



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

HOME CARE BOOKLET

Hematopoietic Stem Cell Transplant (HSCT) TABLE OF CONTENTS

HOME CARE (GIVEN AT DISCHARGE)

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Hematopoietic Stem Cell Transplant Teaching Sheet

Visits to the Jimmy Fund Clinic After Discharge from Hematopoietic Stem Cell Transplant (HSCT)

Where do I go?

The Jimmy Fund Clinic of Dana-Farber Cancer Institute (DFCI) is located on the 3rd floor of the Dana Building. Transplant patients must wear a mask when entering the Dana Building. Patients should continue to wear a mask to clinic until they have returned to school and are allowed to go to public places.

What time should I be there?

Transplant patients generally come to the Jimmy Fund Clinic between 9 and 10 a.m. If you have questions or are going to be late, please call the clinic at (617) 632-3270. See appointment card.

After you arrive to the Jimmy Fund Clinic:

- Check in at the front desk.
- 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.**
- When using the clinic restroom the patient should wear their mask.

What should I bring to clinic visits?

- All your medicines (the actual bottles) and the medication chart or schedule. It is useful to have a medication schedule organized by *time* in addition to a scheduled organized by the *name of the medication*. If you do not have a schedule that is organized by time, the clinic staff can provide you with a medication daily calendar and help you make one. Since the medication schedule and doses may change frequently, we recommend keeping this schedule in pencil. The medication doses and schedule will be reviewed. Always bring the medication schedule and the medication doses needed for the entire day. Please take medications according to schedule because clinic visits may be longer than expected.
- Write down and bring your questions.
- Bring your home phone number, Boston House (if staying there), cell phone numbers, etc. Also, the names and phone numbers that we will need to organize your child's care (for example, home care and supply companies, pharmacy). Also bring the name and phone number and fax number of your oncology doctor and primary care pediatrician so that the transplant team can send them your medical information.
- All discharge papers from Boston Children's Hospital.
- Also bring enjoyable activities! Things to do. You may want to pass the time with books, magazines, games, TV or movies. The clinic has some of these available. The activity therapist or volunteer may also

Visits to the Jimmy Fund After Discharge from Transplant

provide activities. Patients may have time to do their physical therapy exercises. Also, the Blum Pediatric Resource Room has books and information available.

- Feel free to bring food including breakfast, snacks, lunch and beverages. Lunch may be ordered from the cafeteria.

What happens during clinic visits?

You should not wait more than 15 minutes for the clinic assistant or nurse to visit your room. Unless either has told you that they will visit soon, please ring the nurse call button in the room or go to the front desk and tell the nursing clinic leader that you are waiting.

- **Measurements and vital signs**

A clinic assistant will check you in by measuring your child's height and weight and taking vital signs: temperature, blood pressure, heart rate and breathing rate.

- **Laboratory tests**

A nurse will draw the blood for laboratory tests. Usually your primary nurse draws the blood tests. Laboratory test results are usually available within 1 hour to 1 ½ hour.

- **If you take Cyclosporine (Neoral®, Sandimmune®, Gengraf®) or Tacrolimus (FK506/Prograf®).** Do NOT take the morning dose of cyclosporine or FK506 until after the blood work is drawn. You may take the cyclosporine or FK506 after the blood is drawn. It is best to check levels close to 12 hours after the previous dose. Therefore, the night-time dose may need to be taken later or the clinic appointment may need to be earlier. Often levels cannot be checked exactly 12 hours after the night dose, and we consider that when evaluating the drug level. Also, the result of the test may not be available until after 5 p.m. Your healthcare team will call you if the dose needs to be changed. If you do not receive a call, continue taking the same dose. Please review the "Cyclosporine" and "Tacrolimus" teaching sheets.

- **New health issues**

If you have any new issues or concerns, please call the clinic before coming or tell your healthcare providers soon after arriving. This will give them more time to organize and order other necessary tests. Please tell your healthcare team about new or different signs and symptoms of infection, contacts with others with an infection, bleeding, changes in behavior or level of activity (please review the "When to Call" teaching sheet).

- **Patient database**

During one of the clinic visits in the first week after hospital discharge, you will be asked to complete a Post-Stem Cell Transplant Nursing Database, which asks questions about your child's condition.

- **Your visit with your health-care provider**

The fellow, attending, nurse practitioner, or physician assistant may meet with you before or after blood-test results or medications are infused. Ask any questions you may have. The healthcare providers may discuss the following: overall activity level and well-being, blood counts, signs and symptoms of infection, fluids, salts and minerals (electrolytes), nutrition and medications. Graft-versus-host disease and hypertension (high blood pressure) also may be discussed if needed for your child.

- **Medications and prescriptions**

A list of the medications you will need may be provided 1 to 2 days before your hospital discharge. The medications, the medication schedule and any of your questions will be reviewed at each clinic visit. **Please remember to bring all the**

Visits to the Jimmy Fund After Discharge from Transplant

bottles of medications as well as the medication schedule with you to each clinic visit.

How long will I be in the clinic?

All clinic visits soon after discharge from the hospital are usually 2 to 3 hours long but may be as long as 6 to 8 hours. Expected and unexpected issues after a stem cell transplant require longer clinic visits. Sometimes your visit will be longer because you may also need appointments with other specialty providers or have other diagnostic tests.

Common medical treatments and procedures (Your child may not have to do all or any of these at a visit; these are just examples of what might be necessary during a visit):

- Platelet and red blood cell transfusions
- Intravenous electrolyte replacement, such as magnesium, potassium or phosphorous
- Intravenous fluid for hydration
- Intravenous medication (for example, pentamidine)
- Blood pressure management
- Scheduled infusions of intravenous immunoglobulin (IVIG)
- Tests to check for infection: chest X-ray or sinus films, resting and walking oxygen saturation (the red-light Band-Aid for your finger), an NP aspirate (a nose and throat aspirate, which checks the fluid for viruses)
- Symptoms or findings on physical exam may require visits to other specialty providers.

How often will I come to the clinic?

Patients may need to come to clinic one to three times a week during the first few weeks or months after discharge from HSCT. Before leaving clinic, you will book the next appointment.

When do I need to go back to the hospital?

The most common reasons for going back to the hospital are fever, respiratory infection, other infections, dehydration, blood electrolyte (salt and mineral) imbalance, hypertension and graft-versus-host disease.

When can I move back home from the Boston House?

This depends on your child's active medical needs. For patients from other medical institutions, we treat the active medical needs and then talk with the referring healthcare providers. The plan of care will include follow-up visits to the Jimmy Fund Clinic.

Urgent visits, Emergencies

- Bring the patient's medication list, and allergy list.
- If a transfusion is necessary, the blood product needs to be irradiated and leukoreduced (depleted of white cells).
- Patients need to be in a separate room from other patients.

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

When And How To Call Your Healthcare Team

Call the Jimmy Fund Clinic if your child has:

- **Fever**
 - ❖ Call immediately if your child has a temperature of **101.3 F (38.5C)** or higher
 - ❖ If your child has a temperature between **100.4 F (38 C)** and **101.2 F (38.4C)** recheck the temperature in one hour.
 - ❖ In one hour, if your child's temperature is greater than or equal to **100.4 F (38 C)**, call immediately.
 - ❖ If your child's temperature is greater than **100.4 F (38 C)** after that one hour or again within 24 hours, call immediately.
 - ❖ Shaking or chills, or ill-appearing
 - ❖ Do not give any fever reducing medicine (i.e. acetaminophen or ibuprofen) until you have spoken to your healthcare provider
 - ❖ Tips for Taking Your Child's Temperature
 - **Never** take a rectal temperature.
 - If your child appears sick or doesn't feel well, check his or her temperature under their armpit, by mouth, or in their ear.
 - When taking your child's temperature use the same method and same thermometer whenever possible.
 - If you are having difficulty getting a consistent temperature, call your healthcare provider.
- **Unusual bleeding** that you and your child can see:
 - ❖ Nosebleed or bleeding gums that doesn't stop with gentle pressure after 15 minutes
 - ❖ Blood in the urine or bowel movements
- **Easy bruising** or tiny red spots (red "freckles") on the surface of the skin
- **Very fast breathing** while resting
- **Change in vision**, hearing, sense of balance, or decrease alertness
- **Persistent headaches**, especially ones in the morning
- **Rash or change in skin color**
- **Diarrhea**: loose, liquid bowel movements that occur 3-4 times a day (or more)
- **Constipation**: no bowel movement in 2 days
- **Change in appetite or fluid intake**
 - ❖ Nothing to eat or drink for 6 hours while awake if your child is under 1 year of age
 - ❖ Nothing to eat or drink for 8 hours while awake if your child is over age 1 year
- **Vomiting** more than twice in one hour or multiple times in one day
- **Decrease in urine output** or no urination for 6-8 hours while awake
- **Exposure** to chicken pox, shingles, measles, rubella or any other contagious disease
- **Signs of a seizure**: patient becomes confused, dazed and may shake or become unresponsive

Emergencies:

Call 911 immediately if your child has

- Trouble breathing
- Blue or gray skin color
- Unresponsiveness
- Excessive bleeding
- Other life threatening symptoms

Monday – Friday, 8:00am to 5:00 pm:

Call the Jimmy Fund Clinic at **617-632-3270** immediately if:

- your child has any medical issues
- you think your child may need to be seen that day

Evenings (after 5:00pm), Weekends, and Holidays:

Call the Dana-Farber page operator at **617-632-3352**

- Ask to have the pediatric oncology fellow paged
- The doctor on call will call back within 20 minutes
- If you don't hear back within 20 minutes, call the page operator and have the on-call doctor paged again

Less urgent medical questions

1. Prescription refills:

- Call the clinic at 617-632-3270 at least 48 hours before your child will need a medication refill.
- Leave a voicemail message with the patient's name, date of birth, name of the medication, and the pharmacy phone number
- The information will be sent to your healthcare provider.

2. Home health or VNA services:

- ❖ Call the clinic at **617-632-3270** if you have a question about a blood draw or **medications that your child is receiving at home via home health care ("VNA")** services.
- ❖ The triage nurse will either answer your question directly, or will follow up right away with your healthcare team and call you back.

3. Tests and studies:

- ❖ General information about tests and appointments can be located on the MyChildren's Patient Portal <https://apps.childrenshospital.org/mychildrens/>
- ❖ Call the Jimmy Fund Clinic at **617-632-3270** for questions about scheduled radiology tests or other studies to be done at Boston Children's Hospital.
- ❖ If your study has already been scheduled and you need to find out details such as the date and time, the front desk staff will be able to give you that information.
- ❖ If you have other questions about your test or study, or if your test/study has not yet been scheduled, your call will be sent to the triage nurse, who will help answer your question.

4. Health care and supply company services:

- ❖ Call the Jimmy Fund Clinic Case Manager at **617-632-3258** if you have a question about home health care companies, supply companies, infusion companies, or health insurance issues.

5. Division of Psychosocial Oncology and Palliative Care:

- ❖ Call the Division of Pediatric Psychosocial services at **617-632-5425** if you have a question about psychosocial services or need support.

Frequently Used Phone Numbers Numbers at Dana-Farber Cancer Institute

Jimmy Fund Clinic Main Number	(617) 632 3270
DHCI Page Operator	(617) 632 3352
Pediatric Patient Registration	(617) 632 3913
Division of Pediatric Psychosocial Services	(617) 632 5425
School Liaison Program	(617) 632 5909
Resource Specialists	(617) 632 3365
Activities Department	(617) 632 3278
Blum Pediatric Resource Room	(617) 632 3900
Perini Clinic	(617) 632 5124
Neuro Oncology Outcomes Clinic	(617) 632 2680
Financial Office	(617) 632 3455

Frequently Used Numbers at Boston Children's Hospital

6 Northeast	(617) 355 8066
6 West	(617) 355 8069
9 Northwest	(617) 355 8096
Main Number	(617) 355 6000
Hale Family Center for Families	(617) 355 6279
One Mission 6th floor Resource Room	(617) 355 5645
9 th floor Resource Room	(617) 355 7684
Child Life Services	(617) 355-6551
Blood Donor Center	(617) 355 6677
Financial Office	(617) 355-3397
International Office	(617) 355-5209

Hematopoietic Stem Cell Transplant Teaching Sheet

Vaccination Schedule for Patients Post Hematopoietic Stem Cell Transplant (HSCT)

Vaccination or Toxoid (May use combined vaccines)	Time Post Stem Cell Transplant							Notes
	6 months	8 months	10 months	12 months	18 months	24 months	26 - 36 months	
Inactivated Influenza	Yearly seasonal, September through March. Give 3-6 months post-HSCT.							
Diphtheria, Tetanus, Acellular Pertussis	DTaP	DTaP	DTaP	Titers		Titers		TDap Booster at age 11-12 years, then TD every 10 years thereafter
H. Influenzae Type B	HiB	HiB	HiB	Titers		Titers		
Hepatitis B	Hep B	Hep B	Hep B	Titers				
Pneumococcal-Conjugate (PCV13)*	PCV13	PCV13	PCV13	Titers	PCV13	Titers		
Pneumococcal-Polysaccharide (PPV23)					or PPV23			
Inactivated Polio Virus	IPV	IPV	IPV					
Hepatitis A				Hep A	Hep A			
Meningococcal Conjugate ** (age >11, unless asplenic)				MCV				Booster recommended at age 16-18 years
Human Papillomavirus (ages 9-26 years)				HPV	HPV	HPV		
MMR (live attenuated)***	No Live Vaccines are given until at least 2 years post-HSCT and then only when other clinical criteria are met***					MMR	MMR	Second dose can be given one month later
Varicella (live attenuated) ***						VZV	VZV	
Palivizumab****	Administered q28 days from November to April, ONLY in patients that meet clinical criteria							

*If patient remains on systemic immunosuppression, or has chronic GVHD, please check pre and post vaccine pneumococcal titers for each PPV13 dose given, and consider giving a fourth dose of PPV13 at 24 months, rather than PPV23.

Vaccination Schedule for Patients Post Hematopoietic Stem Cell Transplant (HSCT)

**MCV should be administered to patients > 11 years of age, per standard CDC immunization guidelines, but should be given earlier to any patient who is asplenic

***Administration of MMR and VZV should be deferred until patients are 2 years post SCT, off systemic immunosuppression for at least one year, and at least 5 months since last dose of IVIG. For inactivated "dead" virus vaccine, vaccination should be at least 2 months post last dose of IVIG

**** Criteria for Palivizumab administration: 1) < 2 years of age and within one year of allogeneic transplant 2) < 2 years of age and within 6 months of autologous transplant 3) any patient with pulmonary GVHD who remains on systemic immunosuppression

References for Immunizations Post-HSCT

CDC:

- Kroger AT, Sumaya CV, Pickering LK, Atkinson WL. General recommendations on immunization --- recommendations of the Advisory Committee on Immunization Practices (ACIP). MMWR Recommendations and reports: Morbidity and mortality weekly report Recommendations and reports / Centers for Disease Control. 2011; 60 (2): 1-64.

IDSA:

- Rubin LG, Levin MJ, Ljungman P, Davies EG, Avery R, Tomblyn M, Bousvaros A, Dhanireddy S, Sung L, Keyserling H, Kang I. 2013 IDSA Clinical Practice Guideline for Vaccination of the Immunocompromised Host. CID. 2014; 58: e44-e100.

ASBMT:

- -Majhail NS, Rizzo JD, Lee SJ, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation; Center for International Blood and Marrow Transplant Research (CIBMTR), American Society for Blood and Marrow Transplantation (ASBMT), European Group for Blood and Marrow Transplantation (EBMT), Asia-Pacific Blood and Marrow Transplantation Group (APBMT), Bone Marrow Transplant Society of Australia and New Zealand (BMTSANZ), East Mediterranean Blood and Marrow Transplantation Group (EMBMT) and Sociedade Brasileira de Transplante de Medula Ossea (SBTMO). Co-published in Biol Blood Marrow Transplant, 2012, 18(3): 348-371; Bone Marrow Transplant, 2012, 47(3): 337-341; and Hematol Oncol Stem Cell Ther, 2012, 5(1): 1-30.
- Tomblyn M, Chiller T, Einsele H, et al. Guidelines for preventing infectious complications among hematopoietic cell transplantation recipients: A global perspective. Biol Blood Marrow Transplant. 2009; 15(10): 1143-1238

Fred Hutch Long-Term Follow Up Guidelines:

<https://www.fredhutch.org/content/dam/public/Treatment-Suport/Long-Term-Follow-Up/physician.pdf>

NMDP: <https://bethematchclinical.org/workarea/downloadasset.aspx?id=4793>

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Hematopoietic Stem Cell Transplant Teaching Sheet

Chicken Pox and Shingles after Hematopoietic Stem Cell Transplant (HSCT)

- Chickenpox and shingles are highly contagious viral diseases caused by the **varicella-zoster virus (VZV)**.
- Exposure occurs by person-to-person contact. The contact does not need to be direct physical contact; the virus is spread by respiratory secretions being airborne. The virus can also be spread by contact with zoster blisters.
- **Chicken pox** occurs when your child is first infected with the varicella virus. It is usually a short illness with:
 - ❖ an itchy rash
 - made up of tiny fluid filled blisters or vesicles, usually on the chest, abdomen, arms, legs or face
 - ❖ fever
 - ❖ mild cold-like symptoms
- The virus then remains quiet and rests in the nerve cells. If the virus becomes active again, the resulting disease is called **shingles**. Once activated, the virus travels along the nerves to the skin and then breaks out in a rash. It is common for oncology and transplant patients to get shingles.
- **Shingles**
 - ❖ May begin as numbness, intense itching, or pain because the virus involves the nerves.
 - ❖ May be very painful, especially if the virus affects a major nerve root (for example, shooting pain around the trunk or down the leg or the arm).
 - ❖ The shingles rash has blisters that usually form a band or a stripe, on one side of the body.
 - ❖ Sores near the eyes or nose need very careful attention.
 - ❖ It may also infect the liver or lungs.

How long are people contagious?

- People with varicella are most contagious for 1 to 2 days before and shortly after the onset of the rash.
- A person can remain contagious for as long as 5 days after the onset of the lesions. Immunocompromised patients with progressive varicella may be contagious throughout the development of the new lesions.
- Your child may develop chicken pox or shingles 14 to 16 days after an exposure. Some cases occur as early as 10 days or as late as 21 days after contact.

What if the patient has shingles?

- If the patient develops signs or symptoms of shingles, call your health care providers promptly. Antiviral treatment is most effective when it is given early.
- Transplant patients who have varicella zoster must be admitted to the hospital for treatment with intravenous (IV) antiviral medication until the lesions scab over and the patient is stable. Patients are placed in an isolation room.
- Pain medication is given as needed.
- If the virus is in the liver, lungs or eye area, patients will need close observation and may need special testing.
- If family members or others in close contact with the transplant patient have NOT had the chickenpox and have NOT received the vaccine, please inform your health care providers. Those individuals may receive the chicken pox vaccine, but the doctors need to decide if and when the vaccination should be given.

What if the patient is exposed?

- If a transplant patient has already had chicken pox, his or her immune system may still be susceptible to getting the disease.
- Call the transplant team if:
 - ❖ Patient is exposed to someone who has chicken pox
 - ❖ If the patient's sibling is exposed and has not had the chicken pox
- An intramuscular injection called VZIG can be given within 48 and not more than 96 hours after exposure. This sometimes prevents the disease or lessens the severity of the disease.

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Hematopoietic Stem Cell Transplant Teaching Sheet

Cytomegalovirus (CMV)

CMV stands for cytomegalovirus. CMV is a virus that can infect the blood and the respiratory, liver, and gastrointestinal systems. More than 75% of people will have had this virus by adulthood.

Patients and donors are tested before transplant to see if they have had the virus in the past. If the patient has had CMV, the virus may reactivate and cause infection after transplant. If the donor has had CMV, the virus can be transmitted from the donor's hematopoietic stem cells to the patient (although this rarely occurs).

Patients who received a transplant from another person may have a blood test to check for CMV. This will be done every week during the first 100 days after transplant when either the patient or the donor had CMV in the past. For patients who receive outpatient care at another institution, the transplant team will inform the patient's care providers of the need to have a CMV PCR test drawn each week.

It is important that your child have a CMV test every week. If the test shows that CMV is active in the blood, your child will be admitted to the hospital to receive an antiviral medicine to prevent the virus from spreading.

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Hematopoietic Stem Cell Transplant Teaching Sheet

Blood Count Changes After Hematopoietic Stem Cell Transplant (HSCT)

It is common for your child's platelet red blood cell and white blood cell count to go up and down after transplant. Many of these changes are temporary and treatable.

Reasons for changes in blood counts include:

- Medications
- Infection, especially virus
- Problems with the graft
- Graft-versus-host disease
- Relapse
- Low erythropoietin ("epo"), a hormone secreted by the kidneys for red blood cell growth.
- Hemolysis, the breakdown of red blood cells

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Hematopoietic Stem Cell Transplant Teaching Sheet

Discharge after Hematopoietic Stem Cell Transplant (HSCT)

When preparing to be discharged from the hospital, it is very important to know the best ways to stay healthy and avoid infections. Recovery from HSCT is a gradual process.

Before discharge from HSCT:

- ANC must be over 500 for at least three days.
- There must be no infections or fever.
- Your child will need to be able to take enough fluids and food.
- You will need to have transportation to and from the Jimmy Fund Clinic and Boston Children's Hospital, both for scheduled visits and in emergency situations.
- You must have a working phone.

Medications

- Your child will need to be able to take all medications.
- You need to have all your child's prescribed medications before discharge.
- Your child's nurse will review:
 - The purpose of the medications
 - How to give the medications
 - When to give the medications

Preventing Infections

The following precautions will help reduce the risk of infection:

- There are recommended restrictions to daily activities. Your health care provider will discuss when the restrictions can end. The duration of these restrictions may vary for each patient:
 - Autologous transplant: 60 days after transplant
 - Allogeneic transplant: 9 -12 months
- Your child may go to an uncrowded, outdoor place (a park during a time when others are unlikely to be there, mini golf, a driving range).
- Visitors are allowed outside in your yard or porch. These visitors must be healthy, with no recent contact with anyone sick.
- Those allowed to visit inside of your home are restricted to:
 - ❖ Those who live with your child
 - ❖ Home care nurse and other medical professionals
 - ❖ A tutor
 - ❖ An adult may come into your home to help as long as that person is not responsible for the care of other children outside of the patient's home. This needs to be the same person not a rotating group of people.
- Ask visitors as your child should not be around
 - ❖ Anyone who has received the oral polio vaccine with the past 6 weeks
 - ❖ Anyone who has received nasal Flumist within the previous 7 days

Discharge After HSCT

- ❖ Anyone who has not had chicken pox or the vaccine against chicken pox
- Avoid contact with persons who are sick. In unavoidable, limit the time spent together and wash hands often.
- Your child may not visit other people's homes or any indoor public places, such as stores, restaurants, schools, or places of worship.
- Your child may not visit crowded outdoor places, such as professional sporting events or theme parks.
- Your child should avoid construction areas and other dusty environments. If there is construction in your neighborhood, please notify your healthcare team.
- Your child should avoid digging in dirt, sandboxes, soil, plants or areas such as farms, digging sites, and lawn mowing. Always wash hands afterward if there has been contact with dirt or plants.
- Your child may not use public restrooms.

Guidelines for Keeping Your Home Safe

- To prepare your home before discharge, clean it thoroughly to remove dust, mildew, and mold. Continue to clean the home frequently, using antibacterial cleaners when possible.
- You may have one cleaning person coming into your home to clean.
- Please minimize objects or clutter in your child's bedroom, as these may trap dust mites and germs.
- Air conditioners or central heating filters and/or ducts should be cleaned or replaced before discharge and then yearly.
- You may not have any plants, flowers, live Christmas trees inside your home.
- You may not use vaporizers, humidifier or diffusers.

General Food Safety

- Food handlers should wash their hands with warm, soapy water before and after preparing foods.
- Kitchen areas and utensils used for food preparation should be kept clean.
- Do not share utensils, cups, and dishes.
- Dishes must be washed in hot, soapy water, either by hand or in the dishwasher.
- Refrigerate leftovers within 2 hours of cooking; discard leftovers that were kept at room temperature for greater than 2 hours. When in doubt, throw it out.
- Reheat leftovers to a temperature of > 165°F before serving; bring leftover soups, sauces or gravy to a rolling boil before serving.
- All fresh produce should be washed under running water before serving.
- Do not drink unpasteurized milk, fruit or vegetable juices (e.g. unpasteurized apple cider)
- See Discharge Dietary Restrictions Teaching Sheet

Bathing and Swimming

- Your child may not swim as long as a Central Venous Catheter (CVC) is in place.
- Once the CVC has been removed, your child may swim in a private, outdoor pool or the ocean.
- Please speak with your healthcare provider about lakes and rivers. Your child may not swim or wade in ponds, public, or indoor swimming pools.
- When bathing with a CVC, cover the line and dressing with an occlusive dressing, such as Tegaderm® or Aquaguard®.

Discharge After HSCT

Pet Safety

- Your child is allowed to keep any pets you already own except for reptiles and birds.
- If thinking about getting a new pet talk to your healthcare team.
- Pets who live outside may not come into the house. Ensure good hand hygiene after touching the pet.
- Cats may not sleep on your child's bed.
- Always wash your child's hands after touching your pet.
- Your child must not clean animal cages or have contact with animal feces.
- Your child should not bathe or brush their pet.
- For households with cats, litter boxes should not be placed in kitchens, dining rooms, or other areas where food preparation or eating occur.
- Avoid contact with any animal that may be ill.
- Pets should be prevented from having access to garbage, scavenging, or hunting.

Travel Safety

- Speak with your child's healthcare team before making any travel plans.
- Travel on shared rides (trains, buses, shared taxis) is not allowed.
- It is not necessary to wear a mask in the car, but those traveling in the car with your child should be limited to household members.

Hand Washing

Good hand washing is the best way to prevent the spread of infection. If hands are visibly soiled, hand sanitizers are not effective, and hands must be washed with soap and water.

Hand washing is especially important:

- Before and after preparing or eating food
- After touching fresh produce
- After using the bathroom
- Before and after touching wounds
- After touching pets or animals
- After going outdoors

Miscellaneous

- Use sunscreen (SPF 45 or higher) and wear protective clothing when outdoors
- Smoking or exposure to tobacco and/or marijuana smoke are risk factors for lung infections for people with poor immune function and should be avoided.
- Avoid alcohol.

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Hematopoietic Stem Cell Transplant Teaching Sheet

Food Plan After Hematopoietic Stem Cell Transplant (HSCT)

This food plan is for your child to use at home after having a stem cell transplant. It is meant to help your child's body as the immune system heals. At first, foods that are high in bacteria are kept out of your child's diet to lower the risk of an infection. This food plan will change what and how your child eats. Be sure to follow this food plan until your child's care team tells you to stop.

Food Groups	Foods Your Child CAN Eat	Foods Your Child CANNOT Eat
Protein	<ul style="list-style-type: none"> Well-cooked meats, poultry, fish, shrimp, bacon, sausage, hot dogs Sliced deli meats. Ask staff at your deli to wear new gloves when slicing your deli meat. Heat deli meat in an oven or microwave until steaming hot. Homemade chicken salad, tuna salad, egg salad Well-cooked eggs Nut butters (peanut butter, almond butter, soy butter) Whole nuts and seeds without shells 	<ul style="list-style-type: none"> Raw fish Raw shellfish Smoked salmon (also called lox) Sushi Caviar Raw eggs or foods with raw eggs (cookie dough or soft-cooked egg yolks) Wild game meat (like venison, squirrel, rabbit or bear) Nuts and seeds in shell
Dairy + dairy alternatives	<ul style="list-style-type: none"> Pasteurized cow/goat milk Pasteurized soy, coconut and almond milk Shredded mozzarella cheese Pasteurized string cheese Pasteurized sliced cheese from deli Pasteurized feta cheese Cream cheese Packaged ice cream Yogurt 	<ul style="list-style-type: none"> Bleu cheese, brie, camembert, Roquefort, gorgonzola, Fresh mozzarella Soft cheeses from Mexico or South or Central America Soft-serve ice cream or frozen yogurt Hard-serve ice cream from ice cream shops Raw cookie dough
Grains	<ul style="list-style-type: none"> All grains not listed in the next column 	<ul style="list-style-type: none"> Bread, cookies, cupcakes, donuts and other baked goods from bakeries or restaurants Popcorn (until team approves your child's flossing)

Food Plan After HSCT

Fruits & Vegetables	<ul style="list-style-type: none"> • All raw thick-skinned fresh fruits (like banana, orange, avocado, mango, melon) • Raw and/or frozen thin-skinned fresh fruits from the USA or Canada • Raw whole vegetables from the USA or Canada • All canned fruits (like peach slices, pear halves, apple sauce, fruit cocktail) • Dried fruit, (raisins, Craisins, dates, figs, dried apricots) • All cooked vegetables (fresh or frozen from any country) • Note: Carefully wash fruits and vegetables before eating or cooking. 	<ul style="list-style-type: none"> • Alfalfa and bean sprouts • Pre-cut raw fruit or vegetables • Raw and/or frozen thin-skinned fruits from countries outside the USA or Canada • Raw vegetables from countries outside the USA or Canada • Prepared deli salads from grocery store (potato salad, macaroni salad) • Avoid bagged/triple washed lettuce & salad greens, & bagged baby carrots.
Juices & Drinks	<ul style="list-style-type: none"> • Tap water (from a sink), only if it is town or city water. • If you have well water: Water must be boiled. • Bottled Water/Bottled or canned seltzer water • Pasteurized fruit juices • Soda must be from a bottle or can 	<ul style="list-style-type: none"> • Unpasteurized cider or juice • Ice from ice machines • Milkshakes and/or fruit smoothies at restaurants • Frappuccino (Starbucks) or Coolatta (Dunkin' Donuts) • Fountain drinks (like soda from a soda gun or a dispenser at a restaurant or movie theater)
Condiments	<ul style="list-style-type: none"> • Ketchup, mustard, mayonnaise, salt, sugar, jelly, pickles, hot sauce, etc. • Raw and/or cooked herbs/spices 	<ul style="list-style-type: none"> • Honey
Restaurant Foods	<ul style="list-style-type: none"> • Freshly cooked hot food items, (like take-out, drive-through or delivery) 	<ul style="list-style-type: none"> • Prepared green salads and/or deli salads from a restaurant or deli • Desserts from restaurants (cakes, cookies, cupcakes, etc.) • Fountain drinks (like soda from a soda gun or other dispenser) • Ice from ice machines

Other Important Tips

Do not eat foods from salad bars and self-service food bars, such as buffets.

- Slowly add dairy products with lactose in them, such as milk and ice cream, back into diet. Follow the same pattern for fruits and vegetables.
 - If your child has diarrhea and/or cramping, stop feeding him or her dairy products and/or fruits and vegetables for a few days. Then slowly add them back into the diet.
- Throw leftover, cooked foods away after two days.
 - Do not leave cooked food out of the refrigerator or oven for longer than 60 minutes. This is important to remember during the holiday seasons when food tends to stay out on the table for longer periods of time.
- Do not share food.
 - At 100 days (for autologous transplants) or 6 months (for allogeneic transplants), talk with your health care team about your child's diet.

Appointments

To schedule an appointment with a registered, licensed dietitian in the Jimmy Fund Clinic, please call 617-632-3270.

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Hematopoietic Stem Cell Transplant Teaching Sheet

Dental Care and Mouth Problems after Hematopoietic Stem Cell Transplant (HSCT)

During and after transplant, the mouth and teeth need special care. Please check your child's mouth every day for any problems. It is not unusual for your child's gums to bleed a little during brushing or flossing. Tell your health care provider about any mouth problems that you feel or see.

Daily Routine

- Your child should brush 2-3 times a day with a soft toothbrush.
- If not able to brush because of pain or bleeding, swish and spit with water after meals and/or use toothettes with toothpaste.
- Use toothpaste with fluoride. Do not use "tartar control" and "whitening" toothpastes since they may irritate the mouth.
- Your child should floss once a day. If it hurts to floss, avoid that area and tell your health care provider.
- Your child will not need to use fluoride rinses and gels (other than what is in toothpaste) after discharge unless it is recommended.

Dental Visits

- Chemotherapy and radiation may cause changes in the developing teeth. Transplant patients should see a dentist on a regular schedule. Speak to your transplant provider before seeing the dentist for the first time after transplant.
- An antibiotic may be necessary for dental cleanings and other dental procedures. Speak to your health care provider before a dental visit.
- Your child's dentist may take routine X-rays in order to care for your child. The radiation exposure is very minimal and poses no risk to the patient.

Mouth Problems

There are mouth problems that are common to transplant patients. This may include:

- Gingivitis (gum inflammation)
- Thrush (yeast) and viral infections are common when patients are immunocompromised. You may see white plaques (small raised areas) in the mouth and on the tongue. These plaques are from a fungal infection known as thrush.
- Gum swelling as a side effect of medications
- Your child is at risk for developing painful sores in the mouth. The sores may be caused by viruses from the Herpes family as well as other viruses.
- Taste bud changes may lead to changes in food preferences. Taste bud changes are reversible and should resolve in the months following transplant.
- Dry mouth as a side effect of therapy and/or chronic graft versus host disease. Patients with a dry mouth may be at an increased risk for oral infections, including cavities.

Dental Care and Mouth Problems after HSCT

- Rarely, growths on the tongue or other areas of the mouth may develop as a side effect of therapy and/or chronic graft versus host disease

If your child develops any of these problems, please call your health care provider. Medications may be prescribed.

Mouth Problems related to Chronic Graft Versus Host Disease (GVHD)

If your child received stem cells from another person, chronic GVHD may develop in the mouth. The symptoms of this condition may include: soreness, stinging, white lines, red areas, ulcers, and/or dry mouth. The tongue may have an irregular border from the changes or swelling in the tongue. Patients may have difficulty fully opening the mouth and the cheeks may feel tight.

Suggestions for oral care and comfort if you develop chronic GVHD:

- If your child is not able to brush their teeth because of the soreness, rinse the mouth out after meals with water or water mixed with salt and baking soda if the patient can tolerate the salt. Your child can also use the sponge "toothettes" to clean food off their teeth, until able to brush again.
- Your health care provider may prescribe a medication if needed.
- Your healthcare providers may recommend mouth exercises if your child has difficulty fully opening the mouth or the cheek muscles feel tight.

Dietary Suggestions for Patients with Mouth Sores, Dry Mouth, and/or Chronic Graft Versus Host Disease

- Keep the mouth moist by drinking fluids frequently through a straw or sucking on ice chips, popsicles or other cool slushy foods.
- Use gravy, sauces, broth, yogurt or other liquids to soften foods.
- Sugar-free gum and sugar-free candies may help to stimulate saliva flow.
- Eat a bland diet with soft foods, such as cooked cereals, mashed potatoes, and scrambled eggs.
- Take small bites of food, chew slowly, and sip liquids with your meals.
- You may want to avoid:
 - crunchy foods (e.g. nacho chips, potato chips and popcorn)
 - foods that are spicy hot or sour
 - foods that have a very hot temperature
 - tart foods and drinks sugary foods, particularly hard candies
 - carbonated drinks
 - alcohol and cigarettes

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Hematopoietic Stem Cell Transplant Teaching Sheet

Annual Evaluations Post Hematopoietic Stem Cell Transplant (HSCT)

After transplant, your child will need appointments and annual evaluations. These may be scheduled at Dana-Farber Cancer Institute and Children's Hospital or at your local medical facility.

Evaluations may include the following:

- Blood tests that check the function of the kidney, liver, and thyroid
- Hormone testing and Endocrine appointment
- Immunoglobulin levels
- Heart studies such as echocardiogram and EKG
- Lung studies such as pulmonary function testing (PFTs)
- Hearing testing
- Eye exam
- Dental exams
- Immunizations: Patients receive immunizations multiple times post-transplant. Please review the "Immunizations After Transplant" teaching sheet for additional information.

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Fever Information and Temperature Conversion

Fever in children is an important sign that your child is ill. Cancer and hematopoietic stem cell patients are at greater risk of developing infections and may have more difficulty fighting infection.

Call your healthcare provider right away if your child has:

- A temperature of 38.5C (101.3F) or higher
- A temperature of 100.4F (38 C) or higher twice in 24 hours

Tips for Taking Your Child's Temperature

- **Never** take a rectal temperature.
- If your child appears sick or doesn't feel well, check his or her temperature under their armpit, by mouth, or in their ear.
- When taking your child's temperature use the same method whenever possible.
- If you are having difficulty getting a consistent temperature, call your healthcare provider.
- We recommend you recheck a temperature in one hour if it is 100.4 F (38 C) or higher.

Please refer to chart on the following page

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Fever Information & Temperature Conversion

°C	°F	°C	°F
35.8	= 96.6	Fever 38.5	= 101.3 Fever
36.0	= 96.8	38.6	= 101.5
36.2	= 97.2	38.7	= 101.7
36.4	= 97.6	38.8	= 101.8
36.5	= 97.7	38.9	= 102.0
36.6	= 97.9	39.0	= 102.2
36.7	= 98.0	39.1	= 102.4
36.8	= 98.2	39.2	= 102.6
Average normal 37.0	= 98.6	39.3	= 102.8
37.1	= 98.8	39.4	= 103.0
37.2	= 99.0	39.5	= 103.1
37.3	= 99.2	39.6	= 103.3
37.4	= 99.4	39.7	= 103.5
37.5	= 99.6	39.8	= 103.7
37.6	= 99.8	39.9	= 103.8
37.7	= 99.9	40.0	= 104.0
37.8	= 100.0	40.1	= 104.2
37.9	= 100.2	40.2	= 104.4
Fever 38.0	= 100.4 Fever	40.3	= 104.6
38.1	= 100.6	40.4	= 104.8
38.2	= 100.8	40.5	= 105.0
38.3	= 100.9		
38.4	= 101.1		