

# HAEMATOPOIETIC STEM CELL TRANSPLANTATION (HSCT) GUIDE FOR PATIENTS AND CAREGIVERS

1<sup>st</sup> Edition, 2020

# Haematopoietic Stem Cell Transplantation (HSCT) Guide for Patients and Caregivers

1<sup>ST</sup> EDITION, 2020

## WELCOME AND OVERVIEW

Dear parents and caregivers,

The HSCT team welcomes you to our unit. We know that you and your family may feel overwhelmed during this difficult period. While we cannot take away your pain, we would like to help make this journey a little easier for you and your child. This guide contains important information for your reference on what to expect of the transplant and how to provide the best care for your child. It will explain some of the side effects and challenges your child may experience over the course of the treatment and recovery. As each patient is unique, your child may or may not experience all the symptoms and treatment options listed here.

## ACKNOWLEDGEMENT

We extend our heartfelt gratitude to the following contributors who have helped make this caregiver's guidebook possible:

**Associate Professor Tan Ah Moy**

Senior Consultant  
Haematology/Oncology Service  
Department of Paediatric Subspecialties  
KK Women's and Children's Hospital

**Ms Lim Yan Yin**

Nurse Manager  
Children's Cancer Centre, Ward 76  
KK Women's and Children's Hospital

**Ms Chua Yi Xuan**

Senior Clinical Pharmacist  
Pharmacy Department (Oncology Pharmacy)  
KK Women's and Children's Hospital

**Ms Jasly Koo**

Dietitian  
Department of Nutrition and Dietetics  
KK Women's and Children's Hospital

**Ms Vijayakumari K**

Senior Principal Transplant Coordinator  
Haematology/Oncology Service  
Department of Paediatric Subspecialties  
KK Women's and Children's Hospital

**HSCT Medical Team**

Haematology/Oncology Service  
Department of Paediatric Subspecialties  
KK Women's and Children's Hospital

**HSCT Nursing Team**

Children's Cancer Centre, Ward 76  
KK Women's and Children's Hospital

**Oncology Pharmacist Team**

Pharmacy Department (Oncology Pharmacy)  
KK Women's and Children's Hospital

**Dietitian Team**

Department of Nutrition and Dietetics  
KK Women's and Children's Hospital

**Ms Liow Hwee Hsiang**

Senior Certified Child Life Specialist  
Senior Counsellor  
Children's Cancer Foundation

**Patients and families**

who have contributed their stories to this guidebook.

**Marketing Communications Team (KK Women's and Children's Hospital)**

in assisting the editorial of the guidebook.

# FOREWORD

## HAEMATOPOIETIC STEM CELL TRANSPLANTATION AND CANCER IMMUNOTHERAPIES

Traditionally the source of haematopoietic stem cells is the bone marrow, therefore termed “bone marrow transplant” (BMT). Peripheral blood (PB) and cord blood (CB) are the alternative sources of haematopoietic stem cells. In allogeneic HSCT, the stem cells can be from a matched family donor (usually a sibling), or matched unrelated donor. In autologous HSCT, the patient’s own stem cells are used. Recent advances in stem cell transplant technology also make it possible for partially matched related donor (haploidentical HSCT) to be used when no matched donors are available.

HSCT is used mainly for high-risk leukaemia or relapsed leukaemia, but can be used to treat other types of cancers (e.g. high-risk neuroblastoma), as well as non-malignant conditions (e.g. certain blood disorders or immune disorders).

During HSCT for cancers, high doses of chemotherapy, with or without radiotherapy, are usually given to kill cancer cells. However, the body’s normal blood stem cells are also destroyed by the intensive treatment. Healthy blood stem cells from a donor are then transplanted into the body, to replace the destroyed normal cells. Sometimes, the donor stem cells can also have cancer-killing effect.

Cancer immunotherapy is an emerging field that involves the use of the immune system to fight cancer. Examples of cancer immunotherapies include:

- Antibodies to target certain cancers (e.g. anti-GD2 antibodies for neuroblastoma)
- Checkpoint inhibitors that release the “brakes” in the immune system and therefore allow immune killing of the cancer cells.
- Cellular immunotherapies such as “CART cell therapy” that manipulate and redirect the immune cells to kill specific cancers.

Such complex therapies require a clean and safe environment to reduce the risk of serious infections, and support from our multidisciplinary medical teams to monitor and manage any complications.

Therefore, a holistic approach with medical and allied health staff working hand-in-hand with caregivers is of paramount importance to the success of HSCT.

Associate Professor Tan Ah Moy  
Senior Consultant  
Director of HSCT Programme

# CONTENT

<b>1</b>	<b>INTRODUCTION</b>	<b>1</b>
<b>2</b>	<b>PREPARING FOR TRANSPLANTATION</b>	<b>2</b>
	When will transplantation take place?	
	Pre-transplantation family conference	
	Selecting a caregiver	
	Pre-transplantation investigations and procedures	
	Insertion of a central venous catheter	
	Items to bring to the hospital	
<b>3</b>	<b>THE TRANSPLANTATION ADMISSION</b>	<b>5</b>
	Room setting	
	Housekeeping	
	Guidelines for caregivers and visitors	
	Patient and family-centered care	
	General precautions	
	Patient safety	
<b>4</b>	<b>A DAY IN A TRANSPLANTATION ROOM</b>	<b>7</b>
	A typical schedule	
	Vital signs	
	Blood works and lab tests	
	Weighing your child	
	Personal hygiene	
	Medications	
	Intake and output recording	
<b>5</b>	<b>CONDITIONING THERAPY</b>	<b>11</b>
	Thymoglobulin®	
	Busulfan	
	Cyclophosphamide	
	Fludarabine	
	Treosulfan	
	Melphalan	
	Thiotepa	
<b>6</b>	<b>INFECTION PROPHYLAXIS</b>	<b>14</b>
	Anti-viral	
	Anti-fungal	
	Anti-pneumocystis	
<b>7</b>	<b>TRANSPLANTATION DAY</b>	<b>16</b>
	Before stem cell infusion	

## CONTENT

	During stem cell infusion	
	After stem cell infusion	
	Engraftment	
<b>8</b>	<b>MANAGING SIDE EFFECTS AND COMPLICATIONS</b>	<b>18</b>
	Transfusion of blood products	
	Fever and neutropenia	
	Nausea and vomiting	
	Diarrhoea	
	Mucositis and oral hygiene	
	Sinusoidal obstruction syndrome	
	Fatigue	
	Graft versus host disease	
<b>9</b>	<b>DIET AND NUTRITIONAL CARE</b>	<b>30</b>
	Cancer treatment and nutritional needs	
	A balanced diet	
	Low-bacteria diet	
	Food safety tips	
	The use of medical supplements, traditional herbs and organic products	
	Commercial nutritional supplements	
	Feeding by tube and parenteral nutrition	
<b>10</b>	<b>COPING WITH TRANSPLANTATION AND ISOLATION</b>	<b>38</b>
	How can you support your child	
	Supporting siblings	
	Preparing yourself for the transplantation	
	Post-transplantation	
<b>11</b>	<b>PLANNING FOR HOME</b>	<b>45</b>
	Discharge criteria	
	Patient education and caregiver training	
	When to call for medical help	
<b>12</b>	<b>APPOINTMENT AFTER DISCHARGE</b>	<b>47</b>
	How does a day in CDT look like?	
<b>13</b>	<b>USEFUL TELEPHONE NUMBERS</b>	<b>48</b>
<b>14</b>	<b>PATIENT AND CAREGIVER STORIES</b>	<b>49</b>
	An adolescent's journey of undergoing allogenic HSCT	
	A mother's journey with her child undergoing autologous HSCT	

## INTRODUCTION

Haematopoietic Stem Cell Transplantation is also called bone marrow transplantation or stem cell transplant.

### WHAT IS IT ACTUALLY?

“Haematopoietic” basically means blood forming.

“Stem cells” are cells that can continuously replicate cells exactly like themselves or produce different cells that make up the blood, such as red blood cells (bring oxygen to all parts of your body), white blood cells (to fight infection) and platelets (help your blood to clot when you bleed). The stem cell is produced in the bone marrow, a soft spongy area in the center of some of the larger bones in the body. Most of the stem cells stay in the bone marrow until they are transformed into the different blood cells, which are then released into the blood stream. This is a very active process in which millions of different cells are produced every hour.

“Transplantation” is the process of taking the tissue or organ of one person and implanting it in another body. So, haematopoietic stem cell transplantation basically means taking blood forming cells from one person and giving it to another person. The basic idea of HSCT is to transfuse healthy stem cells into the patient after the patient’s own unhealthy stem cells are eliminated by very high-dose chemotherapy and sometimes, a form of radiation therapy known as total body irradiation. The purpose of the chemotherapy and radiation therapy is to kill all cancer cells in the body, as well as any abnormal cells in the bone marrow. After the stem cells are infused into the patient, the new stem cells will start to grow in the body and make new blood cells for the body to function.

There are a few different types of HSCT depending on the diagnosis and goals of the HSCT.

1. **Autologous HSCT** – the donor is the patient himself/herself.
2. **Allogeneic HSCT** – another person is donating stem cells to the patient. The person can be a sibling or an unrelated donor. The stem cells can also come from umbilical cord blood of an unrelated donor. This kind of transplantation will require a sample of blood to determine that the donor and patient have matching tissue type, also known as Human Leukocyte Antigen (HLA) typing. Both the donor and patient should ideally be a 100% match.
3. **Haploidentical HSCT** – another person who has 50% similar tissue type will donate the stem cells to the patient. The person is typically the biological parent or sibling. This kind of transplantation is usually done if a fully-matched donor is not available.

# PREPARING FOR TRANSPLANTATION

## WHEN WILL TRANSPLANTATION TAKE PLACE?

The timing of your transplantation is dependent on many factors, such as the status of the disease and the availability of the donor.

## PRE-TRANSPLANTATION FAMILY CONFERENCE

Before the transplantation admission, the patient and his/her immediate family members will be invited to meet with the transplantation medical and nursing team. During this session, the transplantation doctors will discuss details such as the reason for the transplantation, the process and potential risks or side effects that the patient may experience during and after the transplantation. The patient and family members will have the opportunity to ask questions and clarify any doubts regarding the option of transplantation. Once you agree with the medical decision, we will need you to sign a consent form to proceed with the transplantation.

## SELECTING A CAREGIVER

During the family conference, you will be asked to identify a main caregiver to take care of the child during the transplantation admission. Your child will be expected to stay in the hospital for approximately four to six weeks, depending on the type of transplant he/she is undergoing. The caregiver plays an important role during the admission, providing emotional support and physical care for the child. During this period, the child's immunity will be low. As a result, he/she will be more susceptible to catch any infection during the transplantation admission. The caregiver should ensure that the child is well before going into the transplantation room.

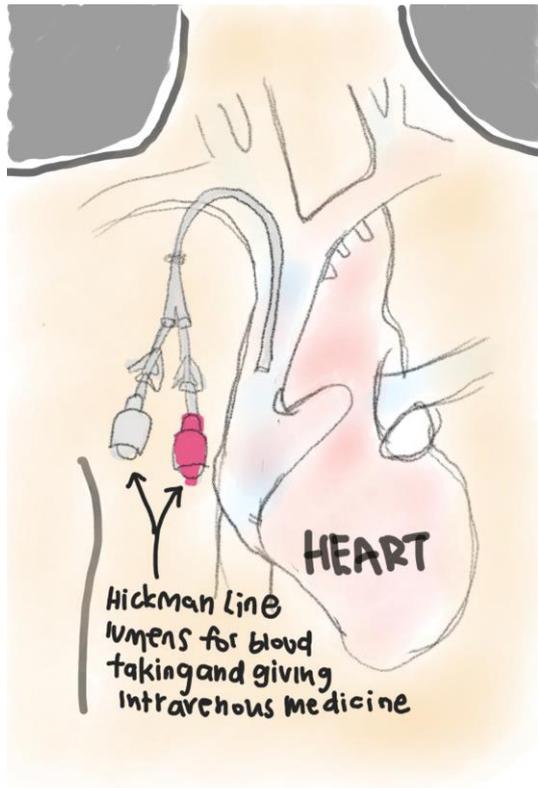
## PRE-TRANSPLANTATION INVESTIGATIONS AND PROCEDURES

The medical team will schedule many tests and appointments before your child is admitted for haematopoietic stem cell transplantation. A schedule of the pre-transplantation evaluation will be provided for your child. The purpose of these tests is to identify any problem that exists before the transplantation and have a baseline result before the transplantation so that the medical team can compare and measure any changes during and after transplantation.

### Tests and appointments may include the following:

- Heart studies: 2D echo (echocardiogram)
- Breathing studies: Lung function test, chest X-ray
- X-ray bone age (left wrist)
- Dental examination, mouth X-ray:
  - o The dentist will discuss any dental problems with the transplantation doctor before filling any cavities or removing any infected teeth
  - o Your child may need to take antibiotics before or after the dental appointment
- Other blood investigations to evaluate the kidney, liver function and viral status

## INSERTION OF A CENTRAL VENOUS CATHETER



Your child will be scheduled for a central venous catheter, also known as a Hickman Line, to be inserted before the transplantation. This is a small soft tube with two lumens that is placed in the blood vessel in the chest that goes to your heart. It is used for taking blood, giving intravenous medicine, stem cell infusion and blood transfusion. The Hickman Line will be inserted by a surgeon in the operating theatre when the child is placed under general anesthesia. Several centimeters of the Hickman Line can be seen remaining outside the body with the catheter stitched onto the skin to prevent it from slipping out. A dressing will be placed over the Hickman Line site to prevent bacteria from entering the body.

### Care of your Hickman Line

If germs get into the catheter, they can go into the blood and make your child sick. It is very important to take good care of the Hickman Line so as to prevent infection. During the hospital stay, the nurses and doctors will inspect the Hickman Line site frequently to look out for signs of infection. However, we asked for your participation in the care of your child by checking the exit site regularly as well, to look out for the following signs of possible line infection:

- Pain
- Swelling
- Bleeding
- Discharge
- Redness

The intravenous line connected to the catheter will be changed every four days, the dressing will be changed at least once a week or whenever it is unravelled or wet. Your child may have multiple intravenous lines connected to the catheter; in which case the lines should be secured well to prevent tension as your child may feel a “pulling” sensation from the site when the line is tugged. Do inform the nurses when the infusion pump alarm is activated so that our nurses can troubleshoot it promptly to prevent line blockage, which can occur if the fluid does not flow through the line continuously.

## ITEMS TO BRING TO THE HOSPITAL

You are allowed to bring some of your child's favourite toys, laptop and computer games that can keep him/her entertained during the hospital stay. Books are allowed but avoid borrowing books from common libraries because the books have been touched by many people and those may carry a lot of germs or dust. Stuffed toys and pillows/bolster are discouraged as well since these items tend to trap dust and dirt. Jackets and socks are allowed to keep the patient warm, but caregivers need to change them daily or when soiled. All items should be cleansed thoroughly and packed in a clean bag.

We ask that you minimise the things that you bring to the hospital as the transplantation rooms are small. Excessive personal belongings can obstruct the space required for the doctors and nurses to examine the child or perform necessary procedures. Another reason is that these items can also gather dust over time when they are not wiped down frequently.

# THE TRANSPLANTATION ADMISSION

## ROOM SETTING

Your child will be admitted to one of the transplantation rooms in ward 76. Transplantation rooms are single (isolation) rooms designed to have positive air pressure. The purpose is to let the air flow out of the room and prevent the air outside from going into the room. In this way, the patient is kept away from air-borne microorganisms. This is also known as reverse barrier nursing or protective isolation. The rooms are also built with HEPA-filter. HEPA stands for “high-efficiency particulate air” and the filter works by removing all airborne contamination to prevent air contamination. As bacteria can thrive in a warm environment, the rooms are generally kept at a lower temperature. The temperature is centrally controlled, and you will not be able to adjust it according to your preference. However, the nurses can help by providing more blankets if you or your child feels cold.

## HOUSEKEEPING

The housekeeper will start to clean the transplantation rooms from 7.00am. He/she will assist in emptying the trash bins, clean the toilet and basin, and wipe the floor surface every morning. We seek your cooperation in maintaining the hygiene of the room by cleaning up surfaces if there are spills. Please keep your personal belongings so that the housekeeper can access areas such as roller tables, sofa bed, window frames and toys daily. We recommend that you use the wet wipes provided to clean these surfaces and avoid using a feather duster or dry cloths.

## GUIDELINES FOR CAREGIVERS AND VISITORS

We understand that emotional and physical support from your loved ones can help the child to adjust to hospital stay. However, to protect the safety and health of your child and all our patients, please follow the hospital’s visiting guidelines.

For **allogenic and haplo-identical HSCT**, only one designated caregiver can enter the room and stay with the patient throughout the transplant admission. No other visitor is allowed until the patient is deemed to have adequate immunity based on blood counts.

For **autologous HSCT**, two caregivers are allowed to visit the child during daytime but only one caregiver can stay during the night with the child. No other visitor is allowed until the patient is deemed to have adequate immunity based on blood counts.

## PATIENT AND FAMILY-CENTERED CARE

KK Women’s and Children’s Hospital practices family-centered care and consider you, the caregiver, as integral in the complete care plan of your child, especially in understanding the needs and changes in your child. The medical and nursing team’s priority is to attend to your child’s medical needs and nursing care. It is essential for parents to be closely involved in the patient’s basic care in partnership with the nursing and medical team to ensure safe and quality care is provided to the child. Every morning, the medical team will discuss your child’s care and you are encouraged to ask questions or raise any concerns regarding your child’s

care. If you have additional questions, please let your nurses know so that the medical team can arrange to meet you.

## GENERAL PRECAUTIONS

You are required to wear a mask at all times to protect your child from catching any infection from you. Washing your hands and your child's hands is the best way to prevent the spread of germs. Our hands pick up germs when we touch people or things. It would be impossible to avoid contact with germs but you can reduce the chances of infecting your child when you wash your hands or perform alcohol-based handrubs frequently. There are "5 moments of hand hygiene" that you should adhere to:

- Before touching the patient
- After touching the patient
- After handling patient's body fluid (e.g. handling vomitus, diapers, assisting the child in the toilet)
- Before aseptic procedure (more relevant for healthcare providers)
- After touching patient's surroundings

The antiseptic soap and alcohol-based handrubs are readily available and easily accessible in the wards. There are also handwashing guidelines placed at every sink to help you remember the "7 steps to handwashing".

As moist environment can promote mold and fungal growth, the toilet should always be kept clean and dry. To prevent infection, the patient is not allowed to enter the bathroom at all times during the transplantation admission. The caregiver can use the toilet in the transplantation room but will need to proceed to the bathroom outside the room and located within the ward for showering.

## PATIENT SAFETY

It is essential that your child wears the identification band **at all times** in the hospital. This is to ensure that the medical staff can identify him/her correctly to provide the right and safe care.

The appropriate type of bed will be allocated to your child for safety reasons and to prevent falls. If your child is less than four years old, he/she will be given a cot bed. Bigger beds are only allowed for children aged four years and above. We **DO NOT** allow any co-sleeping with the child on the same bed for the safety of your child.

Ensuring your child's safety is our top priority, so we encourage you to speak up if you have any concerns pertaining to the care of your child. If you notice that our nurses, doctors or other healthcare team members have forgotten to perform hand hygiene before touching your child, please remind them. Your participation in providing safe care for your child is important.

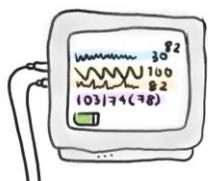
## A DAY IN A TRANSPLANTATION ROOM

### A TYPICAL SCHEDULE

Schedules are customised based on your child's medical needs.

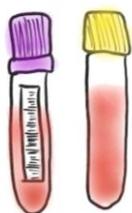
This is a sample of a typical schedule for a patient undergoing transplantation.

3.00am to 4.00am	Vital signs monitoring
4.30am to 6.00am	Blood drawn from the central venous catheter Intravenous (IV) medication
7.30am to 9.00am	Nurses' assessment by morning shift nurses Morning vital signs Oral medications Weight-taking Breakfast Shower
9.00am to 11.00am	Doctor's rounds
11.00am to 12.00pm	Vital signs
12.00pm to 4.00pm	Oral and IV medication Lunch Nurses' assessment by afternoon shift nurses
4.00pm to 6.00pm	Vital signs IV tubing change if due Dinner
7.00pm to 9.30pm	Vital signs Oral and IV medication Nurses' assessment by night shift nurses
11.00pm to 12.00am	Vital signs



## VITAL SIGNS

Your child's vital signs must be checked regularly, and this can range from hourly to every four-hourly. The vital signs include the checking of your child's temperature, blood pressure, respiration and oxygen saturation. It will be recorded in the patient chart that allows us to monitor your child's progress closely during his/her transplantation stay. If your child is asleep and it is time to take the vital signs, we may have to wake him/her. The vital signs may be taken more often such as when patients are receiving stem cell infusion, blood products, IVIG or certain medications. The nurses will let you know when we expect to take vital signs more often than every four-hourly, so you can help to prepare your child.



## BLOOD WORKS AND LAB TESTS

Daily full blood count and renal panel will be taken from your child's central line around 4.30am to 6.00am. Lab tests may be required more often, depending on the condition of your child. The nurses will update you on the full blood count result daily because we understand that you will want to monitor your child's progress. If you need an explanation on your child's lab results, the transplant team is there to help you.



## WEIGHING YOUR CHILD

Your child must be weighed daily, preferably early in the morning before breakfast. He/she should be weighed wearing only pajamas and after passing urine or diaper change to ensure accuracy. A weighing machine may be placed in the room for convenience to weigh your child. Your child must be weighed so that the doctor can calculate his/her medication dosage accurately and make sure the amount of fluid in your child's body is balanced.



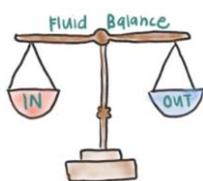
## PERSONAL HYGIENE

Your child will be sponged daily in the morning using packet wipes for body surface. His/her pajamas, bed linen, pillowcase and blanket should be changed daily or when soiled. It is important to moisturise your child's skin using a mild moisturiser to prevent the breakdown of dry skin that can be caused by the medications. Your child is not allowed to enter the bathroom inside the transplantation room at all times. Commode/bedpan or urinal will be provided to assist in your child's toileting needs.



## MEDICATIONS

As nausea and vomiting can occur during your child's treatment, we make every attempt to give your child medications intravenously through the central line. However, there are still some medications that have to be given orally. We seek your cooperation to give the oral medication at prescribed times for optimal results. A soft nasogastric feeding tube may be inserted in your child if your child refuses to take the medication orally. This is necessary to ensure all important oral medications are given.



## INTAKE AND OUTPUT RECORDING

How much your child eats/drinks and the fluids received through the central line is known as intake. This helps us to check if your child has adequate nutritional requirements and fluid balance in his/her body. Output is urine, vomitus and motion that your child passes out. We want to make sure that everything that is going into your child's body is balanced by your child's output. Therefore, it is important that you record how much your child eats, drinks and passes urine accurately. If your child has vomited or soiled a diaper, you may pass it to the nurses to weigh it. The other IV fluids and medications given will be recorded by the nurses. The doctors will use the fluid balance to make decisions about your child's medications and treatments. Sometimes, a medication known as diuretic or commonly referred as Lasix will be given to your child to get rid of extra fluid in the body.



## CONDITIONING THERAPY



**Conditioning therapy** is a high-dose chemotherapy and/or radiation that each patient receives before the haematopoietic stem cell transplantation.

The goals of conditioning therapy is to remove the patient's existing bone marrow cells so that new marrow cells have room to grow, and also to destroy any remaining cancerous cells in the body. If the patient is receiving cells from another person, the conditioning therapy has an additional purpose of weakening the patient's (host's) immune system so that the donor cells can be accepted by the body.

Chemotherapy drugs used in conditioning therapy commonly include alkylating agents such as cyclophosphamide, busulfan, melphalan, thiotepa or nucleoside analogues such as fludarabine. These chemotherapy drugs are usually given as intravenous infusions, and they work by interfering with the replication of DNA in cells. Physicians individualise the conditioning regimen to suit each patient's disease and condition.

Generally, common side effects of chemotherapy include hair loss, inflammation and ulceration of the oral cavity and digestive tract (mucositis), nausea and vomiting, and low blood counts. In addition to the common side effects of chemotherapy, there are some commonly used chemotherapy drugs and the potential side effects unique to each drug.

### THYMOGLOBULIN®

- Rabbit ATG contains antibodies against T-lymphocytes. It is an immunosuppressive agent used to prevent graft-versus-host disease or graft rejection.
- Rabbit ATG commonly causes infusion-related reactions with symptoms such as fever, rash, rigors, or changes in blood pressure. To minimise such infusion-related reactions, rabbit ATG will be infused slowly over several hours and premedications (antihistamine and steroid) will be given as well.

### BUSULFAN

- Busulfan may sometimes cause a serious liver condition known as veno-occlusive disease or sinusoidal obstruction syndrome (VOD/SOS). Doctors will monitor liver function closely with blood tests and clinical symptoms, e.g. yellowing of the skin or eyes.
- Busulfan may cause fits. To prevent this potential side effect, anti-seizure medication will be given during busulfan therapy.
- Rarely, busulfan may affect lung function months or years after treatment. Seek prompt medical attention if your child develops cough, wheezing or feels breathless.

### CYCLOPHOSPHAMIDE

- Cyclophosphamide can form metabolites which may irritate the bladder, resulting in pain or bleeding while passing urine. To prevent this potential side effect of bladder irritation (aka haemorrhagic cystitis), patients are put on vigorous intravenous hydration drip, together with another medication known as Mesna. It is important to pass urine regularly during treatment to prevent accumulation of the metabolites in the bladder.
- High doses of cyclophosphamide have been reported to cause cardiac side effects, including irregular heart rate, heart failure, inflammation of heart muscle, and fluid accumulation in the heart. Doctors will monitor your child's heart function closely.

### FLUDARABINE

- Fludarabine may cause fatigue, numbness and tingling of fingers and toes.
- Very rarely, fludarabine may cause seizures and confusion.

### TREOSULFAN

- Treosulfan may cause skin pigmentation.
- Ensure adequate fluid intake.

### MELPHALAN

- Melphalan can cause damage to the cells lining the mouth and gut, leading to inflammation and ulceration in the oral cavity and digestive tract. It has been found that sucking on ice chips or frozen Pedialyte during administration of melphalan infusion can reduce the severity of oral mucositis. Swish or suck the frozen Pedialyte in the mouth for approximately 30 minutes, starting from five minutes before the melphalan infusion.

## THIOTEPA

- Thiotepea is excreted through the skin. Cutaneous reactions, e.g. hyperpigmentation, redness, blistering and itching of skin may occur during thiotepa administration.

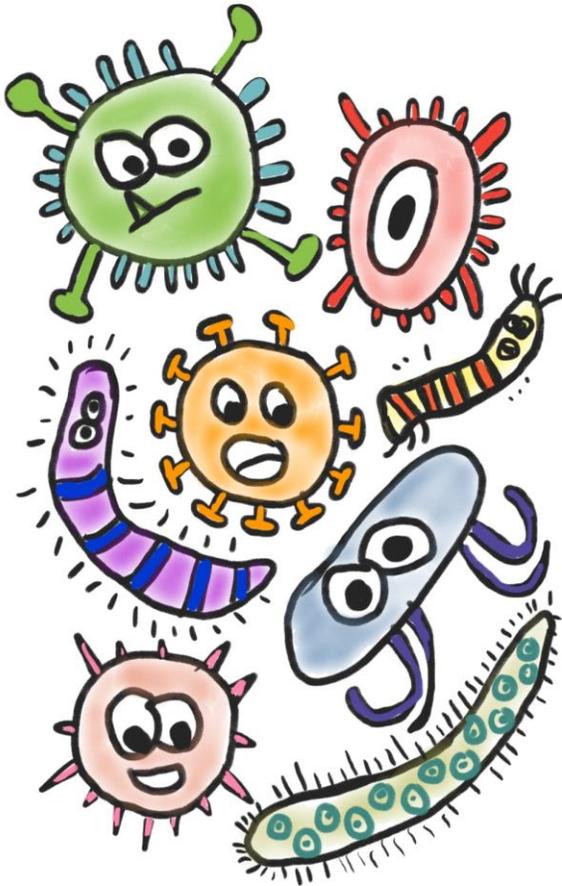
### **Preventive skin measures to adopt during thiotepa administration until 48 hours after the last dose of thiotepa:**

- The patient should have frequent sponge baths every six-hourly with warm water from sterilising filter tap.
- Dry the patient's skin well and pay particular attention to the folds of the skin. Dab the body gently and avoid rubbing to prevent injuries to the skin.
- Sponge bath commences three to four hours after the initiation of the first dose of intravenous thiotepa and this is repeated for the 48 hours after completion of the last dose.
- The patient's clothes and linens are to be changed after every sponge bath and clothing should be loose fitting and minimal.
- The patient should avoid the use of any moisturiser, ointment, barrier cream, antiperspirant or deodorant during the recommended duration for skin care preventive measures.
- For infants and children, diapers should be avoided if possible. If this is not possible, change the diaper hourly or when soiled during the recommended duration for skin care preventive measures. Avoid using baby wipes for cleaning. Use water from the sterilising filter tap to clean the perineum thoroughly instead.
- Avoid tight-fitting clothes and accessories.

### **Care of Central Venous Access Catheter (CVAD) for patients on intravenous thiotepa:**

- CVAD dressing should be changed daily or when soiled.
- CVAD site will be cleansed with normal saline solution and covered with gauze-type dressing with minimal tape.
- Avoid occlusive dressing such as tegaderm during the recommended duration for skin care preventive measures to prevent exposure of excreted thiotepa through the skin.
- Avoid applying any antimicrobial ointment to the CVAD site during the recommended duration for skin care preventive measures.

## INFECTION PROPHYLAXIS



HSCT patients are vulnerable to infections as their immune systems are heavily suppressed. Doctors will monitor patients closely for signs and symptoms of infections and initiate treatment promptly. Prophylactic antimicrobial medications will also be prescribed to prevent some of these infections. These medications will usually be continued for months after initial discharge from the hospital, post-transplantation.

### ANTI-VIRAL

#### Acyclovir

- Acyclovir is given to prevent viral infections from herpes simplex virus (cold sores) and varicella zoster virus (chicken pox, shingles).
- It is given intravenously or orally twice or thrice a day. Intravenous acyclovir is administered over at least one hour to prevent kidney impairment. It is important to ensure that the child is well-hydrated.

### ANTI-FUNGAL

HSCT patients are susceptible to infections caused by fungal organisms, e.g. *Candida* and *Aspergillus* spp. Fungal organisms can lead to infections in the oral cavity, urinary tract, skin, blood, lungs, or liver.

#### Fluconazole

- Fluconazole is given mainly to prevent *Candida* infections.
- Fluconazole is given intravenously or orally once daily and is usually well tolerated.
- Fluconazole can cause drug interactions with other medications - always check with the pharmacist or doctors before taking any other medications.

### Micafungin

- Micafungin is given intravenously once daily over one hour.
- Micafungin may cause side effects such as diarrhoea. In rare cases, it may cause abnormal liver functions.

### Posaconazole

- Posaconazole is available as a delayed-release tablet taken once daily (**DO NOT** crush or chew), or oral suspension taken three times daily after a full meal or liquid nutritional supplement for best absorption.
- Posaconazole may cause side effects such as nausea, vomiting, diarrhea and abdominal pain. Rare but serious side effects of posaconazole include abnormal liver function and heart rhythm problems.
- The level of posaconazole in the body can be monitored with blood tests, and the dose of posaconazole may be adjusted based on the levels measured.
- Posaconazole can cause drug interactions with other medications - always check with the pharmacist or doctors before taking any other medications.

### Liposomal amphotericin B (Ambisome®)

- Liposomal amphotericin B is given intravenously, over a minimum of two hours to prevent infusion-related reactions.
- Other potential side effects of amphotericin B include low potassium and magnesium levels, as well as impaired kidney function.

## ANTI-PNEUMOCYSTIS

Immunocompromised patients are susceptible to lung infection caused by *pneumocystis jiroveci* (formally known as *pneumocystis carinii* and referred to as pneumocystis carinii pneumonia, or PCP). Co-trimoxazole is recommended as the first line agent for PCP prophylaxis. In patients who cannot tolerate co-trimoxazole, pentamidine is used.

### Co-trimoxazole (sulfamethoxazole and trimethoprim)

- Co-trimoxazole for PCP prophylaxis is taken orally twice a day, on two days of the week (e.g. Mondays and Thursdays).
- Co-trimoxazole should not be given to patients with G6PD deficiency and patients who are allergic to sulfonamides.
- Side effects of co-trimoxazole include gastrointestinal discomfort, skin rashes and decrease in blood counts. Seek immediate medical attention if skin rashes appear.

### Pentamidine

- Pentamidine is typically given as an intravenous infusion two-to four-weekly for PCP prophylaxis.
- To prevent the side effects of low blood pressure, the infusion is given over at least an hour, and the patient is advised to lie down during the infusion duration.

## TRANSPLANTATION DAY

Transplantation day is commonly referred to as **Day 0**. It is the day your child receives his/her own stem cells or from another donor. The infusion of stem cells takes place following the completion of the pre-transplantation chemotherapy. This procedure takes place in the patient's room and is similar to a blood transfusion. The stem cells will be infused through the Hickman Line into the blood stream. Stem cells may be given to your child fresh or after they have been thawed from the frozen stem cell unit. Fresh stem cells are collected from the donor and infused immediately to your child. Frozen stem cells may include umbilical cord blood and your child's own stem cells collected earlier through an apheresis machine.

### BEFORE STEM CELL INFUSION:

- Your child will be given medications with/without hydration drip intravenously to prevent possible side effects.
- A cardiac monitor will be used to monitor your child's heart rate, breathing rate, oxygen level and blood pressure during the infusion.

### DURING STEM CELL INFUSION:

- The transplantation team, comprising the nurse, doctor, lab technician and the transplantation coordinator may be present in the room to observe your child closely.
- The infusion time ranges from half an hour to several hours, depending on how much stem cells are required.
- It is important that you understand the possible side effects your child may experience so that you can inform the medical team if such effects occur.

#### Side effects may include:

- o Fever, chills, flushing, rashes and difficulty in breathing.
- o If the patient has any of these symptoms, the infusion will be stopped and medicine will be given to control the symptoms.
- o The infusion is restarted when the symptoms are under control.
- o Your child's urine may become darker because red blood cells break down. If this happens, the patient will receive more intravenous fluid to hydrate the kidneys.
- o The preservative used for stem cells that have been frozen has a "sweet corn" odor. This odor may cause nausea or headache. Anti-vomiting medications will be given to the patient to prevent this.

### AFTER STEM CELL INFUSION:

- Your child will be put on a cardiac monitor for the next 24 hours after infusion is completed to monitor for any side effects that may occur after the infusion.
- The transplantation team will require your assistance to record the intake and output to ensure that your child does not retain too much fluid.
- Inform the medical team immediately if your child is experiencing any of the side effects.

**ENGRAFTMENT:**

After the stem cells are infused into the body, they will travel through the bloodstream to the bone marrow. Engraftment occurs when the stem cells received on infusion day start to grow and make healthy blood cells in your child's body.

Engraftment happens when absolute Neutrophils is  $> 0.5 \times 3$  consecutive days

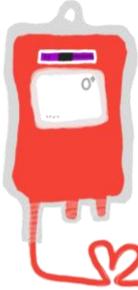
The time of engraftment will depend on the source of your stem cells.

Source	Approximate Duration
Peripheral Blood	~ 2 weeks
Bone Marrow	~ 3 weeks
Cord Blood	~ 4 weeks

During this period, your child will be vulnerable to infection. Strict infection control precaution should be taken to prevent and minimise the risk of infection.

# MANAGING SIDE EFFECTS AND COMPLICATIONS

## TRANSFUSION OF BLOOD PRODUCTS



**Transfusion** is the administration of blood or blood products through your child's central line. It is given for many reasons.

**Red blood cells:** Also known as Haemoglobin (Hb). They carry oxygen throughout the body and give us energy. If your child has a low Hb, called anemia, your child may receive a red blood cell transfusion.

**Platelets:** Platelets help stop bleeding by plugging holes in blood vessels. If your child has a low platelet count, called thrombocytopenia, your child may receive a platelet transfusion.

**Fresh frozen plasma:** Plasma is the clear liquid portion of blood that also helps stop bleeding.

**Intravenous Immunoglobulin (IVIG):** IVIG is a part of plasma that contains antibodies that help fight infection. It is usually given once a week during the transplantation stay.

**Albumin:** Albumin is a blood protein that may be given to treat low blood pressure or excessive blood protein loss.

The amount of blood products depends upon your child's weight. A signed consent from you/the patient's guardian is necessary prior to a blood product transfusion. The consent will be taken by a doctor upon your child's admission.

Your child will have to be monitored closely during the transfusion and vital signs will be taken frequently. The nurse will check the temperature, pulse, respiration, blood pressure and oxygen saturation throughout the transfusion and up to one hour post transfusion. The nurse will also watch out for any side effects or reactions. A red blood cell transfusion will usually take three to four hours to complete; platelets require 45 minutes to 60 minutes to infuse; IVIG may take three to five hours to complete or longer, depending on your child's condition.

### Transfusion reactions:

Common signs of reactions include fever, chills, breathing difficulty, rashes, red face, eye or lip swelling. Please inform the nurse immediately if your child experiences any of the symptoms. The nurse will stop the transfusion if these reactions occur and medication may be given to relieve the symptoms. Your child may then need these medications before each transfusion which is commonly referred as "pre-medications".

## FEVER AND NEUTROPENIA



Fever and neutropenia are common complications of a transplantation treatment.

**Neutropenia** is a decrease in the infection-fighting white blood cells called neutrophils. Your child is considered neutropenic if he/she has an absolute neutrophil count (ANC) of less than one.

**Fever** is defined as when your child's temperature is 38.5 degree Celsius or more than 38.0 degree Celsius measured twice within an hour.

As your child has an increased risk of infection, our care team will monitor him/her for signs of infection and blood will be drawn from all the central lines to check for bacteria. Stool and urine investigations may be done to rule out any infection. Your child will be prescribed with IV antibiotics which may continue even if the fever goes away. Paracetamol may also be given to lower your child's temperature, and cooling measures such as loose light clothing, cold compress and sponging will be offered by the nurses.

## NAUSEA AND VOMITING



Chemotherapy-induced nausea and vomiting is a common side effect which can cause fear among children. At the same time, it is one of the worrisome treatment-related symptoms for parents and caregivers.

**Nausea** is an uncomfortable urge to vomit. Nausea can be experienced before vomiting. Some children may feel nauseous even if they have not taken anything.

**Vomiting** is defined as the expulsion of food from the stomach with fluid contents through the mouth and sometimes, the nose.

Frequent vomiting can cause dehydration and electrolyte imbalance. Some patients may inhale vomited feeds which can cause choking in what we term as aspiration. Fortunately, nausea and vomiting can be prevented or well-controlled with medications. These anti-vomiting medications will be given as an injection through the central venous catheter.

The medical team will ensure appropriate anti-vomiting medication is given approximately 30 minutes before the commencement of chemotherapy/radiation therapy to prevent nausea and vomiting, and will continue to administer it regularly during the conditioning period. However, please inform your nurses if your child is experiencing any nausea so that additional anti-vomiting medications can be given. As it will be harder to control once your child starts vomiting, adequate management before the start of the distressing symptom is crucial in keeping your child as comfortable as possible during the transplantation.

There are conservative measures such as giving your child his/her favourite type of food. Try to avoid unpleasant smells that can trigger nausea. Taking small frequent meals can also help manage nausea. In the event of vomiting, let your child lie on his or her side to avoid choking.

Please inform the nurses immediately if your child vomited blood or vomitus resembling coffee colour. It may signal internal bleeding. If your child's frequency of vomiting is not reduced and he/she has been passing less but dark yellow urine, this may indicate dehydration. More IV fluids will be given to your child through the central line or a soft nasogastric tube may be inserted to keep him/her hydrated.

## DIARRHOEA



**Diarrhoea** can be caused by one or more of the following: chemotherapy, radiation, mucositis, medications, infection, graft versus host disease and certain food or fluids (e.g. dairy and lactose-containing products).

The medical team will try to decrease or change the medications or food that may be causing the diarrhoea. The nurse will require your help to accurately measure and chart down the stool amount, colour and texture. If your child continues to have diarrhoea, we may send stool samples to check for infection. Your child will also be monitored closely as severe diarrhoea can cause dehydration. Intravenous fluids and electrolytes will be given to replace the lost fluids.

The perianal area can become sore and the skin may start to break down. If this happens, your child will be at higher risk of infection. It is very important to keep the rectum clean and dry. We recommend that you use cooled boiled water provided by the nurses to clean your child's rectum after every time he/she passes motion or when you change his/her diaper. Protective barrier cream is recommended to prevent further breakdown and to help the skin heal. You can check with your nurses on the appropriate product to use. Your child may be offered pain medications or gels to relieve any pain or soreness in the perianal area.

Hand hygiene is important in preventing the spread of infection. We ask that all caregivers wash your hands with soap and water before and after touching the patient and upon entering or exiting the inner room.

## MUCOSITIS AND ORAL HYGIENE

Mucositis is the inflammation and ulceration of the lining of the mouth, throat and the rest of the digestive tract commonly developed in most transplantation patients. This is caused by the conditioning chemotherapy/radiotherapy that damage the cell lining. Mucositis usually occurs a few days later after starting the conditioning therapy. The symptoms can persist for seven to 14 days or longer before healing begins. During this period, your child is also more prone to oral fungal and viral infections. Thus, effective oral hygiene is extremely important.



Teeth brushing

- Use a small, soft bristle toothbrush with fluoridated toothpaste.
- Brush at least two to three times a day.
- Rinse toothbrush well after every use and allow to air dry.
- Replace toothbrush every three months or when bristles are worn out to ensure effective brushing and to minimise infection.
- Toothbrush should be changed following an oral infection.
- Foam cleaning sponges (moistened with water or diluted chlorhexidine) may be used when your child is unable to tolerate tooth brushing (e.g. when your child has no teeth or has severe mucositis oral ulcers).



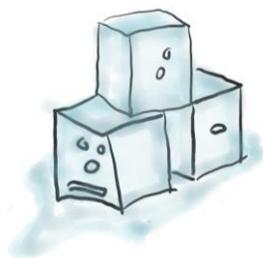
Mouthwash

- Helps keep mouth moist and clean by removing debris.
- Use mouthwash after every meal or brushing, and avoid eating and drinking during the first half an hour after rinsing.
- Either 0.9% sodium chloride or salt-water is recommended.
- Mouthwash containing xylitol or fluoride is recommended if your child can tolerate the taste and is able to spit it out.
- Short-term chlorhexidine mouthwash may be recommended. However, prolonged use may result in brown stains on the teeth.



### Lip balm

- Lip balm can be prescribed to help prevent your child's lips from drying/peeling.

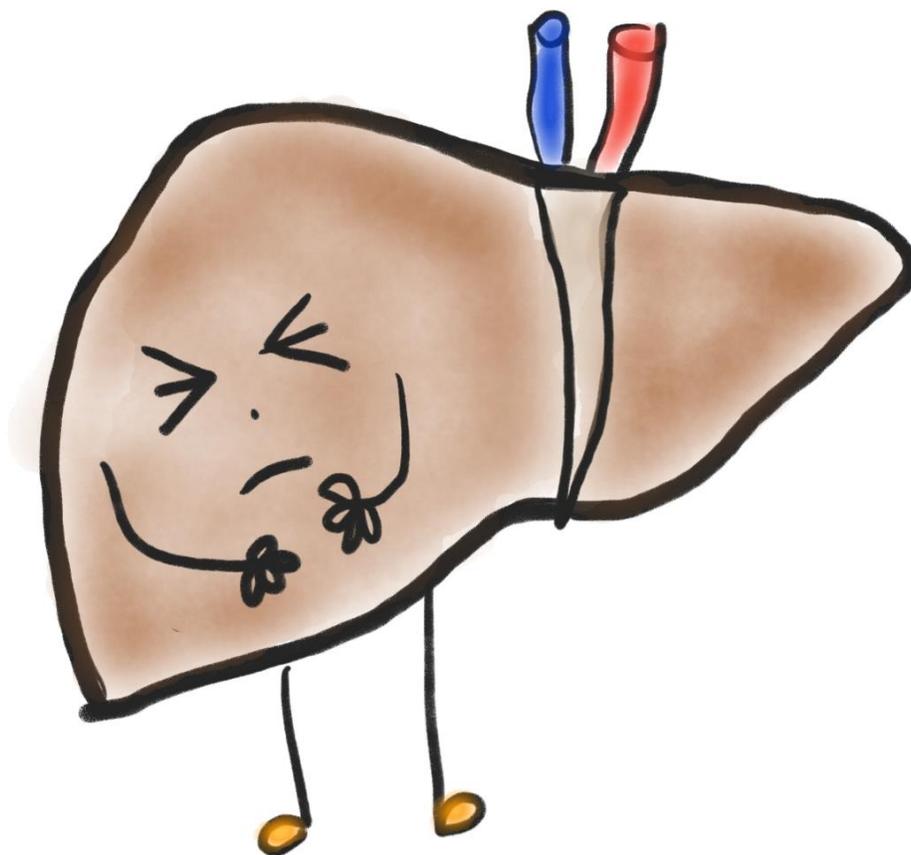


### Oral cryotherapy

- Oral cryotherapy is a treatment using ice chips or popsicles placed in the mouth to prevent the development of oral mucositis if you received a type of chemotherapy called melphalan.
- Your child will be advised to suck the ice chips or popsicles five minutes before the infusion and to continue doing so for the next 30 minutes.

**Important Note:** If your child complains of sore gums or pain during brushing, please refrain from brushing his/her teeth to prevent gum bleed. Frequent mouthwash will be adequate.

## SINUSOIDAL OBSTRUCTION SYNDROME



This is also known as veno-occlusive disease. It is a condition in which the tiny vessels inside the liver are damaged by chemotherapy/radiation, causing blockage and obstruction inside these liver vessels. This leads to enlarging of the liver, causing pain over the right upper quadrant of the abdominal, fluid retention causing weight gain, and yellowing of the skin and eyes. If these symptoms occur, your child may require frequent platelet transfusion.

A preventive medication called ursodeoxycholic acid will be given to your child to reduce this risk. Sometimes, a drug called defibrotide may be given to your child for treatment depending on your child's condition. Supportive care will be provided, such as taking out or reducing the dose of the medications that will further harm the liver, reducing fluid intake or giving medication to pass out excess fluid. Blood tests to check liver function will be taken more frequently to monitor your child's progress.

## FATIGUE



**Fatigue** can be described as feeling more tired than usual. The fatigue that comes with the transplantation treatment is different from the fatigue of daily life because it may last longer, and rest does not always help.

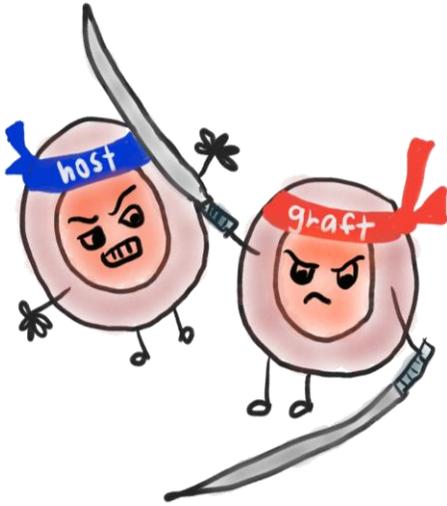
Fatigue can be caused by:

- Treatment such as chemotherapy, radiation or other medications
- Physical factors such as change of routines in sleeping and daily activities
- Mental or emotional factors such as stress, anxiety, worry, sadness or fear

Some of the strategies that may be useful to you in helping your child cope better with fatigue during the treatment period include:

- Frequent short rest periods during the day
- Regular light exercise (e.g. light stretches, changing of position in bed or a daily walk within the transplantation room)
- Develop a normal sleep routine
- Discuss your concerns with the transplantation team
- Discuss with your nurse to develop a routine that may suit your child to minimise disturbance during the stay

## GRAFT VERSUS HOST DISEASE (GVHD)



GVHD is a potential complication of allogeneic and haploidentical HSCT. The conditioning therapy suppresses your immune system to stop your body from rejecting the donor stem cells. Once the donor stem cells begin to engraft and function as your new immune system, the donor T-lymphocytes (a type of white blood cell) of your new immune system (graft) may see your child's body (host) as foreign and react by trying to destroy your child's tissues and organs. However, having mild GVHD can be a good thing if your child has a cancerous disease. The donor T cells, aside from attacking your body cells, will also destroy any residual or remaining cancer cells. Doctors call this the graft versus host disease or tumour effect. This will help to prevent the disease from coming back.

**Acute GVHD** which usually starts within 100 days of transplantation, typically affects three main organs: skin, gastrointestinal tract and liver.

Signs and symptoms may include:

1. Skin
  - Rashes: usually happens on the palms, soles of the feet and behind the ears. Rashes can also appear in other places. It usually causes itchiness and occasionally, pain.
  - If severe, the skin may develop blisters.
2. Gastrointestinal tract
  - Diarrhoea
  - Nausea/vomiting
  - Stomach pain or cramping
  - Little or no interest in eating
3. Liver
  - Abnormal liver function (Raised bilirubin level)
  - Yellowish skin and eyes (Jaundice)

**Chronic GVHD** typically starts after day +100 and may have similar symptoms.

Certain medications are given to prevent GVHD and they are known as immunosuppressants (e.g. ciclosporin, tacrolimus, methotrexate, mycophenolate, sirolimus). Immunosuppressants are given to reduce the risk of GVHD, by reducing the ability of the donor T-lymphocytes from attacking the host's organs and tissues. These medications will be continued for a few months to a year after HSCT, depending on the condition of your child. If your child develops GVHD, doctors may consider the use of corticosteroids for the treatment of GVHD.

### Tacrolimus

- Tacrolimus is given as an intravenous infusion during the initial period of HSCT. It is also available in oral suspension and oral capsules (0.5mg, 1 mg), and is to be taken twice daily. Oral tacrolimus is best absorbed when taken on empty stomach (i.e. one hour before food or two hours after food). If your child experiences stomach discomfort, it may be taken with food. Take consistently with or without food.
- Different brands of Tacrolimus are not interchangeable - it is advisable to only obtain supply from the hospital pharmacy.
- Tacrolimus dose is titrated according to the level of tacrolimus in the blood. Tacrolimus levels will be monitored once or twice weekly. Blood samples are drawn right before the next dose (trough). To ensure accuracy of the blood test results:
  - o Always take the medication at the same time each day (about 12 hours apart), and consistently with or without food.
  - o On the day of blood test, remember to give the morning dose only after the nurse has drawn the blood sample. (Do bring along the medication to the hospital on the day of CDT visit, so that the dose may be given once the nurse has drawn the blood sample.)
- Tacrolimus is subjected to many potential drug interactions, which can result in higher or lower levels of tacrolimus.
  - o A commonly encountered drug-to-drug interaction is that between antifungal medications (e.g. fluconazole, posaconazole, itraconazole, voriconazole) and tacrolimus. Antifungal drugs can cause higher levels of tacrolimus in the blood. Pharmacists and doctors will ensure close monitoring and titration of tacrolimus whenever antifungal drugs are started or stopped.
- Always check with the pharmacist or doctors before taking any medications or supplements. **DO NOT** take pomelo or grapefruit while on tacrolimus.
- Side effects of tacrolimus include: increased blood pressure, impaired kidney function, deranged electrolytes (magnesium, potassium), increased triglycerides, increased blood sugar, insomnia, headaches and tremors. It is important to maintain good fluid intake to reduce the risk of kidney problems.
- Always wear gloves when handling immunosuppressant drugs. **DO NOT** handle with bare hands.

### Methotrexate

- Methotrexate is usually given intravenously on days +1, 3, 6 and 11.
- Side effects of methotrexate include: bone marrow suppression, oral ulcers, impaired liver function.

### Mycophenolate

- Mycophenolate is given twice or thrice a day. Oral suspension and capsules should be taken on empty stomach, either one hour before or two hours after food. However, it may be taken with food if your child experiences stomach discomfort.
- Side effects of mycophenolate include: diarrhoea, stomach discomfort, low electrolytes (magnesium, potassium), headache, anxiety, tremor.
- Always wear gloves when handling immunosuppressant drugs. **DO NOT** handle with bare hands.

### Ciclosporin

- Ciclosporin is given as intravenous infusion twice a day during the initial period of HSCT. It is also available in oral solution and oral capsules (10mg, 25mg, 100mg).
- Different brands of ciclosporin are not interchangeable - it is advisable to only obtain supply from the hospital pharmacy.
- Ciclosporin dose is titrated according to the level of ciclosporin in the blood. Ciclosporin levels will be monitored once or twice weekly. Blood samples are drawn right before the next dose (trough). To ensure accuracy of the blood test results:
  - o Always take the medication at the same time each day (about 12 hours apart), and consistently with or without food.
  - o On the day of the blood test, remember to give the morning dose only after the nurse has drawn the blood sample. (Do bring along the medication to the hospital on the day of Children's Day Therapy (CDT) visit so that the dose may be given once the nurse has drawn the blood sample.)
- Ciclosporin is subjected to many potential drug interactions, which can result in higher or lower levels of ciclosporin.
  - o A commonly encountered drug-to-drug interaction may occur between antifungal medications (e.g. fluconazole, posaconazole, itraconazole, voriconazole) and ciclosporin. Antifungal drugs can cause higher levels of ciclosporin in the blood. Pharmacists and doctors will ensure close monitoring and titration of ciclosporin whenever antifungal drugs are started or stopped.
- Always check with the pharmacist or doctors before taking any medications or supplements. **DO NOT** take pomelo or grapefruit while on ciclosporin.
- Side effects of ciclosporin include: increased blood pressure, impaired kidney function, low electrolytes (magnesium, potassium), increased hair growth, swollen gums, increased triglycerides, headache and tremor. It is important to maintain sufficient fluid intake to reduce the risk of kidney problems.
- Always wear gloves when handling immunosuppressant drugs. **DO NOT** handle with bare hands.

## Sirolimus

- Sirolimus is available as oral tablets and is given once daily. May be taken with or without food. Take consistently with meals to minimise absorption variability.
- Sirolimus dose is titrated according to the level of sirolimus in the blood. Sirolimus levels will be monitored approximately once every week. Blood samples are drawn right before the next dose (trough).
- To ensure accuracy of the blood test results:
  - Always take the medication at the same time each day, and consistently with or without food.
  - On the day of the blood test, remember to give the morning dose only after the nurse has drawn the blood sample. (Do bring along the medication to the hospital on the day of CDT visit, so that the dose may be given once the nurse has drawn the blood sample.)
- Sirolimus is subjected to many potential drug interactions, which can result in higher or lower levels of sirolimus.
  - A commonly encountered drug-to-drug interaction is that of antifungal medications (e.g. fluconazole, posaconazole, itraconazole, voriconazole) and sirolimus. Antifungal drugs can cause higher levels of sirolimus in the blood. Pharmacists and doctors will ensure close monitoring and titration of sirolimus whenever antifungal drugs are started or stopped.
- Always check with the pharmacist or doctor before taking any medications or supplements. **DO NOT** take pomelo or grapefruit while on sirolimus.
- Side effects of sirolimus include: stomach discomfort, increased lipid levels, headache, swelling of hands and feet, and joint pain.
- Always wear gloves when handling immunosuppressant drugs. **DO NOT** handle with bare hands.

## DIET AND NUTRITIONAL CARE

### CANCER TREATMENT AND NUTRITIONAL NEEDS

A child with cancer can have predisposing factors affecting food intake and metabolism. Cancer treatments which include surgery, radiotherapy, and chemotherapy, could complicate a child's nutritional needs. The child's body has to work hard to repair damaged cells, excrete waste products, and at the same time, build new cells to support normal growth and development. Although parents know that children need to obtain adequate energy and nutrients, children who are ill often do not eat well. Some side effects arising from the treatment may compromise the child's nutritional status.



### Goals of nutritional care in cancer treatment

- Achieve normal growth and development.
- Prevent significant weight loss, i.e. **5% to 10%** of usual body weight, to optimise treatment outcomes.
- Enable the child to continue with normal activities.
- Improve quality of life.
- Prevent problems or delays in treatment.

## A BALANCED DIET

Children undergoing cancer treatment can benefit from a well-balanced diet by consuming food from each of the following food groups. It is important that you do not omit any food groups to ensure overall nutrition adequacy (e.g. include at least one food item from each food group per meal).



“My Healthy Plate” is a friendly visual tool on healthy eating habits designed for Singaporeans by the Health Promotion Board (HPB).

	<b>Nutrients provided</b>	<b>Examples</b>
Rice and alternatives	Provides energy, vitamins (especially B vitamins – thiamine, riboflavin, and niacin), magnesium, and fibre (if wholegrain products are chosen).	Rice, noodles, bread, biscuit, cereal, oats, chapatti, thosai, pasta and potatoes.
Meat and alternatives	Essential for growth, healing and a strong immune system.	Meat, fish, poultry, eggs, milk and dairy products, tofu, dried beans, and nuts.
Fruits and vegetables	Provides phytochemicals which act as antioxidants to protect cells from damage. (Note: fruit/vegetable juices should not replace a meal)	Eat a colourful variety of fruits and vegetables (e.g. red, green, yellow, orange), including fresh, frozen and canned fruits, juices.
Dietary fats	Good source of energy and essential for many body functions.	Use healthier unsaturated oil e.g. canola oil, soybean oil or olive oil, margarine (trans fat free), seeds and nuts.

## LOW-BACTERIA DIET

Children who undergo chemotherapy, radiotherapy or bone marrow transplantation may have lower immune functions and are at risk of developing food-related infections. The purpose of a low-bacteria diet is to avoid food that are more likely to contain infection-causing microorganisms.

The appropriate diet will be advised by your doctor and should be strictly adhered to when your child is undergoing intensive treatment.

The table below provides a list of safe food choices. If your child has other symptoms such as loss of appetite, loss of weight, diarrhoea, abdominal bloating, taste changes and severe sore mouth, you may ask for a referral to see a dietitian for further advice.

Food Categories	Recommended Food	Food to Avoid
Rice and alternatives	<ul style="list-style-type: none"> <li>• Cooked rice, porridge, noodles, pasta, oats, chapati, thosai, idli</li> <li>• All types of bread, e.g. dinner rolls, sweet rolls, plain buns, muffins, plain waffles, pancakes, French toast</li> <li>• Boiled, baked or fried potato</li> <li>• All cereals, cooked and ready-to-eat except those containing probiotics</li> <li>• Breakfast cereals, e.g. coco pops, honey stars and commercially packaged baked cereal/muesli bars<sup>1,2</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Reheated rice</li> <li>• Raw grain products e.g. raw oats</li> <li>• Cream-filled buns</li> <li>• Infant cereal with probiotics (<b>Check the ingredient list to see if probiotics is added</b>)</li> </ul>
Meat and alternatives	<ul style="list-style-type: none"> <li>• Thoroughly cooked or canned beef, pork, lamb, mutton, chicken, fish and other seafood such as prawn, crab and squid</li> <li>• Well-cooked egg (firm egg white and yolk)</li> <li>• Cooked tofu (cut into one inch cubes and boiled for at least five minutes)</li> <li>• Well-cooked processed meat (e.g. hotdog, sausage, ham, nugget, crabstick, meat ball and fishball)</li> </ul>	<ul style="list-style-type: none"> <li>• Raw or undercooked beef, pork, lamb, mutton, chicken, fish (e.g. sashimi, sushi, fish roe), seafood, egg, tofu</li> <li>• Meat and cold cut from delicatessens (e.g. ham, smoked salmon, salami, meat pâté)</li> <li>• Tempeh products or fermented soy products (e.g. nattō, fermented beancurd)</li> </ul>

Food Categories	Recommended Food	Food to Avoid
Milk and dairy products	<ul style="list-style-type: none"> <li>• All pasteurised or UHT milk</li> <li>• Formula milk powder for infants or growing children</li> <li>• Medical nutritional supplements without probiotics               <ul style="list-style-type: none"> <li>○ Nutritionally complete (use as advised by dietitian)</li> </ul> </li> </ul> <p><b><i>(Check the ingredient list for probiotics as manufacturers have the tendency to reformulate their products)</i></b></p> <p>Ice cream allowed include:</p> <ul style="list-style-type: none"> <li>• Pre-packaged ice cream<sup>1</sup>, sherbet<sup>1</sup>, fresh homemade milkshake using pasteurised or UHT milk</li> <li>• Dry, refrigerated or frozen pasteurised whipped cream toppings</li> </ul> <p>Cheeses allowed include:</p> <ul style="list-style-type: none"> <li>• Those made from pasteurised milk including processed cheese slices (e.g. cheese spreads, cream cheese, cottage cheese and ricotta cheese)</li> <li>• Commercially packaged hard and semi-soft cheeses (e.g. milk cheddar, mozzarella, parmesan, swiss)</li> </ul>	<ul style="list-style-type: none"> <li>• Unpasteurised or raw milk, cheese, yoghurt and other milk products</li> <li>• Yoghurt and cultured milk beverages (e.g. yoghurt drinks, kefir)</li> <li>• Commercial formulas with probiotics</li> <li>• Yoghurt Melts</li> <li>• Homemade eggnog</li> </ul> <p>Ice cream <b>NOT</b> allowed include:</p> <ul style="list-style-type: none"> <li>• Soft serve ice cream and frozen yoghurt dispensed from machines</li> </ul> <p>Cheeses <b>NOT</b> allowed include:</p> <ul style="list-style-type: none"> <li>• Mold-ripened e.g. Blue, Roquefort, feta and soft cheeses (e.g. Brie, Camembert, goat cheese)</li> <li>• Cheese made from unpasteurised milk (e.g. paneer)</li> <li>• Cheese from food kiosks or fast food outlets</li> <li>• Cheese containing chilli peppers or uncooked vegetables</li> </ul>
Vegetables	<ul style="list-style-type: none"> <li>• Well-cooked fresh, frozen or canned vegetables</li> <li>• Fresh or dried herbs added during cooking</li> </ul>	<ul style="list-style-type: none"> <li>• Unwashed raw vegetables or fresh herbs</li> <li>• Fresh herbs for garnishing</li> <li>• All raw vegetable sprouts (e.g. bean sprouts, alfalfa sprouts)</li> <li>• Salads from delicatessens, salad bars and fast food restaurants</li> <li>• Fermented vegetables (e.g. kimchi, pickles, sauerkraut)</li> </ul>

Food Categories	Recommended Food	Food to Avoid
Fruits and nuts	<p><u>When in hospital:</u></p> <ul style="list-style-type: none"> <li>• Apple or canned fruits are provided</li> </ul> <p><u>When at home:</u></p> <ul style="list-style-type: none"> <li>• Well-washed, peeled fruits (to consume immediately once fruits are cut)</li> <li>• All cooked, canned or frozen fruits</li> <li>• Commercially packaged fruit juice<sup>1</sup></li> <li>• Dried fruit in baked products (e.g. raisin bread/muffin, fruit cake)</li> <li>• Shelled, roasted nuts from a can bottle or packet, and nuts in baked products (e.g. peanut cookies)</li> </ul>	<ul style="list-style-type: none"> <li>• All berries</li> <li>• Bananas</li> <li>• Unwashed fruits with edible skin</li> <li>• All pre-cut fruits sold at shops or supermarkets</li> <li>• Unroasted raw nuts and unshelled roasted nuts</li> <li>• All nuts and dried fruits that are sold in bulk and exposed</li> </ul>
Fats and oils	<ul style="list-style-type: none"> <li>• Margarine, butter, peanut butter</li> <li>• Cooking oil</li> <li>• Commercial, shelf-stable<sup>3</sup> mayonnaise and salad dressing (refrigerate after opening)</li> </ul>	<ul style="list-style-type: none"> <li>• Fresh salad dressings containing cheese with mold (e.g. Blue, Roquefort or raw eggs e.g. caesar salad dressing, homemade mayonnaise, hollandaise sauce)</li> </ul>
Desserts and snacks	<ul style="list-style-type: none"> <li>• Freshly baked commercial and homemade cakes, pies and pastries without cream</li> <li>• Homemade and commercial packaged puddings<sup>1</sup> and jelly<sup>1</sup></li> <li>• Homemade and commercial packaged cookies<sup>1</sup> and biscuits<sup>1</sup></li> <li>• Potato chips<sup>1</sup>, corn chips<sup>1</sup>, pretzels<sup>1</sup></li> <li>• Homemade popcorn</li> <li>• Candy</li> </ul>	<ul style="list-style-type: none"> <li>• Cream-filled cakes and pastry products</li> <li>• Homemade ice cream, mousse, eggnog, soufflé, meringue</li> <li>• Mass-produced snacks from common serving containers (e.g. popcorn, candy floss)</li> </ul>

Food Categories	Recommended Food	Food to Avoid
Beverages	<ul style="list-style-type: none"> <li>• Boiled water</li> <li>• Home-made ice using boiled water</li> <li>• All canned<sup>4</sup>, bottled and powdered beverages</li> <li>• Pasteurised soya milk<sup>1</sup></li> <li>• Instant and brewed coffee and tea</li> <li>• Herbal teas brewed from commercially packaged tea bags</li> <li>• Home-brewed drinks (e.g. chrysanthemum tea - wash chrysanthemum flowers thoroughly and boil together with water, barley water)</li> <li>• Homemade smoothies</li> </ul>	<ul style="list-style-type: none"> <li>• Non-carbonated bottled, mineral, spring and natural water</li> <li>• Unboiled water taken directly from the tap</li> <li>• Water from water coolers and dispensers</li> <li>• Ice from ice machines in public places</li> <li>• Ice-blended drinks or slushies from bulk machines</li> <li>• Tea made from loose leaves</li> <li>• Opened drinks left at room temperature for one hour or more</li> </ul>
Miscellaneous	<ul style="list-style-type: none"> <li>• Salt, granulated sugar and brown sugar</li> <li>• Spreads<sup>1</sup> (e.g. jam and jelly, Kaya - coconut jam, chocolate or hazelnut spread) - refrigerate after opening</li> <li>• Cooked spices</li> <li>• Commercial pasteurised Grade A honey</li> <li>• Tomato ketchup, chilli sauce, mustard, soy sauce, BBQ sauce, oyster sauce - refrigerate after opening</li> <li>• Cooked gravy and sauces</li> <li>• Cream and non-cream-based soups (canned or home-made)</li> </ul>	<ul style="list-style-type: none"> <li>• Pepper</li> <li>• Spices added after cooking</li> <li>• Raw or unpasteurised honey<sup>5</sup></li> <li>• Herbs and herbal supplements<sup>6</sup></li> <li>• Miso products e.g. miso soup</li> </ul>

<sup>1</sup>Use individually packaged or wrapped portions whenever possible.

<sup>2</sup>Only allowed for children above 3 years. Avoid opening the packaging in front of the child.

<sup>3</sup>Shelf-stable refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature; may require refrigeration after opening.

<sup>4</sup>Wash the top of the can with water before opening.

<sup>5</sup>Pasteurised honey products are allowed for children over one year of age and after more than nine months post-transplantation.

<sup>6</sup>Herbs and herbal supplements are not regulated for purity or for effect on health, and may also contain harmful ingredients.

**Important Note:** Avoid purchasing food from food courts, food retail outlets etc.

Food purchased from such places can carry a potential risk for foodborne illness as food safety can be compromised due to inappropriate food handling and food storage temperatures.

## FOOD SAFETY TIPS

### Food preparation and cooking

- Wash your hands before preparing and eating food.
- Avoid cross-contamination by using separate cutting boards for cooked food and raw food.
- Wash fruits and vegetables thoroughly under running water before peeling, cutting or cooking.
- Thaw meat, fish or poultry in the refrigerator or microwave. Do not thaw food by leaving them on the table or countertop at room temperature.
- Cook defrosted meat right away and do not refreeze.
- Cook food thoroughly at high temperatures of 75°C or higher.

### Food storage and reheating

- Store cold food at a safe temperature of 4°C or colder.
- Cooked food should be served and consumed promptly or kept in the refrigerator/freezer within one hour after cooking. Avoid leaving food at room temperature for more than one hour.
- Consume leftover food within 24 hours of cooking.
- Microwave cooking or reheating can leave cold spots in food where bacteria can survive. If there is no turntable appliance, rotate the dish a quarter turn once or twice during cooking.
- No reheating of rice. Avoid reheating all other food more than once.

*Adapted from the Academy of Nutrition and Dietetics, Fred Hutchinson Cancer Research Centre and Memorial Sloan-Kettering Center after discussion with Paeds Onco consultants.*

*Guidelines from Agri-Food & Veterinary Authority of Singapore, The British Dietetic Association 2016 Neutropenic Dietary Advice for Haematology Patients Policy and United States Department of Agriculture Food Safety and Inspection Service Food Safety Information.*

## **THE USE OF MEDICAL SUPPLEMENTS, TRADITIONAL HERBS AND ORGANIC PRODUCTS**

Many parents believe that organic products have additional benefits for their children. However, there is no strong scientific evidence to support this. If you intend to use organic products, you may wish to consider other factors such as cost, availability and convenience. Giving your child traditional herbs is strongly discouraged as there may be some interaction between traditional herbs and cancer treatment. Please seek advice from your child's oncologist if you have any concerns.

Certain multivitamins supplements may interfere with the chemotherapy drugs. Do not give any multivitamins supplements unless prescribed by the oncologist.

## **COMMERCIAL NUTRITIONAL SUPPLEMENTS**

Nutritional supplements may be useful in ensuring your child gets adequate energy, protein and nutrients, particularly when he/she is unable to eat well. It can be used to supplement in-between meals or replace a meal. You may consult your child's oncologist, nurse or dietitian on the age-appropriate nutritional supplements to use.

## **FEEDING BY TUBE AND PARENTERAL NUTRITION**

If your child is unable to eat or drink in adequate amount, your medical team will discuss alternative ways of meeting his/her nutritional needs. This may include tube feeding or parenteral nutrition (PN).

The most common is a nasogastric tube (NG tube), which is inserted via the nose to the stomach. A complete nutritional supplement will be given through the tube to maintain the normal function of the gastrointestinal tract.

PN bypasses the normal digestion process in the stomach and bowel. It is a special liquid food, which contains complete nutrition, given into the blood. PN will be given through the intravenous line, mostly via central line, to provide nutrients if the gastrointestinal tract is not working properly.

## COPING WITH TRANSPLANTATION AND ISOLATION

HSCT is an intensive treatment. It carries both hope and risks for children in their battle against life-threatening illnesses. Parents may have mixed feelings of relief and fear of unknown outcomes. HSCT is not only highly stressful for those undergoing the procedure, but also for their parents and family.

To proceed with this treatment can be a tough decision and parents may have concerns on the medical-related conditions, potential side effects, risks and complications. Having adequate information can help to reduce uncertainty and stress. Similarly, knowing how this treatment may impact everyone in the family psychologically and socially is important for all to learn how best to cope with the challenges.

In this chapter, our aim is to enable you to address questions such as “How are we going to get through this?” or “What can I do to help my child?”.

### HOW CAN YOU SUPPORT YOUR CHILD?

#### Before transplantation

Young children can be very sensitive when they undergo a series of medical tests. They may overhear discussions; observe anxious behaviours or sense distress from adults. Having honest information presented to them in a manner they understand will help them cope with their condition. The amount of information to share or when to tell them will depend on their developmental age, maturity to process information and their coping style.

**Up to 2 years old:** Children in this age group are unable to process verbal information. However, they are sensitive and are attuned to the distress cues of their parents. As a parent, the level of calmness and anxiety you display will have a direct impact on the child. Therefore, preparing yourself mentally for what is to happen and taking care of yourself will help your child feel secure in your presence and remain calm.

**2+ to 6 years old:** At this age, children do not have a good awareness of time and their coping skills may be limited. Telling them about transplantation way in advance may increase their anxiety. For younger children, having a discussion about the hospital trip one or two days in advance may be appropriate whereas three to four days may be more suitable for older children. They may worry about whether the transplantation will be painful; if their parents and loved ones will be with them during the treatment or if they can still engage in their favourite activities. Involving older children in planning what activities they can do while in the hospital will be helpful as it increases their sense of choice and control.

**7 to 12 years old:** Children at this age have slowly developed the capacity to process information but they may need time to reflect on what is presented to them. It may be appropriate to give them more information about one week before the start of the pre-transplantation physical and medical tests and one week before they admit to the hospital for transplantation. It gives them time to ask questions, respond and express their worries. Children this age tend to have fears about pain, loss of control and boredom.

**12+ to 18 years old:** It is helpful to involve children in this age group in the discussion about transplantation from the beginning.

**What to prepare for the hospital stay:** Involving the child in preparing for the admission to the hospital will be helpful. You may want to help your child choose and pack one item which will bring him/her comfort during the hospital stay.

You can approach any of the following healthcare providers to assist and support you and your child before the transplantation:

- Children's Cancer Foundation (CCF) Child Life Specialist or Social Worker\*
- KKH Child Life Therapist
- KKH Medical Social Worker

CCF educational resources that can help your child understand HSCT.

Alternatively, you can also visit the following websites for downloadable publications.

- **Me and My Marrow - A Kid's Guide to Bone Marrow Transplants by Karen Crowe**  
<https://www.bridges4kids.org/Disabilities/meandmymarow.pdf>
- **Ben's Stem Cell Transplant: A Children's Guide to Donor (Allogenic) Stem Cell Transplant by Children's Cancer and Leukemia Group**  
[https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Ben's\\_stem\\_cell\\_transplant\\_2017.pdf](https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Ben's_stem_cell_transplant_2017.pdf)
- **Ruby's Stem Cell Harvest and Transplant: A Children's Guide to Stem Cell Harvesting and Transplant Using Their Own Stem Cells (Autologous Transplant) by Children's Cancer and Leukemia Group**  
[https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Ruby's\\_stem\\_cell\\_harvest\\_and\\_transplant\\_2017.pdf](https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Ruby's_stem_cell_harvest_and_transplant_2017.pdf)
- **At the Hospital: Helping My Child Cope – What Parents Can Do by National Child Traumatic Stress Network**  
[https://www.nctsn.org/sites/default/files/resources//at\\_the\\_hospital\\_helping\\_my\\_child\\_cope\\_parents.pdf](https://www.nctsn.org/sites/default/files/resources//at_the_hospital_helping_my_child_cope_parents.pdf)
- **Stem Cell Transplant: A Guide to Stem Cell Transplantation for Teenagers and Young Adults by Children's Cancer and Leukemia Group**  
[https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Stem\\_cell\\_transplant\\_\(Jan\\_13\).pdf](https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Stem_cell_transplant_(Jan_13).pdf)
- **At the Hospital: Helping My Teen Cope – What Parents Can Do by National Child Traumatic Stress Network**  
[https://www.nctsn.org/sites/default/files/resources//at\\_the\\_hospital\\_helping\\_my\\_teen\\_cope\\_parents.pdf](https://www.nctsn.org/sites/default/files/resources//at_the_hospital_helping_my_teen_cope_parents.pdf)

*\*For paediatric oncology patients only.*

## During transplantation

### Establish a routine

It is helpful to establish a routine for your child on top of the existing hospital procedures and routine (doctor's visit, medicine taking and blood pressure monitoring) because having a routine will give your child a better sense of predictability, control and normalcy. Children and teenagers thrive on stimulation as boredom can be very distressing for them. Routine that includes a variety of activities can help your child increase his/her activity level and reduce effects of negative impact of under-stimulation. Depending on the age of your child, types of activities may include craft projects, reading, listening to music or audio books, doing schoolwork/school projects, playing conventional games, electronic games and surfing the internet. Keep these routines flexible as there may be days when your child feels "under the weather" from the side effects of treatment and needs to rest more.

### Communicate and support your child emotionally

Recognise when your child makes an effort to cope in a healthy and effective manner and offer appropriate rewards. These rewards need not be expensive presents. They can be verbal encouragement or a sticker reward chart for younger children, where they collect a certain number of stickers in exchange for a small reward. You can acknowledge your child's struggles by saying statements like, "It has been a tough day for you. You hardly slept because of the stomachache. Let me give you a hug." However, the timing of the emotional support is crucial. If emotional support is only given intensely when your child is upset or fussing, or if your actions delay necessary medical procedures, your child is likely to perceive your emotional support as an encouragement for him/her to be upset and kick up a fuss. In such situations, your actions may backfire and you may see your child being upset more often in order to get the response he/she wants from you. For an older child or teenager, it will be more useful to share your feelings and how you cope with your emotions in times like these.

### Let your child know what is expected of him/her

Articulating your message clearly in a loving yet firm manner can help your child know what to expect. This sets boundaries for your child's behaviour. For example, let him/her know what is going to happen (e.g. "The nurses will be coming to help change the line dressing in 20 minutes."). When your child reacts negatively, let him/her feel that you know his/her fears or displeasure (e.g. "I know you hate it when the nurses need to do line dressing."). Thereafter, communicate your expectations ("I can see it's hard for you, but I know you can remain still when the nurses slowly take out the dressing and clean the line area."). Take the opportunity to discuss coping techniques with your child ("Is it better when I hold onto your hand while we listen to some music? Or do you prefer to watch a video on your tablet/phone when the nurses are doing the line dressing?"). When the procedure is over, praise your child's coping attempts, for an example, "I see how much you have tried to keep still during the entire time. You did it! Good Job!"

### Be supportive and not overprotective

HSCT can be extremely stressful, especially for adolescents because they may feel very strongly against their loss of control over things happening to or around them. They are forced to be dependent on adults for many things when they have a high need for independence and privacy. They struggle with physical changes that may be intensified during HSCT. At this age, friends become more important. Therefore, social isolation caused by their medical conditions may challenge the formation of their identities. Without illness, a teenager typically experiences mood swings due to physical and hormonal changes. With illness and HSCT, you can expect your teenager to have more mood swings as he/she straddles between wanting to be independent and being humoured like a young child.

You can be supportive by encouraging your teenager to play an active part in his/her treatment and self-care. When he/she is feeling moody or is demanding, consider giving him/her time and space rather than engaging him/her in a verbal confrontation and power struggle.

### Encourage and coach your child on relaxation and coping skills

When a child's mind is idle and he/she feels bored and unoccupied, there is a higher likelihood that he/she will focus on the negative experiences or discomfort. Practice calming and relaxation techniques with your child. You can download some simple to use exercises:

- [https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/Page\\_6-7\\_Muscle\\_Relaxation\\_Activity.pdf](https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/Page_6-7_Muscle_Relaxation_Activity.pdf)
- [https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/Page\\_8\\_Mind\\_Pictures\\_Activity.pdf](https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/Page_8_Mind_Pictures_Activity.pdf)
- [https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/Page\\_9\\_Busy\\_Brainwaves\\_Activity.pdf](https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/Page_9_Busy_Brainwaves_Activity.pdf)

If you notice that your child is not coping well emotionally with the transplantation, you can contact the following people who can work with your child to enhance his/her coping with hospitalisation and treatment:

- Children's Cancer Foundation (CCF) Child Life Specialist or Medical Social Worker\*
- KKH Child Life Therapist
- KKH Medical Social Worker

The Bone Marrow Transplantation room is equipped with a Wii Console. The TV in the room also has pre-downloaded movies that you can watch anytime. You can borrow Wii games and accessories from the CCF Family Resource Room.\*

The CCF Family Resource Room has a range of resources, such as toys and games which the Children Life Specialist or Medical Social Worker can help to arrange for age-appropriate activities for your child on a regular basis.\*

*\*Service is available for both oncology and non-oncology patients.*

## SUPPORTING SIBLINGS

Your child's illness and hospitalisation will be stressful for their siblings as well. Common emotions include jealousy, a sense of unfairness, anger, sadness, confusion and/or guilt. Some siblings block off these feelings by pretending they are fine because they do not want their parents to be upset or they may not know how to show/tell you.

Here are some ways to help your other children cope effectively:

- Engage them and explain to them that their sibling is going for a transplantation. Use words that they understand.
- Tell them that temporary changes will happen within the family, especially if there will be changes to caregiving arrangements. Assure them of your love for them and that the family will make plans to ensure they are cared for during the period of transplantation.
- Keep routines for the other child/children as normal as possible to minimise the changes they will experience as changes can be stressful. If you usually send your other child for art lessons on weekends, see who else in the family can help so that your other child can continue to attend art lessons during the transplantation period.
- Discuss ways for the other child/children to keep in contact with you and the sick sibling during the transplantation period, e.g. through phone calls, face-time, skype, writing letters, etc. CCF has a "VIBS Got Mail"<sup>#</sup> programme where we will provide writing materials to you and help you mail out the letters to your other children free of charge. It is usually a pleasant surprise for your child/children to receive handwritten letters from you.
- Encourage them to reach out to you or other adult family members if they have questions when you are not at home. Some children express themselves better through drawing or writing.
- Try to spend some quality time with each of your children, even if it is very brief.
- You may wish to contact your child's/children's teachers and inform him/her of the situation at home. The teachers can be a source of support for your children and help to monitor how they are coping in school during this transition period.

Discuss with your Social Worker on the needs of your other children.

<sup>#</sup>Children's Cancer Foundation (CCF) has a "Very Important Brothers & Sisters" (VIBS) programme in which a social worker is assigned to support your other children who are above three years old.

*This service is only available for immediate family members of oncology patients.*

## PREPARING YOURSELF FOR THE TRANSPLANTATION

You are likely to have a lot on your mind, such as worrying about your child's BMT, how your child will respond to the transplantation treatment, your child's emotional well-being, other children and family members, finances, your ability to manage the stress of being the only caregiver to the child during the transplantation period, etc. Like your child, you will also feel a loss of control and freedom, and socially isolated during the transplantation.

How well you manage your anxiety and stress will have an impact on your child's coping. As such, just as you prepare your child and family emotionally for the transplantation, you need to prepare yourself too.

Below are some suggestions to get you prepared and cope better during transplantation:

- Gather and clarify as many facts as possible on what to expect during the transplantation, for an example, what are the do's and don'ts or what is expected of you from the medical/nursing team.
- Make your own packing list. The transplantation room may be cold. You may want to bring a thick sweater. Consider packing a small personal belonging that brings comfort to you.
- Identify coping strategies that have worked for you. For an example, activities to distract and occupy your time (reading, downloading movies to watch on your mobile devices, art and craft projects, spiritual/religious rituals or routines, talking to family members, and relaxation techniques like massaging acupoints or doing stretching exercises).
- Although your time seems consumed by the daily caring of your child and the hospital routine, it is important that you take some time off each day for yourself to clear your thoughts or engage in activities that make you feel relaxed.
- To avoid being overwhelmed, schedule a time each day to worry. During that time (e.g. 30 to 60 minutes), write down your worries and consider what you need and can do about them. If your worry is medical related (and likely not within your control), e.g. "what if the blood counts are still low tomorrow?", recall what the medical team had told you about the situation, what to expect, or what the medical team will do.
- When emotions run high, particularly when your child's behaviour frustrates you, take a short time-out. When you are calm, return to talk to your child.

Talk to the following people about your concerns and worries:

- Children's Cancer Foundation (CCF) or Social Worker\*
- KKH Medical Social Worker

The CCF Family Resource Centre has educational resources for caregivers.

You can also visit the Children's Cancer and Leukemia Group website. They have a range of downloadable publications about diagnosis, treatment and after treatment of cancer:

<https://www.cclg.org.uk/publications/All-publications>

*\*For paediatric oncology patients only.*

## POST-TRANSPLANTATION

When your child is discharged from the hospital, he/she is most likely expected to return to the hospital for follow-up treatment and consultation with the doctor. It may be a while before your child is given the green light to return to school or be among friends. You may also have feelings of uncertainty and fear of the unknown future. It is important that you, your child, and the rest of the family return to a normal routine by not ruminating in the illness.

You can support your child's post-transplantation with these steps as a guide:

- Encourage your child to be independent, rather than being a "sick person".
- Let him/her do things that are within his/her abilities and support his/her development by not being overprotective.
- Encourage him/her to explore new interests/hobbies while at home. Although it is easy to keep your child occupied and quiet using electronic devices, prolonged hours on these devices will make his/her transition back to school more difficult.
- Set goals together with your child. It may take some time before your child is well enough to return to mainstream school. Discuss with your doctor and the CCF social worker on the options of referring your child to transitional schools – Place of Academic Learning and Support (PALS) or Arc Children's Centre.

## PLANNING FOR HOME

### DISCHARGE CRITERIA

**Your child may be able to go home if he/she has met the following criteria:**

- When your child's Absolute Neutrophil Count (ANC) has been above 0.5 for two consecutive days.
- When your child does not require platelet transfusion for more than four to five days.
- When your child is able to swallow fairly well or tolerate milk feeding via Nasogastric Tube (NGT) without persistent vomiting.
- When IV medications have been changed over to oral medications and your child is able to tolerate medications either orally or via NGT.
- When your child's drug level for immunosuppressant is within the therapeutic range.
- When your child's infection is under control.

You and your child will receive a detailed briefing from the nurses, pharmacist and dietitian to prepare both of you for home. Your child will only be discharged after the briefing is completed and that you are comfortable with the care at home.

### PATIENT EDUCATION AND CAREGIVER TRAINING

**You and your child will be given the following care advice on areas that are relevant to you:**

- Care of central line and the proper technique for changing the Hickman Line/PICC line dressing.
- NGT feeding and insertion of the NGT if your child is discharged with NGT. A dietitian will provide you with the dilution guidelines for the milk based on your child's calorie intake requirement.
- The pharmacist will coach you on how to give the medications and explain what the drugs are for, as well as what side-effects to look out for. The pharmacist may give you a medication list as reference if your child is prescribed multiple drugs.
- Home preparation:
  - Clean the house thoroughly before your child's discharge. Use a damp cloth to remove dust and keep surfaces clean.
  - Minimise clutter in your child's bedroom as cluttered surfaces tend to trap dust and germs.
  - Air-conditioners should be cleaned or replaced if faulty. Inspect and change filters monthly, and clean the fan blades regularly.
  - You can have plants in your house, but not fresh flowers. Your child should avoid contact with soil or standing water. He/she should stay away from soil digging, re-potting and emptying water from vases.
  - You may keep pets, but it is important to keep them clean. Shower and shampoo them daily. Do not allow your child to handle litter boxes, birdcage linings, and fish or turtle

- bowls. Avoid contact with the saliva, urine and faeces of animals. If you are unable to keep the pets clean, it is advisable to find them a new home.
- Keep your child away from family members or visitors who are sick. Avoid contact with children who have been exposed to chickenpox or measles.
  - Close all windows that face construction sites because bacteria and fungi from the soil can be airborne.
  - Consider having a HEPA air filter to reduce airborne contamination in the house.
  - Set aside specific utensils for your child during meal times. He/she should avoid sharing food with the family.
  - Do not let your child touch raw meat, seafood, unwashed vegetables and eggs.

## WHEN TO CALL FOR MEDICAL HELP

### Things to look out for in your child and when to call for medical help:

- Fever (temperature greater than 38°C measured at least 30 minutes apart or above 38.5°C) or chills.
- Sudden onset of bleeding from the nose, gums or catheter site.
- Blood in urine, stool or coughing out blood.
- Pain, or burning with urination or decrease in urine amount.
- Persistent diarrhoea or constipation.
- Uncontrolled nausea or vomiting.
- Inability to take prescribed medications or fluid.
- Changes in the appearance of central line catheter site (look out for redness, pain, discharge or swelling).
- Sudden onset of skin rashes.
- New pain anywhere or unbearable pain.
- Prolonged weakness, abdomen discomfort or muscle cramps.
- Signs and symptoms of GVHD.
- Avoid sun exposure as it may aggravate skin GVHD. Apply sunscreen, wear a hat, long sleeve and sunglasses when going out.

**Important Note:** This list is not exhaustive. Please call the ward if you have any related concerns not stated here or observed that your child is not feeling well.

## APPOINTMENT AFTER DISCHARGE



After discharge, your child will be seen in Children's Day Therapy (CDT). Your child may require frequent outpatient appointments for blood taking, IVIG transfusion and other investigations. The appointment may be scheduled once or twice a week, depending on your child's condition until blood counts are stable or require less intravenous medication such as IVIG.

### HOW DOES A DAY IN CDT LOOK LIKE?

Please arrive before 9.00am for your appointment as there are a series of procedures to be done for your child.

- Step 1: Go to the CDT triage room and call CDT nurses for infectious disease screening.
- Step 2: Height, weight and vital signs will be measured. A bed or chair will be allocated based on the type of procedures.
- Step 3: Your child will undergo the planned procedures.
- Step 4: Wait for blood result and doctor's review.
- Step 5: To collect medications from the outpatient pharmacy if needed.

### Important notes for CDT visit:

- If your child is on Cyclosporine/Tacrolimus which requires drug level monitoring, do not serve the morning dose to your child before coming in for outpatient visits. Your child will have blood drawn for the drug level. Bring the Cyclosporine/Tacrolimus with you so that your child can take the morning dose after his/her blood is drawn.
- Bring your own medications and food if needed.
- Please inform the CDT nurses early if you would like to order hospital food. We only accept CASH payment.
- Remember to bring your own dressing removal spray and special dressing material if needed.
- The estimated waiting time for medications to be given is around one to one and a half hours; IVIG administration may take approximately four to six hours.
- For haematology cases, all the CDT fees must be paid in cash.

## USEFUL TELEPHONE NUMBERS



**WARD 76 NURSES' COUNTER (Inpatient matters)**

6394-1760/6394-1761

**ONCOLOGY PERIPHERAL NURSE (For fever only)**

81217861

**CHILDREN'S DAY THERAPY (Outpatient matters)\***

6394-2145

**MS VIJAYA (BMT coordinator)\***

81211832

**TRANSPLANT HELPLINE (For medical-related matters)\***

9784-3065

\*Office hours only

## PATIENT AND CAREGIVER STORIES

### AN ADOLESCENT'S JOURNEY OF UNDERGOING ALLOGENIC HSCT

**“The whole procedure of treatment can be very unbearable and painstaking to endure for many. Nevertheless, I tried my best to accomplish these tasks regularly, as they were for my benefits and would pay off in the long run.”**

The care during the stay in the ward and after the transplantation wasn't an easy task to undergo, in both the hospital ward and at home. Multiple precautions had to be taken to ensure maximum health and safety. In the ward, I tried to keep my skin clean and hydrated by moisturising the areas with water and lotion every morning, with the help of my caregiver, my father. Other things I had to do was eat healthy foods to buck up on my nutrition. None of these things were desirable. It honestly felt quite embarrassing to do these things. Nevertheless, I tried my best to accomplish these tasks regularly, as they were for my benefits and would pay off in the long run.

Many of the tasks I had to take up and the daily routines I had to go through were infuriating and annoying to experience. It felt claustrophobic being restrained to four walls in both my house and the hospital ward, being someone who enjoyed sports and activities. It felt excruciating being restricted to either a bed in the hospital ward or my room at home. But I understand that it is a necessary precaution to take to prevent myself from catching any infection. As a teenager, I liked to be out and about and interact with friends, but those weren't possible options in that period of time. Because of that, I looked for other methods of keeping myself occupied for the coming months.

As an adolescent, it is important to keep your mind on what you love to do. That's what I did. I spent my time watching movies, browsing social media, watching YouTube and more. Time flew enjoyably in these moments, and I was also able to get a break from my upset and slightly depressed mood. While it was entertaining, these activities I took up in my electronic devices weren't useful, so I took to studying as well. Not going to school will obviously leave a mark on your education, which was why I studied as much as I could before heading off to school again. I also read many books, which was both useful and entertaining.

To keep in contact with my friends, I merely called them up through my phone. Even though it would be quite a long time before I could interact with them properly, it still felt heartwarming to talk and engage with close friends. I listened to the stories of school they told me.

In terms of nutrition, I couldn't buy the foods I favoured, but had to eat unappetising vegetables and home cooked rice. I longed to head nearby and get myself a burger and a drink, things which I used to buy many times before. However, these types of foods faced the risk of severely harming my health. So, I stuck to a healthy diet. I ate countless fruits and wheat products. I ate all kinds of veggies and greens. Over time, these foods can actually taste good, and you'll come to enjoy them. The main point is to not indulge in unhealthy foods.

The whole procedure of treatment can be very unbearable and painstaking to endure for many. I felt that way many times. I was depressed and sad many times during the treatment process. Following a strict routine and diet was not favourable, but I did it anyway. The payoff was worth it. After months of control and restriction, I was free. I could go to school and gossip all I wanted. I could take part in sports and other activities. I ate what I wanted (though still in control), and it felt great being free.

D, May 2019

**Dietitian's advice:** Nutrition plays an important role in supporting children who are undergoing transplant. The body has to work hard to repair damaged cells, excrete waste products, and at the same time, build new cells to support normal growth and development. It is important to obtain adequate energy to prevent any weight loss. However, children who are ill often do not eat well. Common treatment-related side effects such as nausea, vomiting, change in sense of taste or even lethargy during treatment may affect appetite, which in turn may compromise nutrition status.

We advise that children maintain a balanced diet by consuming food from each category including carbohydrates, protein, fruits and vegetables/dairy. While fruits and vegetables contain vitamins and minerals that are beneficial for health, it is important not to neglect foods that contain energy (such as rice/noodles/pasta/bread/cereals) and protein (such as fish/chicken/meats/eggs/tofu/beans).

Children undergoing bone marrow transplant will have decreased immune function and are at risk of developing food-related infections. They would require a low bacteria diet throughout the course of treatment and will be asked to avoid foods that are more likely to contain infection-causing micro-organisms (such as raw food). Foods that are higher in calorie (such as fried food, cakes and ice cream) may be beneficial, especially for children who are losing weight during treatment. It is important that children enjoy a variety of foods during treatment to maintain their quality of life.

**Learn how dietitians help you/your child in your transplantation journey:** Dietitians are responsible for ensuring adequate nutrition in a patient's diet. They are trained professionally to focus on preventing and treating medical conditions through dietary plans.



## A MOTHER'S JOURNEY WITH HER CHILD UNDERGOING AUTOLOGOUS HSCT

**“With every beautiful sunset we witness, we are grateful for the day that we had. Fear not the darkness of the night, for it will end with a renewed promise in the morning.”**

Hayden was 4 years old when he was diagnosed with Stage 4 Neuroblastoma in 2017. After the induction treatment protocols, Hayden had very good partial response and the next step was Stem Cell Transplantation (SCT) - high dose chemotherapy followed by infusion of his own stem cells. This treatment involved hospitalisation in a protective isolation room with positive air pressure and double door to minimise infection risk. It typically takes about 2 weeks, as immunity drops to zero and bounces back as the new bone marrow starts producing blood cells again. The room environment for this needs to be extremely clean and dry to reduce infection/mold risk and therefore I spent 2 days disinfecting and ziplocking belongings that I planned to bring into the room. It was a balance between minimising items to reduce dust accumulation with enough gadgets to entertain a 4-year-old for a few weeks. Thanks to iPad/phone/laptop/library app that made entertainment so portable. CCF provided a lot of help too with the in-room video game consoles and downloaded movies/ cartoon and access to YouTube via the Smart TV in the isolation room. To prepare him for the isolation, I told him that he and mummy would be staying in a special room for a while and the highlight to him was that there will be Wii games and movies in the room. I could sense that Hayden was kind of looking forward to the isolation after my marketing attempt to package it into a fun adventure.

The first day of SCT (or stem cell transplantation) started with an operation for insertion of Hickman lines used for IV medicine and blood drawing during the transplantation. As the process of gassing out for anaesthetic pre-operation was frightening for the little one, I brought along a bottle of strawberry scent for his inhaler to try to make the experience more palatable. Hayden finds comfort in knowing that mummy has brought "our own strawberry gas". While he was undergoing the operation, I needed to prepare myself for the clean isolation room, took a shower and walked into Room 8, where I would call home for that month. As a paranoid parent, I started wiping everything and anything in the room, although I knew that the hospital had already disinfected the room.

The first week of SCT was uneventful, I kept my daily room cleaning routine. My full-time role was to ensure Hayden was eating enough, given that I knew his appetite would take a hit later. To keep him occupied, I let him ask me a question every morning and we would do research together on the internet on topics like "how our heart/lungs work?". It was near Christmas, I brought along a LEGO Advent calendar which was excellent to keep him occupied and he looked forward to opening a new LEGO figurine daily. A week into SCT, Hayden started to develop diarrhoea. He was tested positive for "C-diff" bacteria which caused severe diarrhoea up to 12 times a day at its worst. It was busy and cautious time trying to keep Hayden clean due to infection risk of raw skin or anal fissure at the perineum.

With white blood count dropping to zero, the doctor made it clear that it was a matter of time before he would spike a fever. The mucositis kicked in as well. As one of his chemotherapy drugs, Melphalan was well known for causing mucositis, the prevention was to suck on ice to contract blood vessels in the mouth while receiving the Melphalan. The nurse had prepared

frozen hydralite (electrolyte drink) and I asked for ice cream for him during the Melphalan infusion and he was sucking on ice/ice cream for more than one hour as I was told that the half-life of Melphalan is 75 minutes. Perhaps that helped and kept his mouth clear of sores. However, sores developed in his throat and at its worst, even swallowing saliva was so painful for him and his food/liquid intake took a toll and he had difficulty swallowing oral medicine. Ice cream was all that he could eat and even that was too painful for him after a few mouths. We had to put him on painkiller so that he felt better and was able to eat and drink again. During SCT, every mouth of food count and when eating became difficult, I made sure he had milk/milo/ice cream every 2 to 3 hours to keep nutrients going.

Hayden's engraftment was later than normal and did not happen even up to Day 28. All was well and calm, and he was active and well despite the low immunity. Things changed on Day 28, as it is the definition of failed engraftment and the panic started when the doctors decided to do a bone marrow aspiration (BMA) to check what was wrong with his marrow. It was times like this that my husband and I were really anxious, and it was important to have positive thoughts, support from family members and to lean onto your faith. I worked out that if this needed to be a marathon instead of a sprint, I would be with Hayden to ace this marathon and if engraftment was taking double the time, I would just do my best to disinfect the environment to ensure no harm to him in this extended vulnerable period.

To the surprise of the doctors, his immunity had a steep jump and he was declared to be engrafted on Day +30 even before the bone marrow analysis was out. The doctors decided to still give him a second infusion of stem cells anyway, to give his immunity a boost. We were relieved and knew that we were in the last lap of the race out of SCT. With his immunity stabilising, we were finally discharged home on Day 43, 50 days after being in isolation.

With every beautiful sunset we witness, we are grateful for the day that we had. Fear not the darkness of the night, for it will end with a renewed promise in the morning.

Rachel, Hayden's mummy. May 2019