



Dana-Farber/Boston Children's Cancer and Blood Disorders Center

EDUCATION GUIDE FOR Hematopoietic Stem Cell Transplant (HSCT) Patients & Families

INTRODUCTION

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Hematopoietic Stem Cell Transplant (HSCT)

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Hematopoietic Stem Cell Transplant Teaching Sheet

Hematopoietic Stem Cell Transplantation: An Overview of Care

Patients are typically admitted to 6 West or 6 Northeast for Hematopoietic Stem Cell Transplantation (HSCT) at Boston Children's Hospital. The HSCT team will let you know the admission schedule.

Conditioning Therapy

Conditioning therapy is high-dose therapy and/or radiation that each patient receives before their hematopoietic stem cell transplant. The days of conditioning are referred to as negative numbers, for example: Day -7, Day -6 or Day -5. After Day 0, the days are referred to as positive numbers, such as Day +1, Day +2, Day +3.

The conditioning therapy will:

1. Destroy the diseased cells in the body.
2. Remove the normal cells in the marrow spaces of the bones so the new marrow will have room to grow.
3. Suppresses the patient's immune system so that the donor's cells will be accepted by the patient if the patient is receiving cells from another person

Day 0: Hematopoietic Stem Cell Infusion

Day 0 is the day that the hematopoietic stem cells are given IV.

Common Side Effects

Patients may experience side effects, such as:

- nausea
- vomiting
- diarrhea
- mouth sores (mucositis)

The conditioning therapy and medications and type of stem cells used during transplant may cause other side effects. Your healthcare providers will explain these side effects if they occur.

Engraftment

Engraftment refers to when the stem cell or bone marrow graft is making enough cells. The number of neutrophils is called the absolute neutrophil count (ANC). The stem cells have engrafted when the patient's ANC is 500 or higher for 3 days following infusion of the stem cells and after the neutrophils have increased from their lowest number. Usually engraftment occurs 2-4 weeks after receiving stem

cells. Patients may continue to receive red blood cell and platelet transfusions for weeks and sometimes months after the transplant.

Discharge

You will receive additional teaching and teaching sheets before discharge to prepare you to care for your child at home.

Who to Call for Patient Care

- Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270
- After 5 p.m. or anytime on weekends and holidays:
 - Solid tumor, neuro oncology, hematologic malignancy patients: Call (617) 632-3352 and ask for the pediatric oncology provider on call.
 - Stem cell transplant patients: Call (617) 632-3352 and ask for the pediatric stem cell transplant provider on call.
 - Bone marrow failure clinic patients: Call (617) 355-6363 and ask for the hematology provider on call.
- For life threatening emergencies call 911.

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Pre-Hematopoietic Stem Cell Transplant Evaluations

Your healthcare providers will schedule many tests and appointments before your child is admitted for hematopoietic stem cell transplantation. The tests are needed to have baseline results before transplant so that your providers can compare and measure any changes during or after transplant. A schedule of the pre-transplant evaluations will be provided for your child.

The tests and appointments may include the following:

- Evaluation of disease status: lumbar puncture, bone marrow aspirate, bone marrow biopsy, X-rays, CT scan, MRI, MIBG.
- Heart studies: echocardiogram (ECHO) and electrocardiogram (EKG)
- Breathing studies: pulmonary function tests (PFT)
- Eye exam
- Dental exam
 - your child's dentist should discuss any dental problems with the transplant provider before filling any cavities or removing any infected teeth.
 - your child may need to take antibiotics before the dental appointment.
- Hearing exam (audiology test)
- Gynecologic and/or reproduction evaluations
- Kidney test (renal test)
- Blood work

Meetings

- Before being admitted for transplant, you will meet with members of the stem cell transplant team to discuss the following:
 - disease status
 - stem cell transplantation process
 - side effects of transplant and possible toxicities
 - risk of infection
 - restrictions after discharge
- If the treatment plan includes apheresis or peripheral blood stem cell collection, you will meet with the apheresis nurses.
- If the treatment plan includes radiation, you will meet with the radiation oncologists to discuss radiation planning.
- An introduction to the inpatient stem cell transplant unit at Boston Children's Hospital.
 - An in person or virtual tour of the unit.
 - A healthcare provider will discuss the daily schedule and routines for the hematopoietic stem cell transplant patient when on the unit and answer any questions you might have.

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Bone Marrow Harvest

General Information

- Bone marrow is the spongy blood forming tissue where all red and white blood cells and platelets are made. These cells are collected during the bone marrow harvest procedure most often from the hipbones.
- A bone marrow donor most often has their bone marrow collected on the same day that the transplant patient will receive the bone marrow.
- The donor bone marrow cells are infused into the patient, similar to a blood transfusion.

Pre-Operative Appointment

- The donor will have an appointment at the pre-operative clinic at Boston Children's Hospital (BCH).
- A healthcare provider will review the consent for anesthesia, the side effects of anesthesia, and will answer your questions.

Day of Bone Marrow Harvest

- The donor will need to come to the BCH surgery unit (3rd floor of main building) as scheduled by the pre-op clinic.
- An intravenous (IV) line will be placed before or after the donor goes to the operating room.

Bone Marrow Harvest Procedure

- A bone marrow harvest is done in an operating room under general anesthesia.
- Bone marrow will be collected from both hip bones.
- After the procedure there will be 2-3 holes on each hip small enough so that no stitches are needed. A large bandage will cover this area.
- The donor will be brought to the post-anesthesia care unit (PACU). The parents or legal guardians may visit the donor as per COVID restrictions. Fluid and pain medicine will be given through the IV.
- The donor is usually admitted to BCH overnight.

Discharge

- The donor will most likely be discharged from the hospital the next day.
- The bandages will be removed that morning and Band-Aids placed over the harvest sites.
- Showers are allowed and band-aids should be changed if they become wet.
- Swimming or baths are not allowed until the sites are healed.

Bone Marrow Harvest

- It is common to have bruising and tenderness during this time. Warm packs and acetaminophen may be used for comfort but not ibuprofen.
- Donors should avoid high impact sports and heavy lifting for six weeks.
- Drink at least 8 eight-ounce glasses of fluid each day to prevent dehydration.
- Continue to take medications recommended by your healthcare provider.
- Contact your healthcare provider with any questions or concerns.

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What May I Bring from Home When Having a Hematopoietic Stem Cell Transplant?

Personal items from home must be clean and able to be wiped down. Keep in mind that storage space in the patient room is limited. Each room has an entertainment system and internet access.

Toys, Games, Books

- Your child may bring a few favorite toys, books, 1 – 2 stuffed animals.
- Your child may bring their own gaming system, DVDs or handheld devices.
- Toys and stuffed animals that are machine-washed and dried at home should be brought to the hospital in a sealed container such as a suitcase or plastic bag.
- New toys in packages can be brought into the room after taking off the wrapping.

Personal Computers and Electronic Devices

- Laptop and tablet computers may be brought from home. If you don't have access to a tablet, you may use one from Boston Children's Hospital.
- The electrical engineers will check all electronics brought from home to see if they are compatible and safe to use.

Clothing

- Clothing can be brought from home after being washed and placed in a sealed container such as a suitcase or a bag. We recommend, comfortable clothing that can be machine-washed and dried in a dryer.
- Bringing nonskid slippers or shoes is recommended.
- Washer and dryer are available on the 6th floor for patients and caregivers. Detergent is provided.

Bed Linens and Blankets

- Any blankets brought from home must be washed twice a week or if soiled.
- Any bed linens brought from home must be washed every day or if soiled.

Pictures

- Pictures brought from home must be wipeable and able to be cleaned.

What May I Bring from Home When Having a HSCT?

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Patient Daily Schedule for Hematopoietic Stem Cell Transplant (HSCT)

This is an example of what a daily schedule may look like for an HSCT patient. Schedules are customized based on your child's medical needs.

12:00AM (MIDNIGHT) – 5:00AM	Blood tests are drawn from the central venous line (CVL)
12:00AM (MIDNIGHT) – 1:00AM	Vital signs
4:00AM – 5:00AM	Vital signs
8:00AM – 9:00AM	Morning vital signs, oral medications, and nursing assessment. Please note a morning weight is critical for all patients.
8:00AM – 12:00PM (NOON)	HSCT Team will round on all patients during this time. The order will vary.
9:00AM – 12:00PM (NOON)	Daily shower/bath/wipes and bed linen change (may be delayed to PM if desired), Activities (play, tutoring, walk in the hall), mouth care
11:00AM – 8:00PM	Visiting hours
12:00PM (NOON) – 1:00PM	Vital signs, oral medications (if prescribed)
1:00PM – 3:00PM	Quiet time (all patients are in their rooms with the hallway lights dimmed)
2:00PM – 4:00PM	Vital signs, oral medications (if prescribed)
5:00PM – 6:00PM	IV tubing changes
6:00PM – 8:00PM	Evening weight and abdominal girth (if needed), activities, walk in the hall
9:00PM – 10:00PM	Vital signs, oral medications, nursing assessment, mouth care

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Infection Guidelines for Hematopoietic Stem Cell Transplant (HSCT) Patients

It is important to prevent infection for all HSCT patients' therefore specific guidelines are followed for patients, caregivers, siblings, friends and family.

General HSCT Guidelines

Once admitted for HSCT, patients may only leave the Unit if medically necessary.

On Admission:

- All HSCT patients will be tested for infections that may require precautions (throat and stool tests).
- He or she must remain in their room until the results are final (usually three days).
- If these tests are negative for infection, then they are able to leave their room to walk in the hallway or be in the activity room.

Weekly screening:

- Throat and stool tests are repeated weekly.
- Patients may need to be isolated in their rooms if these tests are positive for infection.

Activity Room Guidelines:

When open, the activity room is for the use of HSCT patients only. Up to three patients are allowed in the room at one time with one caregiver each.

The following individuals cannot use the activity room:

- Siblings and other children who are not HSCT patients
- Patients and visitors of patients who are in isolation or on precautions
- Non-HSCT patients (including oncology), families, and visitors are not allowed in the activity room.

Because infections can be spread on surfaces, patients should not share toys, games or crafts with others. After activity room toys have been used, they are placed in the dirty toy bin located outside the Activity Room so that they may be cleaned.

Visitors including caregivers, siblings and family members

Unless additional limitations are required by Boston Children's Hospital Policy:

- Do not come to the hospital if you have any signs of infections including cough, fever, rash, vomiting or diarrhea.
- Must have received the chicken pox vaccination or have had the disease.
- Up to three people may be in the patient room at one time
- Visiting hours are 11AM – 8PM
- Must be over 2 years old

Hand washing

- Any person entering the transplant unit must wash hands or use hand sanitizer.
- All individuals entering a patient's room need to wash their hands or use hand sanitizer before entering the room and after leaving the room.
- Wash or use hand sanitizer after picking something up from the floor (The object should be cleaned as well).

Patient hygiene

Patients receive a daily bath with antibacterial wipes. Brush teeth twice a day with a mild toothpaste.

Cleaning of Rooms

Patient rooms are cleaned each day by the Environmental Service Department. The linen is changed daily and more frequently as needed.

Bathroom

All patient rooms have bathrooms with a toilet, sink, and shower. **Only patients and adult caregivers may use these bathrooms.** There are bathrooms/showers for siblings and other visitors located at both ends of the unit. Wash your hands after using the bathroom or helping your child.

Plants and flowers

Plants and flowers are not allowed on the unit.

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