



Dana-Farber
Cancer Institute



Boston
Children's

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

EDUCATIONAL GUIDE FOR HEMATOPOIETIC STEM CELL TRANSPLANT PATIENTS AND FAMILIES

INTRODUCTION BOOKLET

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

Dana-Farber/Boston Children's Cancer and Blood Disorders Center is dedicated to the quality care of patients and their families. We specialize in the care of children, adolescents and young adults who are receiving care for cancer and other blood disorders. Your child will receive care from a team of experts at Boston Children's Hospital and Dana-Farber Cancer Institute's Jimmy Fund Clinic.

The inpatient floors at Boston Children's Hospital that specialize in this care are:

- 6 Northeast 617-355-8066
- 6 West 617-355-8069
- 9 Northwest 617-355-8096

Outpatient care is provided at Dana-Farber Cancer Institute:

- Jimmy Fund Clinic, 3rd floor of the Dana Building 617-632-3270

Health Care Team

The specialized health care team caring for your child includes:

- **Nurses** work closely with you and all members of the team to plan and carry out your child's care, in addition to providing teaching and support.
- The **Nurse Manager/Clinical Coordinator** oversees the unit's daily clinical and administrative needs.
- The **Nurse Director** is responsible for leading and managing the various oncology and blood disorder programs.
- **Clinical Assistants** provide care for your child under the direction of a nurse.
- A **Case Manager** works with the nursing staff to make sure that home care needs, medications and supplies are arranged.
- **Attending Physician, Fellows and Residents, Physician Assistants, and Nurse Practitioners**—these clinicians work together to manage your child's care.
 - The **Attending Physician** is the most senior doctor on the health care team and is ultimately responsible for your child's care.
 - A **Fellow** is a pediatrician who is training in pediatric hematology/oncology.
 - A **Resident** is a doctor with training in pediatrics.
 - **Nurse Practitioners** and **Physician Assistants** are clinicians with an advanced degree and training in pediatrics.
- A psychosocial clinician may be a **Social Worker or Psychologist, or a Psychosocial Fellow**. Your child will be seen by a psychosocial clinician at Boston Children's Hospital and the Jimmy Fund Clinic, providing care throughout treatment. They specialize in providing counseling and support for the entire family.
- **Resource Specialists** help families of on treatment patients access concrete resource assistance.
- **Child Life Specialists** offer developmental play as a way for children to express fears or concerns and understand the hospital environment. They also provide activities as a diversion from hospital routines or treatment.
- **Registered Dieticians** help patients with nutrition and diet concerns.

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

- **Patient Experience Representatives at BCH and Clinical Administrative Support Specialists at DFCI** work at the front desk, answer questions and help you with services you may need.
- **Patient and Family Education Specialists** are located in the Resource Room and can help patients and families find resources about their child's disease, community organizations, and to provide support programs throughout care.
- **Physical Therapists** help patients maintain physical strength during treatment.

Contact Us

For patient care assistance, please call the following phone numbers:

- Jimmy Fund Clinic (617) 632-3270
Business Hours 8 a.m. to 5 p.m., Monday through Friday
- Page Operator (617) 632-3352
Off hours: weekdays after 5 p.m., holidays, and weekends
Page pediatric hematology/oncology fellow on call
- Life Threatening Emergencies dial 911

Inpatient Care at Boston Children's Hospital (BCH)

Information for Caregivers

- All patients under the age of 18 must be accompanied by a parent/guardian, nursing unit staff, or a volunteer when leaving the hospital floor/unit.
- Caregivers can stay in the hospital 24 hours a day. Each patient room has one sleep space where one adult caregiver can sleep at night. Sheets, pillowcases and towels are on the linen cart on your floor.
- All patients must wear an identification band at all times while on hospital property. If you leave the hospital, please let your child's nurse know when you will be gone and a phone number where you can be reached.
- If you are not at the hospital, you may call to speak with your child's nurse.
- For your child's protection, information is only given to parents or legal guardians.
- When your child is admitted to the hospital, you must get a photo identification (ID) badge in the hospital lobby. To receive an ID badge, caregivers must provide a photo ID. This must be worn at all times.
- Caregivers are responsible for siblings and other visitors.
- Boston Children's Hospital Engineering Department must approve all electrical appliances. Speak with your nurse for more information.

Visiting a Patient

- Visiting hours end at 8 p.m. Only caregivers are allowed to visit the hospital after 8 p.m.
- Friends and family members who are ill cannot visit the hospital.
- All visitors under 12 years old must be screened daily for illness by the Information Desk staff in the Main Lobby. If cleared to visit they will be given a dinosaur sticker so they can visit the floor.
- Smoking, alcohol, drugs and weapons of any kind are not allowed at Boston Children's Hospital. If you are legally allowed to carry a firearm, please contact the security office at 617-355-6121.

Visiting a Stem Cell Transplant Patient

- Only visitors who have had the chicken pox or the chicken pox vaccine may visit a stem cell transplant patient.
- No more than three visitors at a time are allowed in a stem cell transplant patient's room.
- Children under two years old may not visit a stem cell transplant patient unless cleared by the healthcare team. Children age two to 18 years old can visit in the patient room.
- There is a bathroom in each patient room for the patient, siblings and parents' use only. Visitor bathrooms are located in the family room and in the hallway.

Patient Rooms

- For the safety of your child, only healthcare providers can touch the IV pump settings or any medical equipment. As the nurse for any questions or concerns.
- The side rails on your child's crib need to always be up. Your nurse will inform you about crib and bed safety.
- Each bed space has a TV with the GetWell Network™
- Internet access is free of charge.
- Each bed space also has a phone.
 - There is no charge for incoming calls.
 - Phone calls that are made in the 617, 508 or 781 area code are free of charge.
- There is a washing machine and dryer located on the 6th floor. See your staff at the main desk on your unit.
- Valuables, money or jewelry should be left at home.
- Please keep decorations and personal items to a minimum to make the cleaning process more effective. NOTE: cleaning personnel will not move personal items to clean underneath them.
- Please hang all decorations, cards and posters on the wall with sticky tack only. Tape may not be used to hang any item.
- Mylar balloons for patients are welcomed but latex balloons are not allowed anywhere in the hospital.
- Due to infection concerns, plants and flowers are not allowed on the 6th floor. Please speak to your nurse if you have any questions about this policy.

Patient and Family Common Areas

Activity Room & Family Resource Centers

- Staff and volunteers are available in the activity rooms and resource centers.
- Patients and siblings of all ages are welcome if accompanied by an adult.
- Toys or DVDs may be brought back to your child's room to play with even if they cannot leave the room.
- Stem Cell Transplant patients can use the **6W** activity room, *three at a time*, after screening for infections. Siblings of stem cell transplant patients may **not** be in the hallways or be in the activity room.

Food Service

- BCH offers a food service for patients that is delivered to the room. When your child is done with their meal, please return the tray to the cart in the hallway.
- Hours: Daily, 7:30 a.m. to 6:00 p.m. (full service). From 6:00 p.m. to 6:30 p.m. cold sandwiches are available. Phone: 617-355-3663 (FOOD).

Nourishment Center

- The nourishment center on your unit has drinks and snacks for patients.
- Each nourishment center has two refrigerators.
 - One is specifically for patient food only.
 - Food from home, labeled with your name and a date, may be stored in the refrigerator for up to three days. Unlabeled items will be thrown away. Please remove all unused food before your child goes home.

Interpreter Services

- If you need an interpreter while you are in the hospital, please ask your child's health care provider.
- Call (617) 355-7198

Pastoral Care

- The Interfaith Chapel is located in the Farley building on the 1st floor and is open 24 hours a day. Chaplains are available to offer spiritual and emotional support.
- Call (617) 355-6664

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Outpatient Care in the Jimmy Fund Clinic at Dana-Farber Cancer Institute

Every visit to the clinic starts at the front desk, where staff will check your child in for the appointment. The length of each appointment varies from patient to patient and is dependent on many things including, but not limited to, blood work and lab results, preparation of medications and/or blood products, and length of treatment. To provide the highest quality of care for all patients, clinicians and staff manage both time and prioritize patient safety at each visit. If you have questions about patient care or wait time, please ask your healthcare team.

Clinic Hours:

- Clinic hours are from 7:45AM to 6:00PM Monday through Friday
- Phones are answered from 8:00AM to 5:00PM weekdays
- Clinic is closed nights, Sundays and holidays
- Clinic is open on Saturdays from 8AM to 3:30PM only for scheduled infusions or lab draws.

Before you arrive to clinic:

- Make every effort to arrive on time.
- We recommend you arrive 15 minutes before your first scheduled appointment of the day to allow time for check-in and vital signs.
- Early or late arrivals will be seen when a healthcare provider is available.
 - If you are going to be late for your child's appointment, call the front desk at 617-632-3270.
- If instructed to do so please arrive with a topical anesthetic applied for port access or injection(s). This helps keep your appointment on schedule, and minimizes wait time.
- Bring a current medication list and your child's medications to each clinic visit.
- Bring items to clinic that your child may need throughout the day such as a change of clothes, diapers, formula or special food that your child may need.

While in the clinic:

- Check in at the JFC front desk.
 - If your child has a fever or seems unwell, let the front desk staff know immediately.
- An identification bracelet will be placed on your child.
- An RTLS (Real Time Locating System) Badge will be given to your child and needs to be worn from when you check in to clinic until you check out. This is how clinic staff find your child throughout your appointment.
- After check-in, remain in the waiting area.
 - Stem cell transplant patients are seen either in the private isolation rooms or in the regular clinic rooms. You should not wait in the main waiting room.
- Let the front desk staff know if you have been waiting for vital signs longer than 20-30 minutes after your scheduled arrival time.
- If labs are drawn in the clinic, it usually takes 1–2 hours for results to be available.

Outpatient Care at the Jimmy Fund Clinic

- While you are waiting, healthcare providers are reviewing lab results, finalizing chemotherapy orders, and preparing medications.
- When your child's treatment is ready you will be brought into the infusion area.
- Patient menus are available at the front desk to order food for your child while in clinic.
- Please do not leave money, jewelry or other valuables unattended at any time while in the clinic.
- Children under 18 need to be supervised by a guardian at all times. If you must leave the clinic for a maximum of 15-30 minutes during your child's treatment, please ask clinic staff so that they can determine if we can safely care for your child in your absence.

Checking out of the Jimmy Fund Clinic:

- When your health care provider has cleared you to leave clinic for the day you will be given:
 - An updated list of all your child's medications.
 - A list of upcoming appointments. Please review the dates and times carefully.
 - Please go to the front desk to schedule any future appointments.
 - Please return the RTLS badge to the RTLS frog drop box in the clinic when you leave.

Visiting a Patient

- Siblings or other family members are welcome in the Jimmy Fund Clinic. Please keep the following guidelines in mind:
 - Friends and family members who are ill can not visit.
 - Children under 18 must be supervised by parents or guardians at all time.
 - Due to limited space, be mindful of the of the number of visitors you bring to clinic.
- Visiting a patient on precautions in a private infusion room:
 - Siblings and visitors must remain in the patient room.
 - Parents or adult caregivers may leave the patient room but must wash their hands before and after entering common areas such as the hallway, resource room, activity room and kitchen.

Clinic Areas

- **The Playroom** is where you can find toys, games and other activities.
- **The Teen Area** is where teens and young adults can spend time with others their own age while in clinic.
- **The Blum Pediatric Resource Room** is where you can find books and information. Art, music and other activities are available for your family.
- **Nourishment stations** are located in the waiting area and the infusion area.

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Family Centered Rounds

Dana-Farber/Boston Children's Cancer and Blood Disorders Center practices family centered care and considers you, the caregiver, an expert on the needs of your child. At Boston Children's Hospital, patients and families can choose to take part in Family Centered Rounds (FCR) each morning.

Every morning, each patient's care is discussed by the medical team. Parents/caregivers are invited to participate in the medical team discussion either at the bedside or outside the patient room. You may also instead choose to have the team summarize the plan for the day for you after the rounds discussion. The members of your child's healthcare team present during Family Centered Rounds may include:

- Attending oncologist
- Fellow (a pediatrician training to be an oncologist)
- Resident physician
- Nurse practitioner/Physician's Assistant
- Charge nurse
- Patient's nurse for the shift
- Pharmacist
- Medical/Nursing students
- Case Manager
- Nutritionist
- Social worker/psychologist

During Family Centered Rounds:

- The resident physician or nurse practitioner reviews your child's case, including the events from the previous 24 hours, vital signs and lab results.
- A physical exam of your child is performed.
- The plan for the day is discussed.
- Plans for discharge, including goals and medications, are reviewed.
- Patients, parents and family members are encouraged to ask questions at the conclusion of the medical team discussion.

Family Centered Rounds usually takes 5-10 minutes per patient. The medical team must meet with all patients, so if you have outstanding questions or concerns outside the current plan of care please let a clinician on the team know so that additional time to meet can be arranged.

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Hematopoietic Stem Cell Transplant Teaching Sheet

Admission for Hematopoietic Stem Cell Transplantation: An Overview of Care

This teaching sheet is a general overview of hematopoietic stem cell transplant (HSCT.) Your health-care team will provide additional teaching sheets that review this in more detail.

Bone marrow cells, peripheral blood stem cells and umbilical cord blood stem cells are all hematopoietic stem cells. Throughout these teaching sheets, all these types of transplants will be referred to as hematopoietic stem cell transplants (HSCT).

Pre-Transplant Appointments

Before HSCT admission, patients will have several appointments, including medical tests and blood work. The Cellular Therapy Coordinators will provide a schedule of the pre-transplant evaluations and appointments. If Dana-Farber is not your primary oncology center, we will try to schedule some of these tests closer to home.

If a patient is receiving an autologous (self) peripheral blood hematopoietic stem cell transplant, the stem cells are collected before the patient is admitted for transplant. Stem cells are collected at the Apheresis Therapeutic Unit at Children's Hospital, 617-355-6270. Stem cell collection is coordinated with your health care team and Cellular Therapy Coordinator.

Admission

Patients are admitted to 6 West or 6 Northeast for HSCT at Boston Children's Hospital. The HSCT team will let you know the admission schedule.

Conditioning Therapy

Conditioning therapy is high-dose chemotherapy 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

The conditioning therapy has two primary goals:

1. To destroy the diseased cells in the body.
2. To remove the normal cells in the marrow spaces of the bones so the new marrow will have room to grow.

If the patient is receiving cells from another person, the conditioning therapy has a third goal.

3. The conditioning therapy suppresses the patient's immune system so that the donor's cells will be accepted by the patient.

Day 0: Hematopoietic Stem Cell Infusion

Day 0 is the day that the hematopoietic stem cells are infused through the central venous line (CVL.)

Common Side Effects

After Day 0, the days are referred to as positive numbers, such as Day +1, Day +2, Day +3. Patients may begin to have some of the common side effects, such as nausea, vomiting, diarrhea and mouth sores.

Other Side Effects

The conditioning therapy and medications used during transplant may cause other side effects. The doctors and nurses will explain these side effects if they occur.

Engraftment

After receiving the marrow, the number of white blood cells and *neutrophils* (a type of white blood cell) increase over 2 to 4 weeks. *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. Patients may continue to receive red blood cell and platelet transfusions for weeks and sometimes months after the transplant.

Graft-Versus-Host Disease

If a patient receives stem cells from someone else, the patient is at risk for *graft-versus-host disease* (GVHD).

Discharge

A patient is discharged when the patient is engrafted, medically stable, and is able to eat and drink enough and can swallow all medications. The patient must also have no infections and any GVHD must be responding well to treatment.

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

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Hematopoietic Stem Cell Transplant Teaching Sheet

Types of Hematopoietic Stem Cell Transplants (HSCT)

Autologous stem cell transplant

Autologous transplant means that your child receives his or her own stem cells. The stem cells are collected by peripheral blood pheresis or a bone marrow collection. The cells are collected before your child begins transplant conditioning therapy (chemotherapy and/or radiation). The cells are stored in a freezer, thawed on the day of the transplant and given to the patient through their central venous line (CVL).

Allogeneic stem cell transplant

Allogeneic transplant means that your child receives stem cells from another person (the donor).

Donor typing, HLA typing

If your child needs cells from someone else (allogeneic transplant), your healthcare team will find the best available donor. Immediate family members (parents and siblings) may have blood drawn for HLA typing which is a test done to see if they match your child.

It is important to find a donor who has a similar HLA type to your child. No two people have the exact same HLA type, except for identical twins. Siblings have an approximately 25% chance of being a match.

Matched or Closely Matched Family donor

If a family member is an HLA match, he or she may be selected as a donor. If more than one family member matches, the transplant doctors will choose the most appropriate donor. The doctors will evaluate the blood tests and clinical information to make this choice. The donor's bone marrow is collected by a procedure called a bone marrow harvest which is done in an operating room

Unrelated donor

If a full match is not found within the family, the transplant team may conduct a search for an unrelated donor through the National Marrow Donor Program (NMDP). The cost of the search will be covered by either your insurance or through a grant from the National Marrow Donor Program.

The transplant team will ask the donor center to contact potential donors to have more blood drawn for further testing. The transplant team meets regularly to review the status of the donor search and will update the patient and family.

Hematopoietic Stem Cell Transplant Teaching Sheet
Types of Hematopoietic Stem Cell Transplant

Mismatched family and haploidentical transplant

Some patients may not have a well-matched donor in their family or in the donor registries. In this case, your transplant team will discuss other transplant options with you.

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Hematopoietic Stem Cell Transplant Teaching Sheet

Pre- Stem Cell Transplant Evaluations

Your care providers will schedule many tests and appointments before your child is admitted for hematopoietic stem cell transplantation. A schedule of the pre-transplant evaluations will be provided for your child.

The tests are needed for two reasons:

- To identify any problems that exist before stem cell transplant
- To have baseline results before transplant so that the care providers can compare and measure any changes during or after transplant

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: PFT (pulmonary function tests)
- Eye exam
- Dental exam
 - your child's dentist should discuss any dental problems with the transplant doctor before filling any cavities or removing any infected teeth.
 - your child may need to take antibiotics before the dental appointment.
- Hearing exam
- Gynecologic and/or reproduction evaluations
- Kidney exam
- Blood work

Meetings

- Before being admitted for transplant, you/your child 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/your child will meet with the apheresis nurses.
- If the treatment plan includes radiation, you/your child will meet with the radiation oncologists to discuss radiation planning.
- An introduction to the inpatient stem cell transplant unit at Boston Children's Hospital.
 - A tour of the HSCT floor
 - The clinical nurse specialist will discuss the daily schedule and routines on the HSCT floor and answer any questions you might have.

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Hematopoietic Stem Cell Transplant Teaching Sheet

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.
- 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 Boston Children's Hospital 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.
- The donor will not be aware of the procedure or other sensations.

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. Fluid and pain medicine will be given through the IV.
- The donor is usually admitted to Boston Children's Hospital 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.
- 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.

Bone Marrow Harvest

- 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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Hematopoietic Stem Cell Transplant Teaching Sheet

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

This teaching sheet outlines the items you may bring from home. Personal items from home must be clean. Cloth items such as clothing, personal linens, stuffed animals (unless new) must be washed and brought into the room in a closed container. Each room has an entertainment system, The Get-Well Network, which has internet access.

Toys, Games, Books

- Your child may bring a few favorite pictures, toys, 1 – 2 stuffed animals, DVDs as well as PlayStation® 4 games.
- Your child may bring their own gaming system or handheld devices.
- Toys 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.

The activity room has many videos, books, toys, crayons, paper and activities that can be brought into individual rooms.

Personal Computers and Electronic Devices

Laptop and tablet computers may be brought from home. If you don't have access to a laptop or 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. We recommend, comfortable clothing (including nonskid slippers or shoes) that can be machine-washed and dried in a dryer. Clothing can be washed at home with the rest of the family's clothing. Once the clothing is dry, it should be placed in a sealed container such as a suitcase or a bag.

- Washer and dryer are available on the 6th floor for patients and care givers. Detergent is provided.

Bed Linens and Blankets

You may bring bed linens and blankets from home, such as pillowcases and comforters. Any linen that touches the skin (sheets, pillow cases) must be washed every day and/or if soiled. Comforters and blankets must be washed twice a week.

Calendars/Pictures

You are welcome to bring a calendar, pictures or other reminders from home to hang in your room with tacks as tape is not allowed.

What May I Bring from Home When Having a HSCT?

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Hematopoietic Stem Cell Transplant Teaching Sheet

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)
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 and bed linen change (may be delayed to PM if desired), Activities (play, tutoring, walk in the hall)
11:00AM – 8:00PM	Visiting hours
12:00PM (NOON) – 1:00PM	Vital signs, oral medications
1:00PM – 3:00PM	Quiet time (all patients are in their rooms with the hallway lights dimmed)
2:00PM – 4:00PM	Oral medications/vital signs
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 – 9:00PM	Vital signs, medications, nursing assessment
12:00AM (MIDNIGHT) – 1:00AM	Vital signs

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The information on this page is for patients who are receiving care at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. The information is not meant as a substitute for professional medical advice. Always speak with your health care provider with any questions you may have. For emergency medical care, call 911

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Hematopoietic Stem Cell Transplant Teaching Sheet

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:

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

- 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

Infection Guidelines for HSCT Patients

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 parents 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.

Contact Us

For patient care assistance, please call the following phone numbers:

- Jimmy Fund Clinic (617) 632-3270
Business Hours 8 a.m. to 5 p.m., Monday through Friday
- Page Operator (617) 632-3352
Off hours: weekdays after 5 p.m., holidays, and weekends
Page pediatric hematology/oncology fellow on call
- Life Threatening Emergencies dial 911

Hematopoietic Stem Cell Transplant Teaching Sheet

Stem Cell Infusion Day Zero

Day Zero is the day that stem cells are infused through the central venous line (CVL).

- Two hours before the stem cells are infused, the patient will receive intravenous (IV) fluids to help hydrate the kidneys.
- The patient will receive pre-medications before the infusion to help prevent side effects.
- A cardiac monitor will be placed to monitor the heart rate and function during the infusion.
- The infusion will take from 30 minutes to 4 hours.

Side effects may include:

- Fever, chills, shortness of breath, wheezing and hives.
- If the patient has any of these symptoms, the infusion will be stopped, and medicine will be given to control the symptoms.
- The infusion is restarted when the symptoms are under control.
- 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.
- The preservative used for stem cells that have been frozen has a strong odor. This odor may cause nausea or headache.

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Ursodiol

Other names: Ursodiol, Actigall, Urso 250, Urso Forte

Use: Ursodiol is a medication that is used to protect the liver during stem cell transplant. It is given by mouth.

Your child may have these following common side effects:

- Headache
- Dizziness

Your child may have these following less common side effects:

- Allergic Reaction
- Nausea
- Diarrhea

Special Instructions:

- Certain antacids may interfere with the absorption of Ursodiol. Ursodiol must be taken at least one hour before or two hours after any antacids.

General Statements:

- If your child has a life-threatening allergy, he/she should wear allergy identification at all times.
- Keep all medicine out of the reach of children and pets.
- Many medications interact with other medications. Keep a list of all your child's medicines (prescription, herbal medicines, natural products, supplements, vitamins, over-the-counter) with you. Give this list to your child's healthcare provider (doctor, nurse, nurse practitioner, pharmacist, physician assistant).
- Talk with your child's healthcare provider before giving him/her any new medicine, including over-the-counter, herbal medicines, natural products, or vitamins.
- An oral dose of medication should be repeated only if a patient vomits within 30 minutes of taking the drug. If your child vomits more than once during the 30 minutes after taking the medication, call your child's healthcare provider.

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Vitamin E

Other names: Alph-E, Aquasol E, Aquavit-E, d-Alpha-Gems, E-Gems Elite, E-Gems Plus, E-Gems, Ester-E, Gamma E-Gems, Gamma-E Plus, High Gamma Vitamin E Complete, Key-E Kaps, Key-E

Use: Vitamin E is an antioxidant used to protect the liver during stem cell transplant. It is given by mouth.

Your child may experience the following uncommon side effects:

- Headache
- Rash
- Nausea
- Diarrhea
- Fatigue (feeling very tired and having low energy that does not get better with sleep)
- Blurred vision

Call your healthcare provider if your child experiences any of these symptoms.

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Mucositis During Hematopoietic Stem Cell Transplant (HSCT)

Sores and bleeding in the gastrointestinal system (stomach and intestines) are common side effects during stem cell transplant and are called mucositis. Mucositis is caused by chemotherapy and total body irradiation. Your child may have sores and changes in his or her mouth, throat, stomach, and/or, or intestines.

Mucositis usually develops several days after the chemotherapy and/or radiation (conditioning regimen) are given and continue until the white blood cell count returns and increases. The mouth and tongue may become swollen or reddened and your child may have pain. White patches or open sores (ulcers) may appear. It is common for the cheeks to swell.

Open areas are a risk for infection. Therefore, good mouth care is important. Mucositis will heal as the white blood count increases. Until it heals, the transplant team recommends the following measures to help:

- Mouth care: rinsing at least twice per day with salt water rinses using toothettes.
- Avoid spicy foods.
- Pain medication: Most patients who develop mucositis need pain medication. There are many different medications that can be used to help relieve the pain. Your child's healthcare team will talk with you about medication options for your child.
- If the throat is too sore to permit swallowing, the patient or parent can use a bedside suction device to help clear the saliva and to decrease the need to swallow.

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