria in food.
- Avoid raw or undercooked meats, fish, poultry, tofu, eggs, and egg substitutes. Ensure eggs have firm yolks and whites.
- Eat food immediately after preparation.
- Discard food left at room temperature for more than one hour.
- Avoid foods with mayonnaise unless consumed immediately after preparation. Do not save for later.



Dairy Products

- Limit dairy intake for 100 days post-transplant due to potential lactose intolerance, which can cause bloating, gas, and cramps.
- Only use pasteurized milk and dairy products.
- Avoid soft, mouldy, or vegetable-infused cheeses.
- Use only sealed, individual cartons of commercial milkshakes or supplements. Discard if the container is damaged.
- Do not use products near or past their expiration date.



Fruits and Vegetables

- Wash thoroughly under running water before eating, peeling, or slicing but do not use soap or detergent to do so.
- Use a vegetable brush to remove dirt.
- Discard produce with cuts, bruises, or visible mould.
- Soak raw produce for at least two minutes before peeling or slicing, even if you plan to remove the skin.
- Avoid all raw vegetable sprouts (e.g., alfalfa, mung beans).
- Avoid unpasteurised juices and smoothies.



Miscellaneous Tips

- Avoid deli items like cold cut meats, cheeses, salads, salsas, and pre-cut produce.
- Avoid fermented foods and drinks.
- Consume only shelled, roasted nuts and commercial, heat-treated honey.
- Store leftovers in the refrigerator or freezer immediately. Label with the date and time.
- Do not eat leftovers stored for more than 24 hours.
- Do not thaw frozen food at room temperature or refreeze defrosted items.



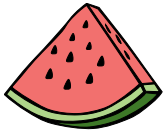


Important Notes

- Follow this diet during your transplant admission and for the first 100 days after discharge.
- Use common sense when making food choices and avoid high-risk items.
- Outside food is not allowed in the hospital unless approved by your transplant doctor.

By adhering to these guidelines, you can help protect yourself from foodbourne illnesses and support your recovery.





MANAGING COMMON POST-TRANSPLANT SIDE EFFECTS

Nausea, Vomiting, and Loss of Appetite

- Prevalence: Common after transplantation, typically improves as blood counts recover.
- Treatment: Strong anti-nausea medications are available. Inform your doctor or nurse immediately when feeling nauseous.
- Dietary Support: Consult the clinical dietitian for tailored food choices.
- Tip: Do not force yourself to eat favorite foods to avoid future food aversions.



Mouth Sores and Swallowing Problems (Mucositis & Stomatitis)

- Cause: Chemotherapy damages cells in the mouth and gut lining.
- Symptoms: Swelling, pain, and difficulty swallowing.
- Management:
  - Brush teeth with a soft-bristle toothbrush after meals and at bedtime.
  - Use salt rinses; avoid alcohol-based mouthwashes.
  - Notify the nurse if pain or bleeding occurs.
  - Keep lips moisturized with lip balm.
  - Clean dentures thoroughly; avoid alcohol-based solutions.
- Tip: Intravenous fluids will replace necessary nutrients if eating is difficult.



Diarrhoea and Constipation

- Causes: Treatment-related intestinal swelling, medications, or antibiotics.



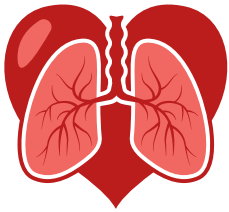
Skin Problems

- Common Issues: Reactions to dressings, adhesive tapes, or medications.
- Action: Report any rashes, redness, lesions, or itching to your transplant team for prompt evaluation.



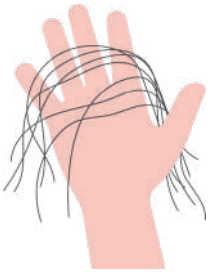
Heart and Lung Problems

- Vital signs monitored every four hours. Abnormalities are reported for further testing, such as an EKG or chest X-ray.



Hair Loss

- Cause: Conditioning therapy.
- Duration: Temporary; hair regrowth typically occurs post-treatment.



Neurological Problems

- Causes: Medications, low blood counts, or electrolyte imbalances.
- Symptoms to Watch For:
  - Headache, visual changes, dizziness
  - Numbness, tingling, or abnormal muscle movements
  - Mood changes, anxiety, or sleep difficulties
- Monitoring: Daily assessments by the transplant team.



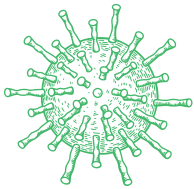
Engraftment Syndrome

- Cause: Cytokine release prior to rising white blood cell counts.
- Symptoms: Fever, skin rash, swelling, rapid weight gain, shortness of breath, and organ function changes.
- Treatment: Steroids, with rapid symptom improvement expected.



Post-Transplant Lymphoproliferative Disorder (PTLD)

- Cause: Epstein-Barr Virus (EBV) linked to immune-suppressing medications.
- Monitoring: EBV levels are checked post-transplant. Early treatment begins if levels rise.



GRAFT VS HOST DISEASE

What is Graft vs Host Disease (GVHD)?
GVHD is a common complication following stem cell transplantation, where the donor's immune cells attack the recipient's body. Despite HLA matching, GVHD can still occur and may range from mild to life-threatening.

Types of GVHD
Acute GVHD

- Onset: Within the first 100 days post-transplant.
- Key Symptoms:
  - **Skin**: Rash, often starting on hands/feet, ranging from mild redness to severe blistering and peeling.



  - **GI Tract:** Diarrhoea, ranging from mild to severe.



  - **Liver:** Abnormal liver function tests, potential jaundice.





- **Action:** Immediate symptom reporting is critical for early intervention.



Chronic GVHD
Onset: Three months to three years post-transplant.

Common Symptoms:

- **Skin:** Darkening, thickening, or hardening; dryness, flaking, peeling.



- **Eyes:** Dryness, irritation, sensitivity, cataracts.



- **GI Tract:** Dry mouth, cavities, gum disease, diarrhoea, liver inflammation, difficulty swallowing.



- **Joints:** Pain, weakness, swelling.



- **Lungs**: Cough, shortness of breath.



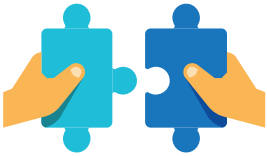
- **Hairloss**



Action: Early symptom recognition and reporting can improve outcomes.

Prevention of GVHD

- **HLA Matching**: Selecting the best-matched donor.
- **Immunosuppressants**:
  - Suppress the host's immune system to prevent donor cell rejection.
  - Calm donor immune cells for a gradual adaptation.





Management

- **Medications**: Steroids and adjusted immunosuppressants are used to control symptoms.

- **Monitoring**: Regular blood tests help your doctor adjust immunosuppressant doses.

- **Your Role**:
  - Adhere strictly to medication schedules.
  - Practice sun protection to avoid triggering skin GVHD.
  - Promptly report symptoms.







GRAFT VERSUS DISEASE EFFECT

Graft-Versus-Disease (GVD) Effect

- **Definition**: When donor cells attack residual cancer cells (leukaemia, lymphoma, myeloma) in the body.

- **Link with GVHD**:
  - The same immune cells responsible for GVD may also cause GVHD.
  - Mild GVHD may indicate a beneficial GVD effect, potentially reducing relapse risk.

- **Current Limitations**:
  - There is no method to enhance GVD while suppressing GVHD.
  - GVD plays a crucial role in non-myeloablative, myeloablative, and reduced-intensity transplants.
  - Donor Lymphocyte Infusions (DLI) leverage GVD to boost anti-cancer effects.



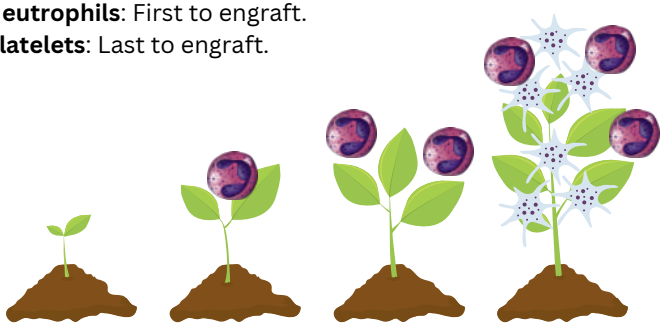
ENGRAFTMENT

A MILESTONE IN RECOVERY

Engraftment signals a significant step in your transplant journey, marking the point when donor stem cells begin to grow and produce new blood cells in your bone marrow.

What is Engraftment?

- **Analogy**: Think of it as a seed planted in soil—it takes time before it sprouts. Similarly, donor stem cells need time to establish themselves and start producing new blood cells.
- **Monitoring**: Your full blood count is the key indicator of engraftment.
  - **Neutrophils**: First to engraft.
  - **Platelets**: Last to engraft.



Chimerism Testing

- This test measures the proportion of donor DNA compared to your DNA in your blood and bone marrow.
- Goal: >95% donor DNA, indicating successful engraftment.
- Low Donor DNA: Suggests possible graft rejection or failure and may require further treatment.



DISCHARGE INSTRUCTIONS

Before you leave the hospital, your transplant team will provide detailed guidance on your home-care. Here's what to prepare:

Caregiver Requirements

- A caregiver is essential for the first 100 days post-transplant, except during hospital visits.
- Caregivers must have an annual flu vaccination.



Home Environment

- Ensure the house is clean.
- Pets:
  - Keep dogs and cats clean and well-groomed.
  - Avoid handling litter boxes, pet waste, or cleaning cages and tanks for animals like hamsters, rabbits, snakes, lizards, or fish.

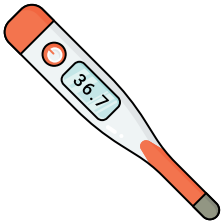






Health Monitoring

- Have an accurate thermometer to monitor your temperature.



Medications & Appointments

- Ensure all prescriptions are filled and you understand the medication schedule.
- Review clinic appointments and follow-up care details.



Alternate Caregiver Plan

- Arrange for an alternate caregiver incase your primary caregiver or children become ill.





Daily Self-Assessments

- Perform a head-to-toe check every day (ideal during a shower).
- Key questions: How do I feel? What's different? What can improve my day?
- Early detection of changes enhances treatment success.





Infection Prevention

Even post-engraftment, your immune system remains vulnerable:

- **Common Threats**:
  - Bacterial: Pneumonia, PICC line infections.
  - Viral: Shingles, CMV.
  - Fungal: Aspergillus, Candida.

- **Tips**:
  - Handwashing is crucial.
  - Avoid sick contacts and take your temperature daily (report temperature ≥38°C).
  - PICC line care: Keep dry, report any issues.
  - Oral hygiene: Use a soft toothbrush, floss daily, and avoid sharing utensils.



Emotional and Physical Recovery

- **Initial Fatigue**: Likely due to increased home activity demands.
- **Emotional Well-Being**: Mood swings, anxiety, or depression are normal.
  - Talk to your healthcare team for support or counselling options.
- **Intimacy**: Open communication with your partner is key. If concerned, speak to your doctor or nurse.
- **Fertility**: Infertility may be a result of conditioning regimens. However, contraception is still recommended.



Activity Guidelines

- **Rest and Light Exercise**: Balance rest with gentle activities like walking.
- **Crowds**: Avoid large gatherings and sun exposure (wear at least SPF 30, long sleeves and a hat).
- **Restricted Activities**:
  - Avoid dental visits and public pools until approved by your doctor.
  - Stay away from gardening, pets, and environments with potential fungal exposure.



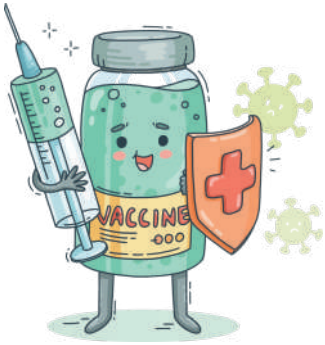
Diet After Transplant

- **Low-Microbial Diet**: Follow for 100 days post-transplant.
- **Taste Changes**: Temporary alteration may occur due to conditioning therapy.
- **Hydration**: Drink plenty of fluids, unless advised otherwise.
- **Variety**: Aim for a balanced diet with nutritious foods and snacks.



Immunisations

- **Re-vaccination**: Childhood immunizations are repeated one year post-transplant.
- **Flu Shot**: Recommended for close contacts; you may receive it six months post-transplant.
- **Avoid Contact**: Stay away from recently vaccinated children who received live virus vaccines (e.g., MMR, polio).



When to Call the Doctor or Nurse
If you experience any of the following, call immediately:

- Fever: Temperature ≥38°C (oral)
- Chills/sweating
- Cough
- Rash
- Difficulty eating or drinking
- Redness or pain at PICC/IV site
- Vomiting
- Mouth sores
- Diarrhoea/constipation
- Bleeding
- Pain
- Painful or frequent urination
- Inability to urinate
- Jaundice (yellow skin)
- General feeling of being unwell or that “something is wrong”



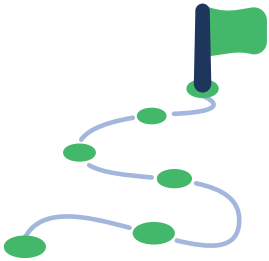
Important: A fever after transplant is an **emergency**. Call right away. Delaying care can lead to serious complications.



Depending on your recovery progress, you may need to stay near the transplant center for easier access to follow-up care.

Follow-Up Appointments

- **Frequency**: Initially twice weekly for six weeks, then weekly, and later every two weeks for six months.
- **Blood Draws**: Regularly conducted to monitor recovery and detect complications.
- **Day +100 Milestone**: Marks full engraftment and reduced complication risk.



Immunosuppression Monitoring

- Regular drug-level checks ensures optimal dosing.
- Tips for Accuracy:
  - Take medication at the same time daily.
  - On test days, delay your morning medication dose until after the blood draw.
  - Avoid grapefruit juice and limit potassium-rich foods.





DONOR LYMPHOCYTE INFUSION

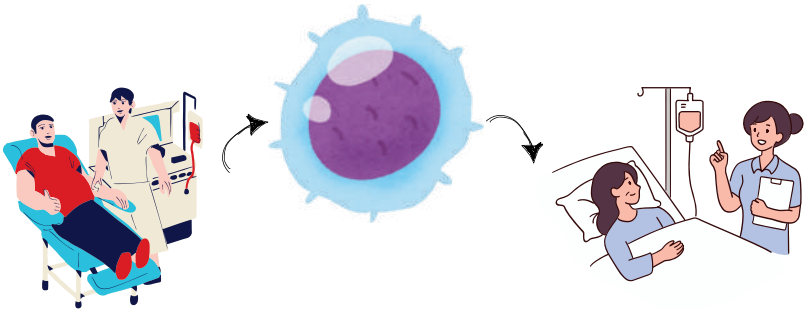
If your cancer returns after SCT or if donor chimerism levels are low, a Donor Lymphocyte Infusion (DLI) may be necessary.

Purpose: Boosts your immune system using donor lymphocytes to fight leukemia (graft-versus-leukemia or GVL effect).

Collection:

- Lymphocytes are collected from the donor via a procedure similar to the stem cell collection, where blood is drawn from one arm, lymphocytes are separated, and the rest is returned to the donor.

Pre-DLI Treatment: Chemotherapy (similar to the initial conditioning therapy) may be administered beforehand.



GVHD and GVL:

- GVHD may occur as the lymphocytes attack healthy tissues but can also indicate that the GVL effect is active.
- GVHD is typically treated with steroids and other medications.

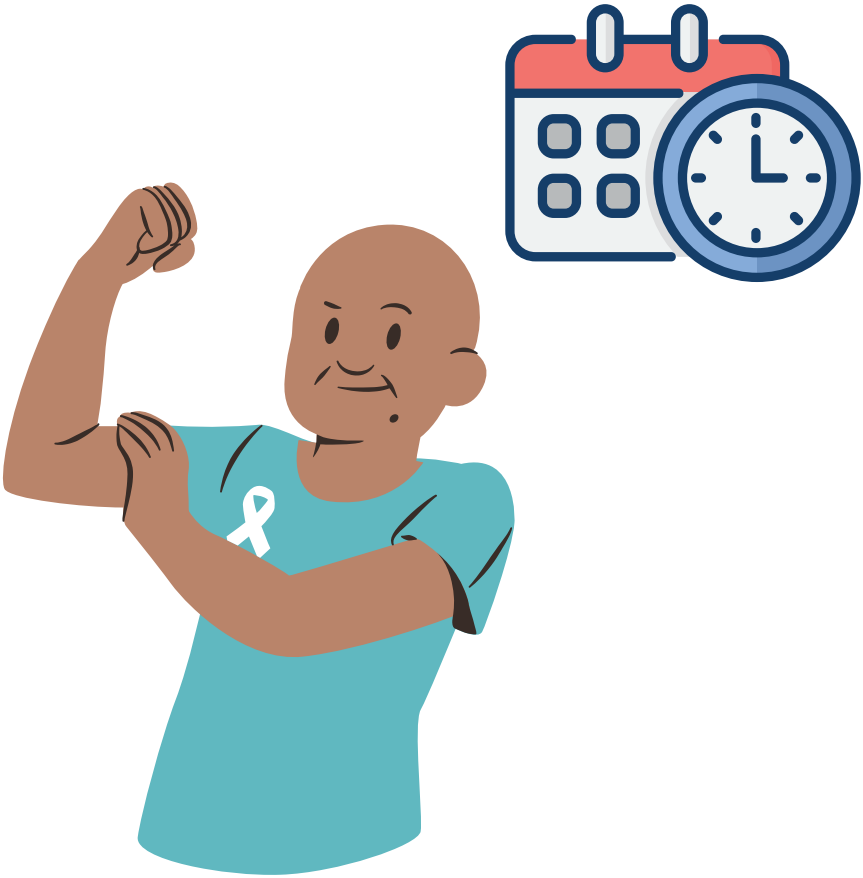
Effectiveness:

- It may take several infusions to see results, and not all patients respond to DLI.
- GVHD may limit how many DLIs you can safely receive.
- Response is monitored through blood tests, bone marrow tests, or PET/CT scans.

LATE EFFECTS AND SURVIVORSHIP

Survivorship begins the moment you are diagnosed with a potentially life-threatening disease, and continues through recovery and after treatments like stem cell transplantation (SCT).

It is marked not only by time but also by the holistic recovery of your physical, mental, emotional, and spiritual health. Survivorship is a continuous journey and while many survivors may return to normal activities by the one-year mark, it's important to be mindful of potential late effects or complications from the transplant, which may appear long after treatment ends.

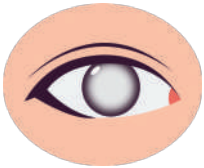


Common Late Effects after SCT

Chronic Graft-Versus-Host Disease (GVHD) This is a common late effect, particularly after allogeneic SCT, where the immune system attacks the patient's own tissues.



Cataracts Cataracts (clouding of the lens of the eye), may develop 3 to 4 years after transplant.



Sexual Dysfunction Both physical and emotional factors may influence a person's interest in sexual activity. Changes in the body, medications, and emotional stress can contribute to sexual challenges. There are treatments and recommendations available, so don't hesitate to address these concerns with your healthcare provider.



Infertility Many patients who undergo allogeneic SCT experience infertility, although there are exceptions. Some transplant centers offer specialized fertility programs to help manage these concerns.

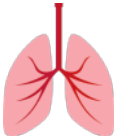


Neuropathy (Numbness and Tingling) Chemotherapy can cause nerve damage that leads to numbness and tingling, particularly in the hands and feet. Nerve recovery can take years, and any symptoms persisting after a year are often permanent.





Organ Toxicities Organs such as the thyroid, lungs, liver, and skin are commonly affected by chemotherapy, and damage can lead to long-term health issues. Less frequently, other organs may also be impacted.

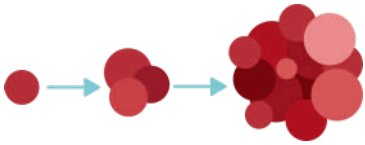








Secondary Cancers The risk of developing secondary cancers increases after chemotherapy and radiation, typically appearing 5-10 years after treatment. These cancers can be challenging to treat.



Adjusting to the "New Normal" Transitioning back into daily life can take time and may involve adjustments in relationships, work, and self-identity.



Critical Elements of Survivorship

1. Continued Routine Surveillance

To monitor ongoing health status:

- Disease status
- GVHD
- Engraftment studies

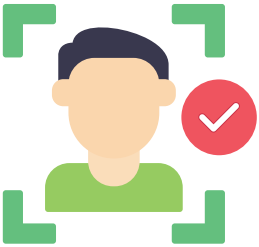






2. Prevention and Early Detection of Disease

Essential steps to maintain overall health include:



- Balanced diet and weight control
- Regular exercise
- Sun protection
- Routine check-ups with your doctor
- Daily self-assessments
- Dental hygiene
- Control of chronic diseases (e.g., diabetes, hypertension)
- Monitoring for late effects
- Re-immunisation

3. Focus on Quality-of-Life

It is crucial to prioritize well-being and find joy in life:



- Return to work/school
- Social life and relationships
- Sexual health
- Engaging in enjoyable activities
- Financial security and health insurance
- Spirituality and emotional health



CONTACT WITH YOUR DONOR

You may wish to contact or meet your matched unrelated donor, but this decision depends on several factors:

Country Regulations:

- Some countries allow anonymous contact only (e.g., letters with no personal information).
- Other countries may allow direct contact or restrict it for a period.
- In South Africa, donor contact is allowed after 3 years; anonymous communication may be possible before then.

Donor Consent:

- Both you and your donor must consent to sharing personal information for direct contact.
- Anonymous communication does not require consent from either side.

Facilitated by SABMR:

- The South African Bone Marrow Registry (SABMR) will handle the process and screen any communication to ensure it follows the necessary regulations.





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.



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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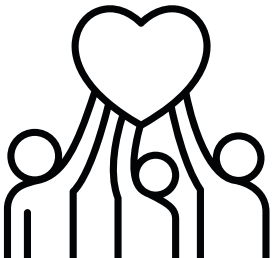

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