

# Hematopoietic Stem Cell Transplant (HSCT) Patients & Families

#### **HOME CARE**





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## Hematopoietic Stem Cell Transplant (HSCT) Table of Contents

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#### **Hematopoietic Stem Cell Transplant Teaching Sheet**

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

The Jimmy Fund Clinic of Dana-Farber Cancer Institute (DFCI) is located on the 3rd floor of the Dana Building. Patients must wear a mask when entering the Dana Building. Patients generally come to the Jimmy Fund Clinic between 8 and 10 a.m. If you have questions or are going to be late, please call the clinic at (617) 632-3270.

#### **Arriving to the Jimmy Fund Clinic:**

- Check in at the front desk.
- Patients will be seen in a private room or exam room and **should not wait in the main waiting room.**
- When using the clinic restroom you should wear a mask and wash your hands well with soap and water.

#### What to bring to clinic visits:

- Home medications in clinic:
  - Please remember to bring all the bottles of medications and your list of discharge medications with you to each clinic visit.
  - The medication doses and schedule will be reviewed.
  - Review all medications from home with your healthcare providers before taking them during clinic.
- For all medications, remember to call your pharmacy for a refill before the medication runs out even if you have a scheduled clinic appointment. Refills may take 48 hours to be filled.
- There are activities in clinic to help pass the time but you may also bring your favorite toys or books with you from home.
- Lunch may be ordered from the cafeteria and you can bring other food with you.

#### **Clinic Visits:**

- A clinic assistant or nurse will be in your room within 15 minutes to do vital signs and/or laboratory tests. If they have not arrived, use the nurse call button.
- The length of your clinic appointment will vary.
- 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 be given the next appointment.
- If you take Cyclosporine (Neoral®, Sandimmune®, Gengraf®) or Tacrolimus (FK506/Prograf®), do NOT take the morning dose of Cyclosporine or FK506 before your clinic appointment.
  - After your blood is drawn, take your home supply of cyclosporine or FK506.

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Visits to the Jimmy Fund After Discharge from Transplant

- Your healthcare team will call you if the dose needs to be changed.
- o If you do not receive a call, continue taking the same dose.

#### **Contact Us**

- 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
  - o If your child has a temperature between 100.4 F (38 C) and 101.2 F (38.4C)
  - o 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
  - o Do not give any fever reducing medicine (i.e. acetaminophen or ibuprofen) until you have spoken to your healthcare provider
  - o 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
  - o 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

When and How to Call Your Healthcare Team

#### **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**

#### **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.

#### 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.

#### **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.

#### **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.

#### **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.

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When and How to Call Your Healthcare Team

## **Frequently Used Phone Numbers Numbers at Dana-Farber Cancer Institute**

Jimmy Fund Clinic Main Number	(617) 632 3270
DFCI Page Operator	(617) 632 3352
Pediatric Patient Registration	(617) 632 3913
Division of Pediatric Psychosocial Services	(617) 632 5425
School Liaison Program Resource Specialists Activities Department	(617) 632 5909 (617) 632 3365 (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 <sup>th</sup> 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

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#### **Temperature Conversion**

°C °F
35.8 = 96.6
36.0 = 96.8
36.2 = 97.2
36.4 = 97.6
36.5 = 97.7
36.6 = 97.9
36.7 = 98.0
36.8 = 98.2
Average normal 37.0 = 98.6
37.1 = 98.8
37.2 = 99.0
37.3 = 99.2
37.4 = 99.4
37.5 = 99.6
37.6 = 99.8
37.7 = 99.9
37.8 = 100.0
37.9 = 100.2
Fever 38.0 = 100.4 Fever
38.1 = 100.6
38.2 = 100.8
38.3 = 100.9
38.4 = 101.1

°C °F
Fever 38.5 = 101.3 Fever
38.6 = 101.5
38.7 = 101.7
38.8 = 101.8
38.9 = 102.0
39.0 = 102.2
39.1 = 102.4
39.2 = 102.6
39.3 = 102.8
39.4 = 103.0
39.5 = 103.1
39.6 = 103.3
39.7 = 103.5
39.8 = 103.7
39.9 = 103.8
40.0 = 104.0
40.1 = 104.2
40.2 = 104.4
40.3 = 104.6
40.4 = 104.8
40.5 = 105.0

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Fever Information & Temperature Conversion

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

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

Vaccination or Toxoid (May use any formulation of combined vaccines)	Time Post Stem Cell Transplant							
	6 months	8 months	10 months	12 months	18 Months	24 months	26 - 36 months	Notes
Inactivated Influenza	Yearly seasonal, October through March. Eligible patients are >100 days post allogeneic HSCT and on <0.5mg/kg/day of systemic corticosteroids; >60 days post autologous SCT							
Diphtheria, Tetanus, Acellular Pertussis (all ages)	DTaP	DTaP	DTaP					TDap Booster at age 11-12 years, then TD every 10 years thereafter
H. Influenzae Type B	HiB	HiB	HiB					
Hepatitis B	Нер В	Нер В	Нер В					
Pneumococcal-	PCV13	PCV13	PCV13		PCV13			
Conjugate (PCV13)*								
Pneumococcal-					or			
Polysaccharide					ממעם			
(PPV23)* Inactivated Polio Virus	IPV	IPV	IDV		PPV23			
Hepatitis A	IPV	IPV	IPV	Ноп Л	Нер А			
Meningococcal				Hep A MCV	пери			Booster
Conjugate **				IVICV				recommended
(age >11, unless asplenic)								at age 16-18 years
Meningococcal B ***						Me	n B	Ages 16-18
(ages 16 – 23)								preferred
Human Papillomavirus				HPV	HPV	HPV		
(ages 9-26 years)								
MMR	No Live Vaccines are given until at least 2 years MMR MMR Second dose							
(live attenuated)****	post-HSCT and then only when other clinical can be given				_			
Varicella	criteria are met***  VZV  VZV  one month							
(live attenuated) ****	later for age					_		
Palivizumab****	Administered a 29 days from Nevember to April							
i anvizamas	Administered q28 days from November to April, ONLY in patients that meet clinical criteria							
COVID-19	ONLY patients that meet current CDC age-based eligibility criteria							
	Eligible patients are >100 days post allogeneic HSCT and >60 days post autologous SCT.							
	If within 2 years post-HSCT or on systemic immunosuppression, give 3 doses,							
	with the 3 <sup>rd</sup> dose given at least 28 days after dose #2.							

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

- \*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.
- \*\*MCV should be administered to patients > 11 years of age, per standard CDC immunization guidelines, but can be given to younger patients who are functionally or anatomically asplenic. Avoid giving Menactra in conjunction with PCV, can be given 4 weeks or more after completion of all PCV doses
- \*\*\*Men B is now recommended for adolescents and young adults at increased risk, with age 16-18 preferred. Can be given at 24 months or later with optional booster 1 year after series completion
- \*\*\*\*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 1 year of allogeneic transplant or less than 6 months off immune suppression following allo-HSCT 2) < 2 years of age and within 3 months of autologous transplant 3) <2 years of age with pulmonary GVHD, regardless of time post-transplant. PRIOR AUTHORIZATION required for outpatient dosing, can give first dose in inpatient setting just prior to discharge.

#### **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.

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

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

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

#### **Contact Us**

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#### Chickenpox (Varicella) & Shingles (Zoster)

**Chickenpox**, also known as varicella, is caused by the varicella-zoster virus. It is spread through the air and is very contagious.

Chickenpox usually starts with:

- A fever and feeling very tired, similar to flu-like symptoms
- · An itchy rash with clear, fluid-filled bumps will appear
- The fluid-filled bumps will open and the spots will become dry and crusted as they heal
- New spots can develop over several days with the rash lasting for approximately 7 days
- Chickenpox can be more serious for children who have a suppressed (weakened) immune system

**Shingles**, also known as herpes zoster, is another infection that is caused by the varicella-zoster virus. After a person has recovered from the chickenpox, the virus stays in the body, causing no symptoms. If the immune system is suppressed (weakened) the virus may become active again.

Shingles usually starts with:

- Pain in one area of the body
- A patch of red blisters that form a line on the skin
- Shingles can be painful and cause a deep burning feeling

#### **Exposure**

- If your child has been exposed to the virus, even if they have received the vaccine, call your healthcare provider right away.
  - Your child may need to receive medication to protect or treat the virus which must be given as soon as possible after exposure.

#### **Treatment**

- If your child has symptoms of chickenpox or shingles, call your healthcare provider right away.
- The healthcare provider may order medicine to be taken by mouth or IV to help control the virus.
- Admission to the hospital may be needed for treatment.
- To protect other patients from exposure to chickenpox or shingles, your healthcare provider will ask you to follow other precautions while in clinic or in the hospital.

#### Contact Us

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

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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.

#### **General goals before discharge from HSCT:**

- ANC over 500 for at least three days
- No infections or fever
- Ability to take enough fluids and food
- Clear follow up plan

#### **Medications**

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

#### **Preventing Infections**

- Good hand hygiene is the best way to prevent the spread of infection. If hands are visibly soiled, hand hygiene must include washing with soap and water.
  - Hand hygiene 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

There are recommended restrictions to daily activities. Your healthcare provider will review with you how to do this safely. The following will help reduce the risk of infection:

- Your healthcare provider will discuss when the restrictions can end. The duration of these restrictions may vary for each patient:
  - o Autologous transplant: 60 days after transplant
  - o Allogeneic transplant: 9 -12 months
- 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:

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Discharge After HSCT

- 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.
- Your child should not be around:
  - Anyone who has received the oral polio vaccine within the past 6 weeks
  - Anyone who has received nasal Flumist within the previous 7 days
  - o Anyone who has not had chicken pox or the vaccine against chicken pox
- 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 should avoid:
  - o contact with persons who are sick. If unavoidable, limit the time spent together and wash hands often.
  - crowded outdoor places, such as professional sporting events or theme parks.
     construction areas and other dusty environments.
  - digging in dirt, sandboxes, soil, plants or areas such as farms, digging sites, gardening and lawn mowing.
  - o public restrooms
- 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).

#### **Guidelines for Keeping Your Home Safe**

- Before discharge, clean your home 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 should be cleaned or replaced before discharge and ducts should be vacuumed.
- You may not have any plants, flowers, or live Christmas trees inside your home.
- You may not use vaporizers, humidifiers 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.

#### **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.

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#### Discharge After HSCT

 When bathing with a CVC, cover the line and dressing with an occlusive dressing, such as Tegaderm® or Aquaguard®.

#### **Pet Safety**

- Your child is allowed to keep any pets you already own except for reptiles and birds.
- Pets who live outside may not come into the house.
- Your child should not bathe, brush or clean up after their pet.
- Cats may not sleep on your child's bed.
- Litter boxes should not be placed in 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.

#### **Miscellaneous**

- Use sunscreen (SPF 45 or higher) and wear protective clothing when outdoors.
- Smoking, vaping 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 as it may interact with your medications.

#### **Contact Us**

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  Business Hours 8 a.m. to 5 p.m., Monday through Friday
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#### Hematopoietic Stem Cell Transplant Discharge Diet

#### What is the stem cell transplant discharge diet?

- After your child starts making healthy blood cells (a process called engraftment), they will need
  to follow a special diet for several weeks or months after having a stem cell transplant. After a
  transplant, your child takes medicines to keep their body from rejecting the transplanted cells.
  These medicines are called immunosuppressants.
- Immunosupressants may make your child more likely to get an illness or infection. Certain foods can carry bacteria or other germs that can cause illness. To prevent foodborne illness, it's important that your child does not to eat these high-risk foods after the transplant.
- Be sure to follow this food plan until your child's care team tells you to stop.

Food group(s)	Foods allowed	Foods NOT allowed
Protein	<ul> <li>Well-cooked meats, poultry, fish, shrimp, bacon, sausage, hot dogs</li> <li>Well-cooked eggs</li> <li>Nut butters (peanut butter, almond butter, soy butter)</li> <li>Whole nuts and seeds without shells</li> <li>Cooked shellfish</li> <li>Homemade chicken salad, tuna salad, egg salad</li> <li>Sliced and heated (in an oven or microwave until steaming) deli meats. Ask staff at your deli to wear new gloves when slicing your deli meat.</li> </ul>	<ul> <li>Sushi</li> <li>Raw shellfish</li> <li>Smoked salmon (lox)</li> <li>Nuts and seeds with shells</li> <li>Wild game meat (venison, squirrel, rabbit or bear)</li> </ul>
Dairy + dairy alternatives	<ul> <li>Pasteurized cow/goat milk</li> <li>Pasteurized soy, coconut, rice and almond milk</li> <li>Shredded mozzarella cheese</li> <li>Pasteurized string cheese from deli</li> <li>Cream cheese</li> <li>Packaged ice cream</li> <li>Yogurt, Kefir</li> </ul>	<ul> <li>Bleu cheese, brie, camembert, Roquefort, gorgonzola</li> <li>Fresh mozzarella</li> <li>Imported soft cheeses</li> <li>Soft-serve ice cream or frozen yogurt</li> <li>Hard-serve ice cream from ice cream shops</li> </ul>
Fruits + vegetables	<ul> <li>Raw, cooked, and/or frozen vegetables</li> <li>Any raw, frozen or canned fruit</li> <li>Dried fruit (like raisins, figs dates, apricots)</li> <li>Pickles</li> <li>Note: Carefully wash fruits and vegetables before eating or cooking.</li> </ul>	sprouts Salad bars, Prepared Pre-cut raw salads from grocery
Grains	<ul> <li>Cold cereals, including those with dried fruits</li> <li>Hot cereals</li> <li>Breads, pasta, rice</li> <li>Raisin bread and raisin bagels</li> </ul>	Bread, cookies, cupcakes, donuts and other baked goods from bakeries or restaurants

© Boston Children's Hospital, 2022 All rights reserved • Publication Date: 2022 Page 1 of 2 Stem Cell Transplant Discharge Diet

Food group(s)	Foods allowed	Foods NOT allowed		
Drinks	<ul> <li>Tap water</li> <li>Any branded bottled water, bottled or canned seltzer water</li> <li>Pasteurized fruit juices (like Naked Juice, Odwalla)</li> <li>Tif you have well water: water must be boiled for 2 minutes</li> <li>Canned or bottled soda</li> <li>Homemade smoothies and milkshakes</li> <li>Hot drinks from coffee shops (milk and creamer must come from home)</li> </ul>	<ul> <li>Unpasteurized cider or juice</li> <li>Ice from ice machines</li> <li>Milkshakes and/or fruit smoothies at restaurants</li> <li>Frappuccino from Starbucks, Coolatta from Dunkin' Donuts or other beverages with ice</li> <li>Fountain drinks</li> </ul>		
Candy	Candy or gum in individually wrapped, pre- packaged bags	Open bins of loose candy		
Snack foods	<ul> <li>Individually pre-packaged bags of snacks, like chips, crackers, cookies, Oreos, Pop Tarts, Nutri- grain bars, granola bars</li> </ul>	Popcorn (allowed when able to floss)		
Condiments	<ul> <li>Ketchup, mustard, mayonnaise, salt, pepper, sugar, jelly, hot sauce, maple syrup, cooked herbs/spices</li> </ul>	• Honey		
Energy systems of	Freshly cooked hot food (like take-out, drive- through or delivery)	<ul> <li>Prepared green salads and/or deli salads from a grocery store, restaurant, or deli</li> <li>Buffet food</li> <li>Desserts from restaurants (like cake)</li> </ul>		
Foods from outside of the hospital		Ice from ice machines		

#### **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
- If you would like to schedule an appointment with a registered dietitian, call the Center for Nutrition at 617-355-4677 or email nutritiondept@childrens.harvard.edu.

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#### **Mouth Care**

Keeping the mouth and teeth as clean as possible is important and may prevent infection and/or mouth sores.

- Children under six years old should have their mouth care done by an adult caregiver.
- Children over six should brush their teeth with a soft toothbrush after each meal and before bed.
- Electric soft toothbrushes can be used.
- Rinse the mouth with water frequently to keep your child's mouth moist.
- Recommended amounts of toothpaste:
  - o Children under six years old, place a pea size drop of toothpaste on brush.
  - o Children over six years old, place about 1 inch of toothpaste on brush.
- Do not use mouthwashes that contain alcohol as it is very drying to the mouth.

#### **Dental Visits**

Patients should see a dentist regularly. Scheduling a dental appointment is dependent upon blood counts and treatment. An antibiotic may be necessary. Speak to your healthcare provider before seeing the dentist.

#### **Mouth Sores**

Some chemotherapy medicines and radiation therapy can cause sores known as *mucositis*. Mucositis can also occur throughout the digestive system (mouth, throat, stomach and intestines). If mouth sores are painful, contact your health care provider.

Your child's mouth or tongue may look reddened or have white spots. Sometimes white plaques (small raised areas) occur, an infection known as thrush. A medicine will be prescribed to treat the infection.

#### Some things that may help:

- Drink cold or room temperature fluids through a straw
- Avoid hot, spicy or acidic foods
- Eat foods that are soft, tender or puréed (beaten or blended)
- Cut food into small pieces

#### When to call:

- · Your child cannot drink fluids
- Your child can not swallow
- Your child is in pain

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