Dana-Farber Cancer Institute | Boston Children's

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

EDUCATION GUIDE

for Patients & Caregivers at Dana-Farber/Boston Children's Hospital

SCAN ME

Dana-Farber Cancer Institute | Boston Children's

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

Your Child's Care Team

The care teams at the Dana-Farber Jimmy Fund Clinic (JFC) and Boston Children's Hospital (BCH) will work together to coordinate your child's care. There are other members of your care team who are not listed below. Staff can connect you to them as needed.

Clinic Day: ____

Attending Physician: ________________________________

Fellow: ____

Nurse Practitioner/Physician's Assistant:

____

Nurse Director/Nurse Manager (JFC):

____

ONN/ Oncology Nurse Navigator (JFC):

____

Psychosocial Clinician (BCH): _______________________

Psychosocial Clinician (JFC): ________________________

Resource Specialist: ______________________________

Genetic Counselor: _______________________________

Who to Call for Patient Care

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

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

At Dana-Farber/Boston Children's Cancer and Blood Disorders Center, we specialize in the care of children, teens, and young adults with cancer and blood disorders. A team of experts at Boston Children's Hospital (BCH) and the Jimmy Fund Clinic (JFC) at the Dana-Farber Cancer Institute (DFCI) will care for your child. In this joint program:

- Inpatient care is at Boston Children's Hospital.
- Outpatient clinic visits are at the DFCI Jimmy Fund Clinic, Floor 3 of the Dana Building.

DFCI/BCH Medical Care Team

A team of hematology/oncology/stem cell transplant clinicians work together to manage your child's care. The team may include an **Attending Physician, Clinical Fellow, Medical Resident, Nurse Practitioner, Nurses, and Physician Assistants.** They will provide direct medical treatment and talk with you about your child's daily care.

Other Support

- **Clinical Assistants** care for your child under the direction of a nurse.
- A **Case Manager** works with the nursing staff to make sure that all plans are made for home care needs, medications, and supplies.
- A psychosocial clinician may be a **Social Worker, Psychologist, or a Psychosocial Fellow.** Your child will be seen by a psychosocial clinician at BCH and DFCI, providing care throughout treatment. They will provide counseling and support for your family.
- **Resource Specialists** help families connect to support for things like transportation, places to stay, and financial aid.
- **Child Life Specialists** use play to help children express fears or worries about medical care and understand the hospital environment. They also provide activities to help your child and family through treatment.
- **Registered Dieticians** help patients with nutrition and diet needs.
- **Patient Experience Representatives at BCH and Clinical Administrative Support Specialists at DFCI** work at the front desk and are available to help you.
- **Patient and Family Education Specialists** work in the Resource Room. They can help you find resources about your child's disease, community organizations, and support programs.
- **Physical Therapists** help your child with physical strength during treatment.
- **Occupational Therapists** help your child maintain or return to normal daily activities.
- **Music Therapists** use music as a tool to help children meet physical and emotional milestones, cope with medical care, and express themselves.
- **Genetic Counselors** assess for hereditary risk and arrange for genetic testing as needed.

Phone Numbers

Dana-Farber Cancer Institute

Jimmy Fund Clinic Main Number	(617) 632 3270
DFCI Page Operator	(617) 632 3352
Pediatric Patient Registration	(617) 632 3913
Pediatric Psychosocial Services	(617) 632 6080
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 (Billing)	(617) 632 3455

Boston Children’s Hospital

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

Brigham and Women’s Hospital

Radiation Oncology	(617) 732 6310

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Inpatient Care at Boston Children's Hospital (BCH)

Information for Caregivers

- Patients must always wear an identification wristband in the hospital.
- All visitors must be screened at the information desk. You will then be given a hospital ID to wear in the hospital at all times.
- All patients under 18 years old must be with a caregiver, nursing unit staff, or a volunteer when leaving the hospital unit.
- Caregivers can stay in the hospital 24 hours a day. Each patient room has a sleep space where one adult caregiver can sleep. Sheets, pillowcases, and towels are on the linen cart on your unit.
- If at least one caregiver cannot be at the bedside, tell your child's nurse and confirm that the contact information in your child's medical record is up-to-date.
- If you are not at the hospital, you may call to speak with your child's nurse. For your child's safety, information is only given to parents or legal guardians.
- Caregivers are responsible for siblings and other visitors.
- Visit BCH Hale Center for Families (in the hospital lobby) to learn about resources and services.

Visiting a Patient

Visiting hours and other rules are set by BCH Policy and subject to change.

- Visiting hours are 12 p.m.- 8 p.m. Only caregivers can visit after 8 p.m.
- Friends and family members who are sick cannot visit BCH.
- All visitors must be screened at the information desk. They will then be given a hospital ID to wear in the hospital at all times.
- Smoking, alcohol, drugs, and weapons of any kind are not allowed at BCH. If you are legally allowed to carry a firearm, please call the security office at (617) 355-6121.

Patient Rooms

- Do not touch the IV pump settings, alarms, or any medical equipment.
- If your child is in a crib, always keep the side rails on the crib up. Your nurse will tell you about crib and bed safety.
- To prevent infection, many units do not allow plants and flowers.
- BCH Engineering Department must approve all electrical appliances.
- Each bed space has a TV with the GetWell Network™.
- Internet access is free.
- Each bed space has a phone to receive incoming calls.
- Please bring a phone charger to charge your phone in the room. There are also charging stations in the hospital lobby and other areas.

- There is a washing machine and dryer on the 6th floor. If you want to use them, ask the staff at the main desk on your unit.
- Leave valuables, money, and jewelry at home.
- Please bring only a small number of decorations and personal items for the room. This makes room cleaning easier. Cleaning staff will not clean under personal items.
- Use Sticky Tack® to hang all decorations, cards, and posters on the wall. Do not use tape.
- Latex balloons are not allowed in the hospital. Mylar balloons are ok.

Patient and Family Common Areas

Activity Room & Family Resource Centers

- Staff and volunteers are in the activity rooms and resource centers during posted hours.
- Patients and siblings can visit the activity room if they are with an adult, except:
  - Patients on precautions (and their family members) may not visit the activity room.
  - For patients on the Stem Cell Transplant (SCT) unit, ask Child Life staff to plan time in the activity room.

Food Service

- BCH has food service for patients. Food is delivered to the room.
- Ask for a menu for more information and hours. Guest meals are deliverered for a fee.
- Put the tray on the cart in the hall when your child is done with their meal.
- Hot food is available on a limited basis.
- Phone: (617) 355-3663 (FOOD)

Nourishment Center

- There are drinks and snacks for patients on the unit.
- Each nourishment center has 2 refrigerators. One is for patient food only. You may keep food from home in the refrigerator for up to 3 days. Put your name and date on all items. Anything without a name and date will be thrown away. Before your child goes home, please take all your food out of the refrigerator.

Interpreter Services

- If you need an interpreter while in the hospital, please tell your child's care team.

Pastoral Care

- An Interfaith Chapel is open 24 hours a day. For a chaplain, call (617) 355-6664.

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Guidelines for Outdoor Spaces & Indoor Gardens at Boston Children's Hospital

This sheet explains who is at high risk for fungal infections and rules about going outdoors during your child's hospital stay.

Key points

- Children with a weakened immune system are at increased risk for a fungal infection.
- There are restrictions (rules) around going outdoors during your child's hospital stay. This is to lower their risk of exposure to fungus in the environment.

What is fungus?

Fungus is an organism that can be found in soil, water, and air.

Why is fungus a concern?

- Fungus is generally not a risk to people with healthy immune systems.
- Fungal infections are rare. But people with some conditions are at a higher risk to develop fungal infections at certain points in treatment.
- Fungal infections tend to affect people when their immune system is most suppressed.
- Fungal infections can range from mild to life-threatening.

Are fungal infections contagious?

Most kinds of fungus like this don't spread between people.

How can my child avoid getting a fungal infection?

- If your child is immunocompromised, you can take steps to lower their risk of exposure to fungus in the environment.
- While your child is at Boston Children's Hospital, there may be times when they cannot go to the outdoors and garden spaces (including all indoor gardens), and the traffic circle.
- Your child should also avoid dusty areas, construction sites, and activities involving close contact with dirt or dust and renovation or demolition sites.

Should my child have tests to see if they have a fungal infection?

Your child only needs testing if your care team is concerned about signs or symptoms of a potential new fungal infection.

What are the rules at Boston Children's?

A team of clinical experts set the rules for your child while they are at the hospital to lower their risk of exposure to fungus.

Children with the conditions listed in the following chart, and in certain phases of treatment, are high-risk and cannot use the outdoors and garden spaces, including indoor gardens at Boston Children's or the area in the front of the hospital. Talk to your child's care team if you have any questions about your child's infection risk or about these guidelines.

Children considered *high risk* are not allowed to go to outdoor spaces at Boston Children's.	
Children with cancer	• Acute lymphoblastic leukemia (ALL) patients in all phases of therapy except continuation. • Acute myeloid leukemia (AML) patients in all phases of therapy except acute promyelocytic leukemia (APML) post-induction. • Relapsed ALL and relapsed AML patients in all phases of therapy. • Advanced stage non-Hodgkin's lymphoma (NHL), recurrent NHL, or recurrent Hodgkin lymphoma treated with intensively myelosuppressive chemotherapy.
Children with immunodeficiency	• Severe combined immunodeficiency (SCID) patients.
Children with a hematopoietic stem cell transplant (HSCT)	• All allogeneic HSCT patients (regardless of ANC). • Autologous HSCT patients less than 60 days after their transplant.
Children with bone marrow failure	• Severe aplastic anemia children getting ATG/cyclosporine treatment.
Children with solid organ transplant	• No restrictions unless they are severely immunosuppressed and neutropenic.

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

Clinic Hours

- Clinic hours are weekdays from 7:30 a.m. to 5:30 p.m.
- Phones are answered weekdays from 8:00 a.m. to 5:00 p.m.
- Clinic is open on Saturdays and Sundays from 8:00 a.m. to 3:30 p.m. for scheduled infusions or lab draws.
- Clinic is closed nights and holidays.

Before You Come to Clinic

- If your child feels unwell, please call the Jimmy Fund Clinic (JFC) before coming in.
- Make every effort to arrive on time.
- Plan to get to clinic 15 minutes before your first appointment to allow time for check-in and vital signs (blood pressure, temperature, etc.).
- If you are going to be late for your child's appointment, call the front desk at (617) 632-3270. If you are late or very early for your appointment, you will be seen when your provider is available.
- If told to do so, please apply a numbing cream (Emla) for port access or injections. This helps keep your appointment on schedule, and you will have less time to wait.
- Bring to clinic:
    - A current medication list and your child's medications.
    - Anything you may need for the day (change of clothes, diapers, formula, special food).

At the Clinic

- Check in at the JFC front desk.
- Your child will be given an identification wristband to wear. Please make sure they wear this wristband for the entire time at the JFC.
- Your child will be given an RTLS (Real Time Locating System) badge to wear from when you check in to clinic until you check out. This is how staff find your child at clinic.
- The length of your appointment depends on many things, including blood work and lab results, preparation of medications and/or blood products, and length of treatment. If you have questions about patient care or wait time, please ask your care team.
    - After check-in, you will be directed to either the waiting area or a private isolation room depending on your child's needs.
- Let the front desk staff know if you have been waiting for vital signs for more than 20 minutes after your appointment time.
- If your child's blood is drawn in clinic, it will take 1–2 hours to get the results.
    - While you wait, the care team will be looking at the 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 at the front desk to order food for your child while in clinic.
- Please keep any money, jewelry, or other valuables with you at all times.
- Patients under 18 must be accompanied by a caregiver to all appointments.
- Children under 18 need to be supervised by their caregiver at all times. If you must leave the clinic briefly during your child's treatment, please ask clinic staff so that they can decide if we can safely care for your child while you are out.
- Smoking, alcohol, drugs, and weapons of any kind are not permitted at DFCI.

Checking Out of the Jimmy Fund Clinic

- When your care team has cleared you to leave clinic for the day:
    - Look carefully at the dates and times of all scheduled appointments.
    - Return the RTLS badge to a drop box in the clinic.

Who Can Come to Clinic

- The clinic is a small space, so please think about that as you decide who comes with you.
- Family and friends who are sick cannot come to clinic.
- When possible, only bring to clinic your child receiving treatment.
    - There is no childcare available for siblings in clinic.
- If your child is on precautions in a private infusion room:
    - All visitors must stay in the patient room.
    - If anyone needs to leave the patient room, they must wash their hands before and after entering common areas.

Clinic Areas

- <u>The Playroom</u> is where you can find toys, games, and other activities.
- <u>The Teen Area</u> is where teens and young adults can spend time together while in clinic.
- <u>The Blum Pediatric Resource Room</u> is where you can find books and information. There is also art, music, and other activities there for your family.
- <u>Nourishment Center</u> (for snacks and drinks) are in the waiting area and infusion area.
- <u>AYA Young Adult Lounge</u> is where patients 18 and older may wait between appointments.

MyChildren's Patient Portal

MyChildren's lets patients and caregivers connect with care teams using secure messaging.

- You can use it to:
    - Address simple, non-urgent medical concerns.
    - Discuss test results, referrals, or ask follow-up questions.
    - Send photos and videos to your care team before coming in for a scheduled visit.
    - Ask a question about scheduling or billing.
- <u>Do not</u> use it for:
    - Issues that need a response right away.
    - New medical concerns.
    - Complex medical questions or concerns.
    - Mental health emergencies.

**Please note that messages will be responded to Monday-Friday from 8am to 5pm. There is a 48-hour business day turnaround time for portal messages. If you need same day or urgent attention, please call.

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  - Stem cell transplant patients: Call (617) 632-3352 and ask for the pediatric stem cell transplant provider on call.
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- For life threatening emergencies call 911.

Paying for Your Child's Care

Health insurance is important for patients and their families. The information here can help you learn about your child's coverage and who to call if you need help with billing and financial services.

If you do not have insurance or you switch to a new insurance plan, call a financial counselor at either Boston Children's Hospital (617) 355-7201 or Dana-Farber Cancer Institute (617) 632-3455.

If you are from a country other than the United States, please speak with your case coordinator in Global Services. If you don't have a case coordinator, please contact: pedi_international@dfci.harvard.edu or call 617-355-5209.

Understand Your Insurance Plan

Calling your insurance company is the most important financial step you can take during your first few days at Dana-Farber Cancer Institute (DFCI) and Boston Children's Hospital (BCH).

You should be able to find your insurer's phone number on your health insurance card. When you call, ask to speak with member services and be sure to ask these questions:

- Are DFCI and BCH in my insurance plan's network?
- What is my coverage for inpatient care?
- Are referrals or authorizations required for outpatient services?
- What is my coverage for prescription medications?
- How much are my co-payments?
- Am I eligible to have a case manager?
- Am I eligible for home care benefits?

Common Questions About Insurance

Is it in my best interest to get a case manager at my insurance company?
Yes! A case manager at an insurance company advocates for you (they work to help you).

How can parents select the best possible insurance and coverage?
A representative at your employer's Human Resources department can help you review health insurance options available to you as an employee.

What happens to health insurance coverage if I change jobs?
Make sure that you do not let your insurance coverage lapse! COBRA regulations require a former employer to continue your health insurance coverage for a period of time. For more information, contact the employer that provided your health insurance benefits.

What happens when a child is not covered by insurance?
Our financial counselors can help you apply for publicly assisted insurance programs.

If my child participates in a clinical trial, will my insurance cover all of the costs?
Coverage varies by insurance company and your state of residence. Please talk with a financial counselor at the hospital(s) where your child is being treated.

Is my child eligible for Supplemental Security Income (SSI)?
SSI is a federal program that pays benefits to disabled adults and children who have limited income and resources. A resource specialist or financial counselor at DFCI or BCH can help you start the SSI application process.

Where can parents learn about potential sources of support?
To find out what assistance you may qualify for, please email our team of Pediatric Resource Specialists at: DFCIPediResourceSpecialists@partners.org

Billing Questions

If you have questions about a bill, start by calling the phone number listed on the bill.
If you are unable to resolve the issue, call one of the numbers below.

You should expect to receive bills from any hospitals or doctors that provide care for your child. DFCI and BCH work together to provide care for children with cancer and blood disorders. In some cases, Brigham and Women's Hospital may provide radiation therapy.

Boston Children's Hospital

- Business Office (617) 355-3397
- Patient Relations (617) 355-7673

Dana-Farber Cancer Institute

- Patient Billing Solutions (866) 408-4669

Mass General Brigham

- Patient Billing Solutions/Customer Service (617) 724-1914
- Radiation Oncology Billing at Brigham & Women's Hospital (617) 632-7009

Financial Counselors

For help applying for insurance coverage, please contact a financial counselor:

Boston Children's Hospital
Farley building, 1st
300 Longwood Ave., Boston
(617) 355-7201
8:00 a.m. to 4:00 p.m.

Dana-Farber Cancer Institute
Central Registration, 2nd floor
450 Brookline Ave., Boston
(617) 632-3455
8:00 a.m. to 5:00 p.m.

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When to Call Your Care Team

Call if your child has a temperature of:

- **101.3 F (38.5 C) or higher or**
- **lower than 96.8 F (36.0 C) or**
- **100.4 F (38.0 C) or higher twice in 24 hours**

Note: If your child's temperature is **between 100.4 F (38.0 C) and 101.2 F (38.4 C)** wait 1 hour and check the temperature again. In 1 hour, or any time in the next 24 hours, if your child has a temperature of **100.4 F (38.0 C) or higher**, call right away. If at any time you think your child's temperature has increased (gone up), take the temperature again.

Also call if your child has:

Shaking or chills or looks sick.	**Diarrhea** • Loose, liquid bowel movements 3 or more times a day.	**Constipation** • No bowel movement in 2 days.
Unusual bleeding • Nosebleed or bleeding gums that don't stop after 15 minutes of gentle pressure. • Blood in urine or bowel movements.	**Change in appetite or fluid intake** • For child under 1 year old: Nothing to eat or drink for 6 hours while awake. • For child over 1 year old: Nothing to eat or drink for 8 hours while awake.	**Signs of a seizure** • Confused, dazed, shaking, or looks awake but not responsive.
Easy bruising or tiny red spots (red "freckles") on the skin.	**Headaches**	**Rash or change in skin color**
Change in vision, hearing, or balance, or seems less alert.	**Vomiting** multiple times in one day.	**New or unusual pain**
Less urine output (pee) than usual or no urination for 6-8 hours while awake.	**Exposure to** a person who has chicken pox, shingles, or any other contagious disease.	**A change** that worries you, or if you think your child may need to be seen that day.

Phone Numbers to Call

- Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270
- After 5 p.m. or anytime on weekends and holidays:
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In an Emergency

Call 911 right away if your child has:

- Trouble breathing.
- Blue or gray skin color.
- Unresponsiveness (not waking up or not responding to you).
- Signs of a seizure if you do not have a plan from your care team for responding to seizures.
- Excessive bleeding that seems life threatening.
- Other life threatening symptoms.

Less Urgent Medical Needs

Prescription Refills

Call the clinic at (617) 632-3270 at least 48 hours before your child will need a refill. When you ask for a refill, you will need to give:

- Your child's name and date of birth.
- Name of the medication.
- Pharmacy phone number.

The information will then be sent to your care team.

Home Health or VNA Services

- If you have a question about a blood draw or medications that your child gets at home via home health care (VNA) services, call that healthcare company directly. If they are unable to help you, call the clinic at (617) 632-3270.
- 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.

Tests and Studies

- For questions about scheduled tests or results at Boston Children's Hospital, call (617) 355-6000.
- General information about tests and appointments is on the MyChildren's Patient Portal: ***https://apps.childrenshospital.org/mychildrens/***

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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Temperature and Fever

Fever is a sign of infection. It is a serious concern in patients whose bodies cannot fight infection well. If your child has a fever, call your care team right away, day or night.

A fever is a temperature of:

- 101.3 F (38.5 C) or higher, or
- 100.4 F (38.0 C) or higher twice in 24 hours

If you think your child does not look well or might have a fever:

- Take your child's temperature under their armpit, by mouth, forehead, or in their ear. **Never** take a rectal temperature.
- Take temperature the same way with the same thermometer, when possible.
- Do not give medicine to lower a fever until you ask your care team if it is ok.

Call the care team right away if your child's temperature is:

- **Lower than 96.8 F (36.0 C)**
- **101.3 F (38.5 C) or higher**

If your child's temperature is between 100.4 F (38.0 C) and 101.2 F (38.4 C), wait 1 hour and take your child's temperature again.

⇒ When you check again in 1 hour, or any time in the next 24 hours: if your child's temperature is 100.4 F (38 C) or higher, call your care team.

How to Call Your Care Team

- **Weekdays 8 a.m. to 5 p.m. (617) 632-3270**
- **After 5 p.m. and on weekends and holidays:**
  - ◊ **Call the page operator (617) 632-3352.**
  - ◊ **Ask for the pediatric oncology or stem cell transplant provider on call.**

In a life threatening emergency, call 911.

Call right away if your child has any signs of fever or infection.

Temperature Chart

°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
37.0	98.6
Average Normal	
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
38.0	100.4
38.1	100.6
38.2	100.8
38.3	100.9
38.4	101.1
38.5	101.3
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

This information is for patients receiving care at Dana-Farber/Boston Children's Cancer and Blood Disorders Center.
It is not meant to replace medical advice. Always ask your care team if you have any questions. For emergency medical care, call 911.

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Complete Blood Counts

A complete blood count (CBC) is a blood test that shows the type and number of cells in the blood. Complete blood counts are checked often throughout treatment.

Blood Cells

Blood cells are made in the liquid in the center of bone, called ***bone marrow***. There are 3 main types of blood cells: red blood cells, white blood cells, and platelets. Each type has a specific function. Some types of chemotherapy and radiation temporarily decrease the types of blood cells or the production of cell types.

Red Blood Cells

Red blood cells (RBCs) are the cells that carry oxygen through the body and give us energy. If you have a low number of RBCs, it is called ***anemia*. **A blood test (Hemoglobin) will be done to show how much oxygen the red blood cells are able to carry to different parts of the body. If the red blood cells drop below a certain level or your child has symptoms of anemia, they may need a red blood cell transfusion.

Signs and symptoms of anemia:

- Tired
- Dizzy, or light-headed
- Pale skin
- Short of breath
- Headache
- Fast heart rate

It may make your child feel better to take short rests between activities when their red blood cell count is low.

Platelets

The body uses platelets to stop bleeding by forming clots. When the platelet count is low, your child is at risk for bleeding. If you have a low platelet count, it is called ***thrombocytopenia***.

Signs and symptoms of low platelets may include:

- Bruising
- Bleeding
- Small purple dots called ***petechiae*** (pah-teek-e-i) on the skin or in mouth

To lessen the risk of bleeding when platelet count is low:

- Do not give your child medicine that contains aspirin or ibuprofen unless ordered by the care team. These drugs can make platelets less effective.
- Try to avoid cuts and tears in the skin.
- Be very careful when cutting nails.
- If you shave, use an electric razor.

Your child may be told not to do certain activites that would put them at greater risk for bleeding.

White Blood Cells

When your child's white blood cell (WBC) count is low, your child is less able to fight infections.

- Neutrophils are one type of WBC that fight infection.
- The **absolute neutrophil count (ANC)** is the total number of neutrophils in your child's white blood cell count. When your child's ANC is low, this is called ***neutropenia***. When the ANC drops below 500, the risk of infection is very high.
    - The ANC often determines when chemotherapy can be given.
    - A blood test called a ***differential*** will show your child's ANC.

To help protect against infection:

- Clean hands often with hand sanitizer or soap and water. Always wash hands before eating, after using the bathroom, and any time you can see that they are dirty.
- Avoid crowded places.
- Avoid people who are sick.
- Shower or bathe every day.
- Wash skin right away with soap and water if there is a cut or burn, even if it is very small. Bandage the cut if needed. Change bandage every day until cut is healed.
- Avoid going barefoot.
- Use cuticle cream remover instead of picking, tearing, or cutting cuticles.
- Never use rectal thermometers or medications.
- Do not clean out litter boxes, birdcages or fish tanks. Avoid all contact with animal urine or stool.
- Do not use tampons or douches.

Your child may be told not to do certain activities that would put them at greater risk for infection.

Your care team can help you understand your child's lab results.

The normal ranges for blood counts are listed below. The expected range for your child depends on their age and their treatment.

Cell Type	**Normal**	**Low (may need attention)**
White Blood Cells (WBC) ANC	5,000 – 10,000 2000-5000	<5,000 <500
Red Blood Cells (RBC)	Hemoglobin (Hgb) 11 – 14	<7
Platelets	150,000 – 450,000	10,000 – 20,000

Blood counts often drop during treatment. This is called bone marrow suppression (or ***myelosupression***). The lowest point the blood cell counts reach after chemotherapy is called the ***nadir***. Low blood counts may require blood and/or platelet transfusions. These transfusions are given at the hospital or clinic.

How long it takes for your child's blood count to improve may depend on their treatment. Your child's care team will help you know what to expect.

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Fever and Neutropenia

Neutropenia is a common side effect of some types of treatment.

Neutropenia is when there are low numbers of neutrophils in the blood. **Neutrophils** are a type of white blood cell, and they are important to fight infection. You are usually considered to have neutropenia when blood counts show that the absolute neutrophil count (ANC) is less than 500.

If your child is neutropenic, they are at risk for serious infection. Fever can be a sign of infection. If your child develops a fever and may have neutropenia, you must call your care team and take your child in to be evaluated.

Fever with neutropenia often requires treatment with IV antibiotics. Some children will need one dose of IV antibiotic (this can often be given in the clinic or emergency room), while some children may need to stay in the hospital to continue IV antibiotics.

It is always important to monitor your child for fever and other signs of infection, and to contact the care team if your child appears unwell.

- A fever is a temperature of 101.3 F (38.5C) or higher OR a temperature of 100.4F (38.0 C) or higher twice in 24 hours.
- Some signs of infection include:
    - Skin feels warm to touch, or there is redness or swelling at an injury, wound, or IV site.
    - Shaking, chills, body aches or feeling very tired.
    - Diarrhea, or rectal pain with bowel movement.
    - Dizzy, confused, or weak.

Call the care team right away if your child has a fever or signs of infection.

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Diagnostic Tests, Scans, and Procedures

Before any test or procedure, your care team will explain what to expect and answer any questions you may have. During some tests, caregivers can be there to comfort their child. Child Life staff and music therapists can also offer support and distraction.

For many of these tests, your child will need to lie still. For some procedures, sedation or general anesthesia may be needed.

For more information about diagnostic tests, scans, and procedures, please visit:
Treatments | Www.childrenshospital.org | Boston Children's Hospital

Audiogram
A test in which a child wears headphones and listens for sounds, measuring how well they hear. A child may be tested multiple times during their treatment course.

Biopsy
A procedure to collect a sample of tissue that is then looked at for abnormal cells.

Bone Marrow Aspiration and Biopsy
A procedure to collect a sample of bone marrow. Bone marrow is usually taken from the hip bone. The sample is then looked at for abnormalities (anything unusual) or to see how a child's body is responding to treatment.

- For an aspiration, a needle is placed in the hip and a syringe is used to take a small amount of the bone marrow.
- If a biopsy is done, a small piece of bone is taken from the same place in the hip.

Bone Scan
A test to look at bones for disease, fractures, or infection. A small amount of dye is given through an IV before the scan. To take the image, a child lies on the table below a large camera that will move slowly around their body. They may be asked to move into different positions but will have to lie still while the image is taken.

Computerized Axial Tomography (CAT Scan or CT Scan)
A CAT or CT scan uses a type of x-ray equipment and computers to take pictures of the body. The detailed images help the care team with diagnosis and treatment. To see more detail in the images, a child may be given a contrast dye by IV, orally (by mouth), or both.

24-hour Urine Test
A test that measures how well the kidneys are working. All of a child's urine is collected in a container for exactly 24 hours. The lab then uses the urine to measure kidney function.

Echocardiogram (echo)
A test that uses sound waves (ultrasound) to make pictures of the heart and its chambers, veins, and arteries (blood vessels).

Electrocardiogram (EKG or ECG)
A test that measures heart rhythm and the rate of the heartbeat. Small stickers are placed on a child's arms, legs, and chest. The stickers are connected to clips and wires on a machine that records heart rhythm and rate.

Gallium Scan

A test in which gallium is given by IV. Gallium is a radioactive dye that is only absorbed by certain tissue types. After 2-3 days, pictures are taken to show where possible cancer cells are in the body. More pictures are often needed 2-4 days later.

Glomerular Filtration Rate (GFR)

A test to measure kidney function that is done before and after some chemotherapy treatments. A child receives contrast by IV, followed by timed blood collections to measure how well the kidneys are working.

Lumbar Puncture (LP)

Also called a spinal tap, this is a way to tell if there are cancer cells or how well a treatment is working. An LP collects a sample of cerebrospinal fluid (CSF), which surrounds the brain and spinal cord. A special needle is inserted between the bones (vertebra) of the lower back into the space that has the CSF. If a child needs chemotherapy in the CSF, it will be injected slowly through the needle that is already there.

Magnetic Resonance Imaging (MRI)

An imaging test used to identify and measure if there are abnormal cells. It uses a magnet and radio waves to take pictures of organs and tissue. The child lies on a table and is given ear plugs or headphones because the machine is very noisy. They are then moved into a tunnel-like machine and have to lie still for 20-90 minutes. To see more detail in the images, a contrast dye may be given by IV.

MIBG Study

A test that uses images and a small amount of radioactive dye to help find certain types of cells in the body. After about 24 hours, pictures are taken to see where there is activity within the body. For the pictures, the child lies still on a table with cameras above and below them. The camera comes close to the child but does not touch them.

Positron Emission Tomography (PET Scan)

A test that makes 3D (three-dimensional) images of the body and provides important information about how the body functions.

Pulmonary Function Tests (PFTs)

A test that shows how well the lungs work by measuring how much air they can hold and how well the child can blow the air out.

Ultrasound

A test that makes images of the inside of the body using high frequency sound waves.

X-Rays

An x-ray takes a picture of your child's bones and organs using a small amount of radiation.

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Clinical Trials

Many children with cancer and blood disorders are treated on a clinical trial. The goal of clinical trials is to develop treatments with the best chance for cure with the fewest side effects. Plans for new trials are based on the results of past trials and what we know about the disease and treatment.

Clinical trials have different phases. Each one is designed to answer certain questions.

- **Phase I** clinical trials offer a treatment to a small number of patients to learn how much of a medicine can be given safely.
- **Phase II** clinical trials look at the effect of a treatment on specific types of disease.
- **Phase III** clinical trials compare a new or changed treatment plan with standard treatment.

As with all treatment options, your care team will talk with you about different options and any concerns you may have.

- You will be asked to sign a consent form that fully explains the clinical trial.
- If for any reason the treatment plan is found not to be the best for your child, they would be taken off the clinical trial and your care team would talk with you about a new plan.
- At any point you may choose to stop your child's participation in a clinical trial.

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Helping Your Child with Medical Care

There are many ways to help your child get through medical procedures. Below are some things to try. The Child Life staff and psychosocial team are also here to help.

Before Medical Care

- Ask your care team what you can expect will happen at a visit or during a procedure. To learn more about specific procedures:
  Treatments | www.childrenshospital.org | Boston Children's Hospital
- Think about how your child has coped with stressful times in the past. Some children are helped by knowing a lot about the procedure ahead of time, while others do better with less time to think about it.
- Tell your child simply and honestly what is going to happen and why it is happening.
  - Tell them what they can expect to see, hear, smell, taste, and feel.
  - Answer their questions honestly so they know they can trust you.
  - Give lots of praise where you can.
  - Give choices and control when possible (like which arm to use for an injection).
- Work with the care team to make a plan ahead of time for how best to help your child. If it seems right or possible, have your child help with the plan too. Let them ask questions and tell you anything that worries them. If you are seeing a new provider, tell them what works best for your child.
- Once you have a plan, stick to it as best you can. Children do well with routines.

During Medical Care

Comfort

- When possible, do not have your child lay flat on their back with their legs or arms being held down. Being held down can feel scary and takes away their control.
- For young children, have them sit in your lap. They can face you, sit sideways, or have their back against your chest.
- Touch is comforting for some children. Hold their hand or rub their arms, legs, or head.
- Comfort items help some children (a blanket, stuffed animal, toy, pacifier).

Support

- Have one person talk to your child at a time. More than one person talking can be stressful and make it harder for your child to focus on what they are being asked to do.
- Let your child know that you hear them and understand why they feel this way. Assure them that they are safe ("It's ok to be scared, but you are safe.")
- A calm, soothing voice can encourage your child and also show trust in their care team. Don't say things that may not feel true to your child, like "you're fine," "it's almost done," or "it's okay."

Breathing

- Taking deep breaths can help children cope and relax. Help your child by doing this with them.
- Have your child blow on a pinwheel or pretend to blow out birthday candles.

Distraction

- Many children do well being distracted (thinking about or doing other things) during procedures.
- Other children do better watching the procedure. Do what is best for your child.
    - Try things like light spinners, books, stress balls, iPad, humor, telling stories, etc.
    - Use one distraction at a time to avoid having it be too much for your child.

After Medical Care

- Let your child know you are proud of them.
- Praise your child for trying, even if not successful "You did a good job trying to stay still".
- If your child tends to respond well to rewards, try using a sticker chart or other positive reinforcement. This can help children stay motivated to get through treatment and medical procedures.
- If your child can talk about it, ask what went well for them and what could be done in a different way in the future.
- Consider using medical play toys at home with your child to help them become more comfortable with certain instruments (e.g. stethoscope, needles, syringes). This can help children build confidence and lower their anxiety.

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Giving Your Child Medication

When giving your child medicine, always follow the directions given to you by your child's care team. Keep all medicine out of the reach of children and pets.

Medication Types

You may be asked to give your child medicine at home. Ways to give them are described below.

Medication is not given rectally during treatment.

Ear Drops

- Children less than 3 years old: Gently pull the top of the ear back and down while placing the drops in the ear.
- Children 3 years and older: Gently pull the top of the ear up and back while placing the drops in the ear
- Keep your child lying flat on their side for 2 minutes after you put in the drops.

Eye Medications: Drops and Ointments

- Keep the medication clean. Do not touch the tip of the bottle or tube with your hands or touch your child's eyes with it.
- If possible, give your child eye ointments before bedtime or at naptime since their vision may be blurry for a while.

To give your child eye medication:

1. Place an infant or small child lying down on their back. An older child may sit up with head tilted back.
2. Ask the child to look up.
3. Use one hand to pull the lower lid down, making a little "cup," and put the solution or ointment into the "cup".

Intravenous Medications (IV)

- An IV medication is given directly into a vein. Some patients need medication to be given this way at home. If needed, your care team or homecare company will teach you how to do this.

Liquids

- Measure liquid medicine using an oral syringe, medicine cup, or measuring spoon from the pharmacy or hospital. Do not use a regular spoon. Pour the exact amount listed on the prescription.
- Ask your care team if flavor can be added to improve the taste of a medicine. You can buy flavored syrup at the pharmacy.

Subcutaneous Injection

- A subcutaneous injection is given using a small needle placed under the skin. If your child needs a subcutaneous injection, a nurse will teach you how to give them so that you can do it at home.

Nasogastric (NG) Feeding Tube

- An NG tube is a soft, flexible tube used to give medicine or feedings if a child is unable to take enough in by mouth, or if it is unsafe to do so. The tube goes into the nose and down the esophagus ("food tube") into the stomach. It is held in place with tape on a child's cheek.

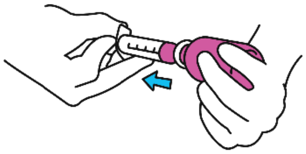
Tablets, Capsules, Pills

- If your child cannot swallow pills, talk to your care team about other options.
  - Always check with the care team or pharmacist before you crush, cut, or dissolve pills.
  - Use a pill cutter to crush a pill, break a pill in half, or into smaller pieces if that is easier for your child to swallow.
- For pills that can be crushed, ask your care team if flavored syrup can be mixed with them to improve the taste. You can buy flavored syrup at the pharmacy. For some children this makes taking pills easier.
- If your child throws up an oral chemotherapy right after taking the medication, read the medication information sheet you were given or call your child's care team to see if you should give the medication again.
- If your child cannot take the medicine, call the care team.

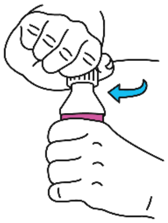
Giving Medicine by Mouth

For babies (under 1 year old)

Give your baby liquid medicine using a medicine dropper, syringe, or baby bottle nipple:



1. Fill the dropper or syringe with the correct amount of medicine.



2. Screw the cap back on the bottle. Put it out of your baby's reach.

3. Place your baby in your lap or on someone else's lap. If this is not possible, place your baby on a mattress.

4. Gently place the dropper or syringe in your baby's mouth along the inside of the cheek. Allow your baby to suck the liquid from the dropper or syringe. If your baby does not suck, squeeze a small amount of the medicine into their mouth and repeat.

5. If your baby starts to cough or gag, stop and sit your baby up straight. Wait a few minutes before giving the rest of the medicine.

To use a nipple:

1. Follow steps 1 through 3 above.
2. Place a clean baby bottle nipple in your baby's mouth. Squirt the medicine from the syringe or dropper into the nipple.
3. Allow your baby to suck and swallow all the medicine.

Giving Medicine to 1-3 Year Old Children

- Let your child pretend to give medicine to a doll or a stuffed animal.
- Give the medicine with a medicine spoon, medicine cup, or oral syringe. Make sure your child swallows all of the medicine. Never use a kitchen spoon to measure medication.
- When using a medicine spoon or oral syringe, place it toward the back of your child's mouth, along the inside of the cheek. Give the medicine slowly so your child does not choke.
- Children 2 years or older can take medicine as chewable tablets. Make sure your child chews and swallows all the medicine. Ask your pharmacist what drinks your child can take the medicine with. Then let your child choose a drink.
- Children 2 years or older can also take oral-disintegrating tablets (tablets that melt in the mouth). Place tablets on your child's tongue and let them dissolve. You don't need to give your child water. Do not let your child chew, break, or crush the tablet.
- Give your child choices, like "Do you want to sit on my lap or in the chair when you take the medicine?"

Giving Medicine to 4–6 Year Old Children

- Ask your pharmacist what drinks are ok to take the medicine with. Then let your child choose a drink. Give choices such as, "Do you want to take your medicine with water or juice?"
- Explain to your child why this medicine is needed.
- Children this age can usually take liquid and chewable medications on their own, but you should still make sure all medication is taken.
- If your child has loose teeth, be careful when giving chewable medicine or when using an oral syringe.

Tips for Swallowing Pills

- Practice with your child. Place very small pieces of food or candy (like cake sprinkles) toward the back of the tongue and let them melt.
- Have your child take sips of water with the candy on the back of the tongue and swallow it.
- Slowly work up to swallowing larger pieces of food or candy. Then try a small pill.
- Have your child drink from a straw after putting the pill on the tongue. This can help wash it down.
- Give your child lots of praise as they do this. You can say things like, "You're doing a great job!"
- Mix the pill with a small amount (1 to 2 tablespoons) of food that your pharmacist says is ok. Give it to your child right away.
- Be careful the pill is not crushed or broken unless your child's pharmacist tells you it is OK.
- Never call medicine "candy." Be honest with your child so they do not feel you are trying to trick them.

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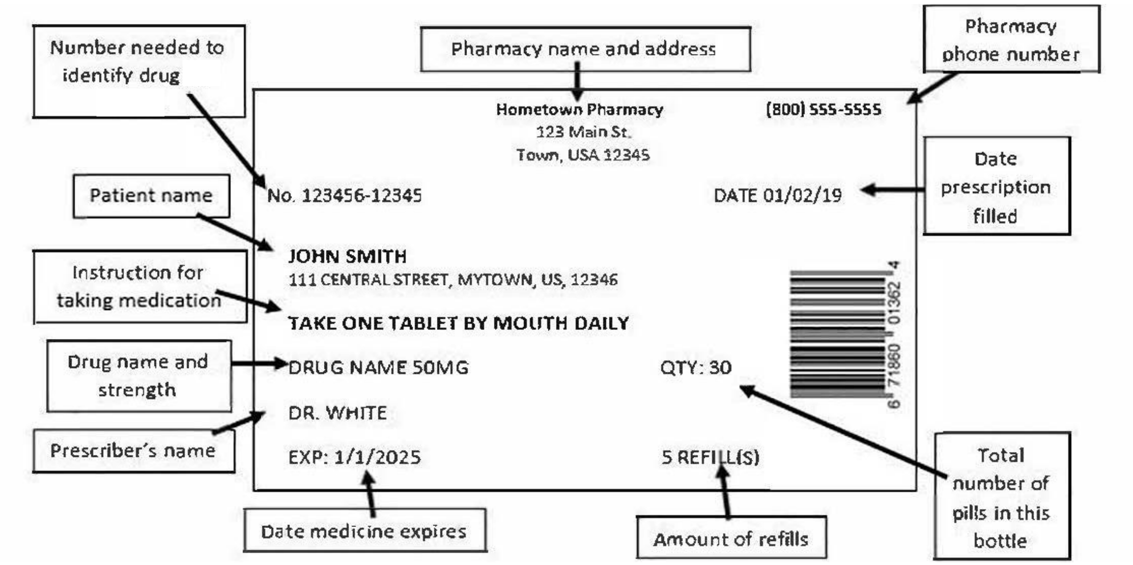
Refilling Medication

It is important to call your pharmacy to order a medication refill <u>before</u> the medication runs out. Refills may take 48 hours or more to be filled**.**

- If you do not have refills left on a medication you need, call the Jimmy Fund Clinic at (617) 632-3270 during clinic hours <u>at least 5 business days before the medication runs out</u>. It can take time to get the insurance approval needed for many medications and also time to prepare the medication.
- If it is after clinic hours and you have an urgent need for a medication refill, call (617) 632-3352 and ask to page the pediatric hematology/oncology fellow on call.
- If you need to move your prescription to a different pharmacy, please call the pharmacy that you want to change to, and they can help you with it.

Reading a Prescription Label

Always read the prescription label carefully when you pick up medications from the pharmacy. If you have any questions or concerns, ask your pharmacist.



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Chemotherapy Safety at Home

It is important to be very careful when storing, preparing, or giving chemotherapy. Once chemotherapy medications are taken, they pass through the body and are in blood, urine, stool, and vomit. You must follow safety precautions when your child is receiving chemotherapy and for 48 hours after the last dose.

To safely prepare oral chemotherapy medications:

- When you pick up your child's prescriptions, please make sure that you understand the information on the label. Always read the label on the bottle and follow the directions. If you have any questions, please ask your care team.
- When handling or preparing these medications, avoid contact with your child's bodily fluids during the time the medicine is being given and for 48 hours after.
- Always wash your hands before preparing or giving chemotherapy medications.
- Always wear medical gloves when handling chemotherapy.
- Put paper towel or a disposable cloth on the table or counter before you mix any oral chemotherapy medication, empty a capsule, or crush or cut tablets.
- Wear a mask when opening a capsule or cutting or crushing a tablet to mix with food or liquid.
- To cut or crush a tablet, use a pill crusher or cutter. Wash the pill crusher or cutter with soap and water before using.
- Keep these medications away from food and places where food is prepared. Always keep them out of reach of children and pets.
- Return unused oral chemotherapy to the pharmacy where the prescription was filled. Do not flush it down the toilet, dump it in the sink, or throw it away in the trash.

For chemotherapy medications given through an IV (intravenous):

- Always wear a new pair of medical gloves when touching IV chemotherapy medicines, infusion pumps, and equipment for flushing IV lines.
- If IV tubing gets loose or disconnected, put on a pair of medical gloves and clamp the IV tubing. Then call your care team or the home care company.
- Put all gloves, bags, and tubing containing chemotherapy in a plastic chemotherapy waste bag.
- Put all expired or unused chemotherapy in a sealed plastic bag to return.

During chemotherapy and for 48 hours after the last dose, everyone who cares for your child should:

- Wear medical gloves when disposing of stool and urine.
- Close the lid and flush the toilet twice to prevent possible spray or splash of chemotherapy.
- Wear medical gloves when handling diapers.
- Put diapers in a separate bag and throw away with regular trash.
- After taking off gloves, wash hands with soap and water.
- If pregnant, do not handle patient body waste.

If chemotherapy gets on or in the eye:

- Rinse the eye with a lot of water for 15 minutes.
- Call your care team if the eye gets red or irritated.

If chemotherapy gets on the skin:

- Wash the skin well with soap and water for 15 minutes.
- Call your care team if the skin turns red or is irritated.

If clothing or bedding comes in contact with chemotherapy medication or body fluids:

1. Put on medical gloves.
2. Remove all soiled clothing.
3. Put the clothes or bedding in the washer right away without any other laundry. If you do not have a washer, put it in a plastic bag until it can be washed. Close the bag tightly.

If chemotherapy medication spills:

1. Put on medical gloves.
2. Keep people and pets away from the spill until it is cleaned up.
3. For clean powder spills, use wet (with water) paper towels.
   For liquid spills, use a dry paper towel.
4. Wash the area thoroughly with soap or other household cleaner.
5. Put all paper towels used to clean up the spill, and anything else used to wash the area, in a plastic bag. Close up the bag and put it out with your regular trash.
6. Remove gloves while avoiding contact with the skin and place in a plastic bag.
7. Wash hands with soap and water.

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  - Bone marrow failure clinic patients: Call (617) 355-6363 and ask for the hematology provider on call.
- For life threatening emergencies call 911.

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Allergic Reactions

An allergic reaction may include itching, rash, hives (one or more small red bumps that appear on the skin), difficulty breathing, wheezing, choking, or facial swelling. Allergic reactions can be caused by medications, blood products, latex, food, or things in the environment. When in the clinic or hospital, your child will be watched for any signs of an allergic reaction.

An allergic reaction may happen:

- During the first dose of medication or after many doses.
- Right away during an infusion or hours later.

If your child has an allergic reaction:

- Medications can be given to lessen symptoms of a reaction.
- Medications can be given to prevent reactions in the future.
- Your care team may change the medication that caused the reaction or may give it in a different way.

If your child has a life-threatening allergy:

- Tell your child's care team.
- They should wear an allergy ID band at all times.
- Keep a list of your child's allergies and all reactions they have had (including to medications and blood products).

When to Call

- If you are at home and your child is having a hard time breathing, is choking, or their face is swelling, call 911 right away.
- If your child starts to itch or gets a rash or hives, call your care team.

Who to Call for Patient Care

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Blood Transfusions

A blood transfusion is when blood or parts of blood are taken from one person and put into the bloodstream of another person. The blood is usually given through an intravenous (IV) line.

Your child may get a blood transfusion if they don't have enough red blood cells or platelets.

Possible Risks

While all blood transfusions have a small chance of causing problems, getting donated blood is safer than it has ever been because of better screening and testing.

Transfusion reactions

The most common side effects (these happen in less than 5% of people who get transfusions) are mild rashes, hives, itching, and sometimes a fever. These often get better without treatment. Rarely, someone has a severe allergic reaction (trouble breathing) or red blood cells breaking down too fast (*hemolysis*).

Infection

All blood is screened for viruses and other infections, such as those that cause hepatitis, human immunodeficiency virus (HIV), human T-cell lymphotropic virus (HTLV), syphilis, and West Nile Virus. The chance of getting infected with one of these viruses is very small.

Metabolic problems

Changes in blood salts (high potassium or low calcium levels) may happen after a transfusion.

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Constipation

Constipation is when stool is hard, difficult to pass, or less regular. Some foods and medicines may cause constipation.

Things That May Help

- Drink plenty of fluids, such as water, sports drinks, or juice.
- Eat food with fiber, such as oatmeal, bran, whole wheat breads and cereals, beans, nuts, dried fruit, vegetables, and fresh fruit.
- Move and be active if possible.
- Stool medications as ordered by your care team.

When to Call

Call your care team if your child has:

- No stool for 2 days.
- Abdominal (belly) pain that makes it hard to do normal activity.
- Pain when trying to have a bowel movement.

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Diarrhea

Diarrhea is having loose stool or more bowel movements more often. Many things can cause diarrhea, including some medications or infection. Diarrhea may cause dehydration or skin breakdown in the rectal area.

Before giving your child any medicine to treat diarrhea, talk to your care team.

Things That May Help

- Have your child try to drink small amounts of fluids at least every 2 hours.
- Give your child drinks that have electrolytes, such as sports drinks.
- If you breastfeed your child, continue to breastfeed.
- Avoid milk and other dairy, apple or grape juice, spicy foods, and fried or fatty foods. These may cause more loose stools.
- Clean rectal area well after each stool and apply ointment.

When to Call

- If your child has a change in their normal stooling or has loose, liquid bowel movements 3 or more times a day.
- If your child has signs of **dehydration**, such as:
    - Less urination (peeing) or no urination for 6 hours.
    - Fewer than 4 wet diapers a day.
    - If your child is <u>less</u> than 1 year old and has not had anything to eat or drink for 6 hours while awake.
    - If your child is <u>more</u> than 1 year old and has not had anything to eat or drink for 8 hours while awake.

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Fatigue

Fatigue is a feeling of being more tired than usual. Treatments such as chemotherapy, other medications, radiation, or surgery can cause fatigue. Stress, anxiety, fears, and sadness can also cause fatigue. Fatigue that comes with illness and treatment is different from the fatigue of daily life because it can last longer and rest does not always help.

At times your child may not have the energy to go to school or do activities with family and friends. It may also be difficult to focus, think, or make decisions.

Things That May Help

- Taking short rests.
- Being flexibile with routines.
- Getting light exercise, such as a short walk, playing outside.
- A sleep routine such as no screen time before bed, keeping the bedroom dark and cool, going to bed at the same time each night, and waking at the same time each day.
- Eating a well-balanced diet.

Please tell your care team if you have concerns about your child's fatigue.

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Hair Loss

Hair loss (***Alopecia***) can be caused by chemotherapy and radiation treatment. It may start about 14-21 days after getting chemotherapy. Hair loss can be anywhere on the body. How much hair is lost can range from a little thinning to complete baldness. Hair will grow back for most patients. For some, the color or texture (curly or straight, thick or thin) may be different.

Some people choose to wear scarves, hats, or a wig.

If your child wants a wig:

- Have them choose one before their hair falls out, if possible. It can take time for a wig to arrive.
- Ask for a prescription for a wig from your care team.
- Insurance companies or other resources may help cover the cost.
- Make a wig appointment with the Friends' Place at Dana-Farber. If you need help with this, please ask your care team.

Friends' Place
1st floor, Yawkey Building, Dana-Farber
Weekdays 9 a.m.-5 p.m.
(617) 632-2211

Your child's scalp may feel itchy or sensitive during this time. Some things that may help:

- Sleep on a silk or satin pillowcase.
- Brush thinning hair gently with a soft hairbrush (a baby brush can be good).
- Use a gentle shampoo and conditioner.
- Protect the scalp from the sun with sunscreen or a head covering.

To learn more about hair loss and head coverings, please ask in the JFC Resource Room about the Noodle Caboodle cart. The cart has head coverings as well as supplies for craft activities related to hair loss.

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Mouth Care

It is important to keep your child's mouth and teeth clean to prevent infection and mouth sores.

Brush after each meal and before bed using a soft toothbrush with fluoride toothpaste. Most children under 6 years old should have their mouth care done or supervised by an adult caregiver.

- Soft electric toothbrushes can be used.
- How much toothpaste to use:
    - Age 3 and under: A small smear.
    - Ages 3-6: A pea size drop.
    - Over age 6: About 1 inch.
- Rinse the mouth with water often to keep it moist.
- Do not use mouthwash that contains alcohol as it can dry the mouth.

Dental Visits

Patients should see a dentist regularly. Good dental care is important during treatment. Speak to your care team before seeing the dentist.

Mouth Sores

Some chemotherapy medicines and radiation can cause sores known as *mucositis* in the digestive system (mouth, throat, stomach, and intestines).

Things That May Help

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

Call your care team if your child:

- Has pain or problems eating or drinking.
- Develops spots or sores in their mouth.

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Nausea and Vomiting

Chemotherapy and radiation can cause nausea and vomiting. How much nausea and vomiting depends on the treatment. Nausea and vomiting can be helped by ***antiemetics*** (anti-nausea medications).

- Acute nausea may start right after treatment.
- Delayed nausea may start hours or days after chemotherapy.
- Some chemotherapy medications can cause both acute and delayed nausea.
- Some patients develop anticipatory nausea (before treatment) when they think about coming to the hospital or clinic, or with certain smells, sights, or sounds.

Things That May Help

- Take antiemetic medicine with a small sip of water. Wait 30 minutes before having more fluid or food.
- Try small sips of cold, clear liquids.
- Try to eat small meals or snacks throughout the day until nausea passes.
- Avoid strong smells and spicy foods. The smell of things like food and perfume may make your child feel sick.
- Wear Sea-Bands® -- wristbands with a small button that puts pressure at a point on the wrist that may help with nausea.
- Try relaxation and distraction methods like deep breathing and imagery. You can find relaxation apps on a phone or tablet.
- Drink ginger ale, ginger tea, or have ginger chews.

When to Call

- If nausea does not get better, or your child does not stop vomiting after taking antiemetics, there are other medications to try. Your child's care team can help you find the one that works best for your child.
- If your child has signs of **dehydration**, such as:
    - Less urination (peeing) or no urination for 6 hours.
    - Fewer than 4 wet diapers a day.
    - If your child is <u>less</u> than 1 year old and has not had anything to eat or drink for 6 hours while awake.
    - If your child is <u>more</u> than 1 year old and has not had anything to eat or drink for 8 hours while awake.
- If you see blood in the vomit.

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Nutrition Therapy During Treatment

Nutrition is an important part of your child's treatment. Eating and drinking well before, during, and after treatment can help your child feel better and keep up their strength and energy. However, some medications, chemotherapy, radiation therapy, or surgeries can cause symptoms that may make it hard to eat or drink enough. This can put your child at risk for malnutrition.

The care team may refer your child to a dietitian to help with nutrition needs both during and after treatment. If you have questions about nutrition, please ask your care team or dietitian.

During treatment, it is important to call your care team if you think that your child may not be eating or drinking enough. They will need to be seen by a medical provider if they are not drinking at home.

Nutrition Goals

During treatment, the goal is for your child to grow and develop normally. This means not gaining too much weight and not losing too much weight, but growing and gaining weight that is right for their age and height. We also want to use nutition to help them:

- Heal.
- Keep their strength and muscle.
- Be active.
- Get the vitamins and minerals their body needs.
- Feel good about food and their body.

Nutrition Support

Treatment can sometimes make it hard to get enough to eat or drink orally (by mouth). This can cause children to lose weight, have less energy, and feel bad overall. When this happens, there are other ways to make sure your child gets the nutrition they need.

Oral Nutrition Support

- Appetite Stimulants
  There are some medications to help increase appetite. These are not right for everyone and your care team will talk with you about what may be best for your child.

- Commercial Oral Supplements
  These nutrition drinks or shakes are usually given along with meals and snacks throughout the day for extra calories, protein, vitamins, and minerals. You can buy them at grocery stores and drug stores, and they come in different calorie amounts, flavors, and ingredients (milk based, non-dairy, etc.). Your dietitian can give help you figure out which will be best for your child's needs and tastes.

Non-Oral Nutrition Support

- Enteral Nutrition Support or Feeding Tubes
  A feeding tube is one way to give a child nutrition, and the most common is a nasogastric tube (NG Tube). An NG tube is a soft, flexible tube that goes into the nose and down the esophagus ("food tube") into the stomach. It can be used at home to give a child needed nutrition and hydration. Feeding tubes may be used for a short time (a few weeks) or a longer time (a few months). If a feeding tube is needed, the care team and dietitian will work with you to develop a plan that meets your child's needs.

- Parenteral Nutrition Support or IV Nutrition
  For children in the hospital who may have symptoms like diarrhea, mucositis (sores along the gastrointestinal tract), or severe nausea or vomiting, your care team may recommend parenteral nutrition or IV nutrition. This is nutrition that is given through your child's central line. It is mostly given in the hospital.

Working With Your Dietitian

If your child is admitted to Boston Children's Hospital (BCH), they may be followed by the inpatient nutrition team. When your child is home and being seen at the Jimmy Fund Clinic (JFC), they may be followed by the outpatient nutrition team. The nutrition staff at BCH and JFC work together to support your child's nutrition needs.

Your dietitian can help you think about:

- Your child's growth and goals.
- How to manage treatment side effects, such as taste changes, low appetite, or nausea.
- Nutrition support options.
- Ideas for healthy eating.

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Nutrition-Related Side Effects

Nutrition is an important part of your child's treatment. Eating can sometimes be hard though due to side effects of medications, chemotherapy, or radiation therapy. Side effects can include:

- Constipation
- Diarrhea
- Mouth sores
- Nausea
- Vomiting
- Weight gain
- Weight loss
- Changes in taste or sense of smell

General Tips

- If you have questions or concerns about your child's eating, drinking, or growth, please ask your care team or dietitian.
- Meet with a dietitian regularly for help with symptoms and to monitor growth.
- When coming to the hospital or clinic, bring food and drinks that your child likes, or formula, in case your child is hungry or thirsty while you are there. You can also get some snacks, drinks and formula in both the clinic and hospital.
- Your child may develop lactose intolerance. This is temporary (it will not last). If they do, try using Lactaid® milk or giving them Lactaid® tablets when eating dairy products like milk, ice cream, and cheese. Ask your dietitian about non-dairy products if needed.
- Some children and teens find it hard to eat during treatment and need other kinds of nutrition support, such as a nasogastric tube (NG tube). Your care team will talk about these options with you if they might be right for your child.

Not Hungry or No Appetite

- Give your child 5 or 6 small meals or snacks throughout the day.
- Offer higher calorie and protein-rich foods, like nuts and seeds (without shells), avocado, lean meats, eggs, and full-fat dairy. Add oil, butter, dips, and spreads to foods.
- Keep nutrient-dense snacks like nuts and seeds (without shells), protein bars, and nut or seed butters with crackers where they are easy to grab for a snack.
- At meal and snack times, have your child eat solid foods first. Drinking can make your child feel full and less interested in eating solid foods.
- Give sips of high-calorie drinks like whole milk (or non-dairy) smoothies or shakes, after meals and snacks throughout the day.
- Set times for your child to eat meals and snacks, with family or friends when possible. Try using an alarm to remind your child that it is time to eat. Give a snack before bedtime.
- Some children have a time of day when their appetite is best, like first thing in the morning or later in the evening. Make the most of this good appetite by offering nutrient-dense foods with heart-healthy fats, proteins, and fiber.
- Give appetite stimulants as prescribed.

Nausea and Vomiting

- Give prescribed anti-nausea medications 30 to 60 minutes before eating.
- Keep your child sitting up for at least 2 hours after eating.
- Try dry, salty foods, such as crackers or pretzels.
- Avoid foods with strong smells.
- Avoid foods that are greasy or deep-fried.
- Give cool liquids between meals. Try using a straw.
- Offer ginger products like tea, dried ginger, ginger biscuits, or ginger chews.
- Try aromatherapy. Have your child smell lemon or orange slices. Try essential oils such as lavender, ginger, peppermint, or spearmint (only to smell -- do not eat them!).

Constipation

- Be sure your child is drinking enough each day. Your care team or dietitian can tell you how much your child should be drinking.
- Give foods with fiber, such as whole grain breads, oatmeal, and bran cereals; fruits like pears, apples with skin, citrus (oranges, clementines), and dried prunes; and vegetables like green peas, broccoli, sweet potato.
- Encourage your child to move and be active as much as possible. Even short walks are good.

Diarrhea

- Have your child drink extra liquids (such as water, broth, coconut water, or diluted juices and sports drinks).
- Limit milk as it can make diarrhea worse. Try lactose-free milk or non-dairy milks (like soy or oat milk).
- Limit gas-forming foods (like beans, cabbage, or carbonated (bubbly) drinks).
- Limit greasy, spicy, or very sweet, sugary foods.
- Offer foods high in potatssium (like coconut water, bananas, and peeled potatoes).
- Offer foods high in sodium (like broth, soups, crackers, or pretzels).
- Try bland foods (like bananas, rice, applesauce, white toast, plain noodles, plain chicken, soft tofu, and eggs).
- Avoid raw vegetables and the skins and seeds of fruits. Slowly add higher fiber foods back into the diet when the diarrhea starts to get better.

Mouth Sores

- Give your child soft, moist, bland foods and liquids.
- Avoid hard, rough, acidic, salty, and spicy foods that may irritate the mouth and throat.
- Offer nutrient-dense liquids such as whole milk, shakes, smoothies, for extra nutrition when your child is eating less solid food.
- Plan for meals or snacks after your child takes pain medication.

Taste and Smell Changes

- Try new spices and flavors (like garlic, pickles, olives, or new spice blends).
- Try salty or highly flavored foods (like soy sauce, vinegars, BBQ, and curry sauces).
- Avoid very sweet foods. Taste changes often happen with sweets, and they taste "like cardboard" or "just not right."
- Sour and tart candies or sucking on a lemon or lime slice before eating generates saliva (spit) and can help cover any "metallic" taste.
- Encourage good, regular, gentle tooth brushing.
- For changes in sense of smell, try aromatherapy before or during meals, and try to avoid strong smells.

If you have questions about your child's nutrition or want to meet with a dietitian, please call Jimmy Fund Clinic (617) 632-3270 or Boston Children's Hospital (617) 355-4677.

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Pain

There are many reasons for pain, and it can be short term (acute), long term (chronic), or related to procedures (procedural). Your care team will try to lessen pain during treatment and procedures. Most pain can be helped with coping methods and medications.

There are many ways that children show pain. Some will say when they are in pain. Others will get tense, squirm, make a face, make tight fists, pull up their legs, moan, cry, or scream. If you know how your child shows they are in pain, share that with the care team.

How to Help Your Child With Pain

Ask your child about their pain. This lets them know that you understand they are in pain and that you want to help.

- Help your child get in a comfortable position.
- Help your child focus on other things by singing softly, telling stories, counting, or playing on a tablet.
- Use breathing exercises or blow on a pinwheel to help your child try to relax.
- Have your child imagine going to a favorite place or doing something they like to do.
- Put heat or cold where the pain is.
- Make the room feel calm and relaxing.
- Work with Child Life staff who can help you and your child figure out what works best for them.

<u>For more help with pain management that does not include medication</u>, ask your care team about a Psychology Pain Consultation.

<u>For help with medicine for pain</u>, ask your care team about a consultation with PACT (Pediatric Advanced Care Team) or the Acute Pain Service.

<u>If your child will have orthopedic surgery as part of their treatment</u>, ask about a COPE consult before surgery to help manage pain after surgery.

Common Questions

- **Can babies feel pain?** Yes, babies feel pain.
- **Can children describe pain?** Children as young as 18 months old may have words for pain. By 3 years old many children can say how much it hurts by answering "a little" or "a lot."
- **Is pain medicine safe?** Before prescribing any medications, your care team will talk with you about the risks and benefits. Pain medicine can help children sleep better, heal, and prevent complications. It can also sometimes cause constipation, nausea, or drowsiness. Your care team will work to help you manage any side effects.
- **Could my child or teenager become addicted to pain medicine?** Pain medicine is often needed because many diseases cause pain, and the treatment can also have painful side effects. Children and teens may need opioids during treatment and are not at risk for addiction when the medicine is taken as prescribed. When the pain medicine is no longer needed, your child will be safely weaned off it. Ask your care team if you have questions.
- **What should I do if my child's pain continues?** Ask the care team for help if your child continues to have pain.

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Skin Care During Treatment

Chemotherapy, radiation, and some medications may cause skin changes. If your child has rashes, redness, open areas, or any other skin irritation, please tell your care team.

Some common skin changes during treatment are:
- Dryness or peeling.
- More likely to sunburn.
- Rashes or open areas that may be slow to heal.
- Irritation in the area around the anus, vagina, or penis.
- Dry, chapped lips.
- Skin getting red or darker.
- Risk of skin infections.

Things That May Help With Side Effects
- Take a bath or shower every day with a gentle, scent-free soap.
- Ask your care team before using any medicated cream, ointment, or lotion.
- If your child is receiving radiation or total body irradiation, do not use any lotions, creams, or ointments.
- Do not share any skin care products, including makeup.
- Clean and cover any broken skin.
- Drink a lot of fluids.

Sun Protection
It is very important to be protected from the sun when receiving chemotherapy, radiation, after stem cell transplant (SCT), and when taking certain medications.

Use sunscreen even on cloudy days and when near snow, sand, and water (all reflect sunlight).
- Put sunscreen on 30 minutes before going outside.
- Use a *water resistant* sunscreen that is SPF 30 or higher and has UVA <u>and</u> UVB protection.
    - *Hypoallergenic* sunscreen may be less likely to cause a rash or an allergic reaction.
    - *Noncomedogenic* sunscreen may be better for your skin if you have acne. And for some people's skin, gels are better than cream.
- Put sunscreen on all skin that is not covered (including head and ears) at least every 1-2 hours. Put it on again after swimming, sweating, or using a towel to dry off.
- Use sunscreen and lip balm with SPF 30.

Sun Protective Clothing
- Wear sunglasses and hats that cover face, neck, and ears while outside.
- Wear SPF clothing for extra protection.

Outdoor Activities
- Avoid direct sun, especially from 10 a.m. to 4 p.m.
- If outside during these hours, stay in the shade.

Artificial Tanning
- Do not use tanning salons or tanning beds.
- Chemicals in self tanners dye the skin to create a tan. If you use self tanners, remember they are NOT sunscreens, unless the product says that it contains SPF.

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- After 5 p.m. or anytime on weekends and holidays:
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  - Stem cell transplant patients: Call (617) 632-3352 and ask for the pediatric stem cell transplant provider on call.
  - Bone marrow failure clinic patients: Call (617) 355-6363 and ask for the hematology provider on call.
- For life threatening emergencies call 911.

Steroids: Mood and Behavior Changes

Steroids can be an important part of treatment. These drugs may have side effects that can cause changes, such as:

- Physical side effects (pain, nausea).
- Being very hungry.
- Having a hard time sleeping.
- Mood changes (sadness, crying, anger).
- Anger, upset, or frustrated over small things.
- Verbal aggression (yelling).
- Physical aggression (hitting, slamming doors).
- Not acting like oneself.
- Hard time making decisions.
- Attention problems.
- Hyperactivity.
- Confusion or hallucinations.

Tell your care team right away if while taking steroids your child seems confused, has hallucinations, has unbearable insomnia (cannot sleep), hurts themself or others, or is doing things that get in the way of their treatment.

Things That May Help

- Identify physical symptoms (pain, nausea, hunger).
- Make sure that your child and others are safe.
- Focus on what is important and try not to worry too much about small things.
- Make changes to reduce stress where you can.
- Take turns with other adults who can care for your child.
- Encourage your child to say or show how they are feeling (with words, drawings, or in play).
- Speak clearly and calmly.
- Do not try to reason with your child while they are having a tantrum.
- Hold and comfort your child to stop them from hurting themself.
- Praise and reward positive behavior with attention, activities, or special time.
- Try to avoid new situations and changes in routines.
- Eat snacks and many small meals.

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Vaccines

Talk to your care team before your child receives any vaccines.

While your child is on treatment, they should receive vaccines for flu (influenza) and COVID-19 if their care team decides that they are eligible. Other routine vaccines are not recommended. This is because they are not likely to be effective due to treatment effects on the immune system. Your child should never receive live vaccines while undergoing treatment.

Examples of live vaccines are:

- Measles, mumps, and rubella (MMR) vaccine
- Chickenpox vaccine
- Oral rotavirus vaccine
- Nasal flu vaccine
- Oral polio vaccine

In general, patient's brothers and sisters can get all routine vaccines required for healthy children.

Flu Shots

All patients (if eligible) and others that they live with should get a flu shot each year.

- Patients, siblings, family members, and caregivers should not get the nasal flu vaccine (Flumist®). Contacts who get the nasal flu vaccine by mistake should not be with the patient for 7 days after getting it.
- Parents, siblings, and caregivers can get flu shots from their own healthcare provider or at flu shot clinics.

Stem Cell Transplant (SCT) Patients

SCT patients must tell their care team if anyone in their household recently got the chicken pox vaccine and developed a rash from it.

- Your child will get the flu and COVID-19 vaccines around 60 days after SCT (for autologous SCT) or 100 days after SCT (for allogeneic SCT).
- Around 6 months after SCT they will start to get their newborn and pediatric vaccines, even if they had them before SCT.
- It may take up to 2 years to get back up to date on vaccines.

Until 60 days after autologous SCT, or until 3 months after all immunosuppressive medications have been stopped for allogenic SCT recipients, the patient should not be around:

- Anyone who has received the oral polio vaccine in the past 6 weeks.
- Anyone who has received nasal Flumist® in the past 7 days.
- Anyone who has not had chicken pox or the vaccine against chickenpox.

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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 (spreads easily from one person to another). While rare, people with weakened immune systems can also get chicken pox from the vaccine. If you or someone else who lives with your child recently got the chickenpox vaccine, or plan to get the vaccine, please talk to your child's care team.

- Chickenpox often starts with a fever and feeling very tired (flu-like symptoms).
- Next an itchy rash with clear, fluid-filled bumps will usually 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, and the rash lasts about 7 days.
- **Chickenpox can be more serious for children who have a weakened immune system.**

Shingles (also known as *herpes zoster*) is an infection that is caused by the varicella-zoster virus. After a person has recovered from the chickenpox, the virus stays in the body with no symptoms. If the immune system is suppressed (weakened), the virus may become active again. People with weakened immune systems can also get shingles after the chickenpox vaccine. If you or another adult who lives with your child recently got the shingles vaccine, or plan to get this vaccine, please talk to your child's care team.

Shingles can be painful and cause a deep burning feeling. This often starts with:

- Pain in one area of the body.
- A patch of red blisters that form a line on the skin.

Exposure

Call your child's care team right away if your child has been around someone with chickenpox or shingles, even if your child already got the vaccine.

- Your child may need medication to protect against or treat the virus.
- Medication must be given as soon as possible.

Treatment

If your child has symptoms of chickenpox or shingles, call your care team right away.

- Your child may need medicine to help control the virus.
- Admission to the hospital may be needed for treatment.
- To protect other patients from chickenpox or shingles, the care team will ask you to follow specific precautions while in clinic or in the hospital.

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Infection Control

Treatments such as chemotherapy, radiation, and surgery can make it harder for your child's body to fight infection. This is because the treatment can lower the number of cells that fight infection. Below are ways to help your child avoid infections.

Hand Washing

Washing your hands is one of the best ways to prevent the spread of infection.

- Wash your hands with soap and water for 20 seconds:
    - After you use the bathroom.
    - After you touch animals.
    - After you go outdoors.
    - After you blow your nose, cough, or sneeze.
    - After you touch produce (fruits and vegetables).
    - Before touching your eyes, nose, or mouth.
    - Before and after you eat, drink, or handle food.

When hands are not visibly dirty, it is also ok to use antibacterial hand gel to clean them.

Preventing Infection in Your Home, School, and Community

- Personal Care
    - Take a shower or bath every day, if possible. You can also wipe the skin to keep it clean.
    - Brush teeth at least 2 times a day.
    - Do not share cups, eating utensils (straws, forks, spoons), or toothbrushes.
    - Only touch your eyes, nose, or mouth after you have washed your hands.
    - Ask everyone to wash hands when entering your home.
- Food safety
    - Wash your hands.
    - Clean kitchen surfaces and utensils before and after handling food, especially meat or poultry (like chicken or turkey).
    - Wash raw fruits and vegetables.
    - Always refrigerate leftovers and any items that spoil.
    - Do not drink unpasteurized milk.
    - Do not eat uncooked or raw meat, poultry, clams, fish, or eggs.
- When your child's white blood cell counts are low:
    - Avoid people who are sick.
    - Avoid crowded areas.
    - It is recommended that they wear a mask when out in public places.
- Let the school nurse know that your child may be at increased risk for infection. Ask them to tell you if there are any contagious illnesses (ones that spread easily) at school.

- Carefully follow directions for care of a central line or port.
- If fever or illness develops at home, call your care team right away.
- If your child has been with someone who has a contagious illness, call the care team right away.
- Because pets can be a source of infection:
  - Your child can keep any pets you already own except for reptiles and birds.
  - Pets who live outside should not come into the house.
  - Your child should not bathe, brush, or clean up after their pet.
  - Pets should not sleep on your child's bed.
  - Your child should not handle a pet's litter box.
  - Litter boxes should not be in areas where you eat or prepare food.
  - Avoid contact with any animal that may be ill.
  - Pets should be prevented from getting into garbage, scavenging, or hunting.

Preventing Infection at the Clinic or Hospital

It is a priority to minimize any spread of infection in the clinic or hospital. There are rules in place to protect your child.

- If you or your child has a fever, cold-like symptoms, diarrhea, vomiting, new rash, conjunctivitis (also called pink eye) or any other illness, please call the clinic. If symptoms develop right before an appointment, let a clinic assistant, front desk staff member, or your child's nurse know right away.
- Do not bring siblings who are sick to the clinic or the hospital.
- Sometimes masks may be used for the safety of your child and staff.
- Some illnesses require a private room called an isolation room. If your child is on isolation:
  - Patients, siblings, and visitors must stay in the isolation room.
  - Patients, siblings, and visitors cannot visit common areas on the unit such as the resource room, activity room, or kitchen.
- All visitors must be screened at the information desk. They will then be given a hospital ID to wear at all times in the hospital.

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Food Safety During Treatment

When your child's immune system is not working as well as it should, your child is at risk for foodborne infections. Children with *neutropenia* (less white blood cells or neutrophils) are most at risk since it is hard for the body to fight infections.

To make sure food is safe for your child to eat:

- Wash your hands and your child's hands well with soap and warm water before and after preparing, cooking, and eating meals.
- Clean all cooking tools with soap and warm water before and after each use.
- Use water and a clean brush to scrub fresh fruits and vegetables before eating or cooking them.
- Throw away hot or cold foods that have been at room temperature for more than 2 hours.
- Throw away milk or formula that has been at room temperature for more than 1 hour.
- Keep refrigerated foods at 40 F (4.4 C) or lower.
- Thaw frozen food in the refrigerator or run it under cold water. Do not thaw at room temperature.
- Use a cooler with ice or ice packs to keep food cold when away from home.
- Keep refrigerated leftovers for no more than 2 days and reheat until hotter than 165 F (73.8 C).
- Check the internal temperature of cooked dishes in several places with a food thermometer to make sure the food is fully cooked. To see what the temperature should be, please see the **FDA Safe Food Handling** webpage.

Foods to Avoid

Do not give your child:

- Food from street vendors, salad bars, or shared bins (grocery store "bulk bins")
- Raw meat
- Raw poultry (like chicken, turkey, duck, or goose)
- Raw eggs
- Raw fish, seaweed, and sushi
- Raw seed sprouts (like alfalfa or bean sprouts)
- Raw shellfish
- Uncooked hot dogs
- Unpasteurized milk products and juices

Do not let your child:

- Taste foods that contain raw eggs (like cookie dough), raw meat, fish, or poultry.
- Eat food that has fallen on the floor.

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Emotional Support for the Whole Family: Pediatric Psychosocial Oncology

A serious illness can be hard for the whole family -- mentally, emotionally, and socially. Patients, parents, siblings, and other caregivers may feel all kinds of emotions. The Pediatric Psychosocial Oncology team is here to support you and your family's emotional health during this time.

As part of a young person's ongoing care at Dana-Farber/Boston Children's, a clinical social worker or psychologist will meet with your family to get to know you and to talk about what psychosocial support may be useful. You may also meet with a resource specialist about whether there are financial assistance programs that could help you. There are also psychiatrists (who can prescribe medication) to meet with if needed.

We can help your child and your family:

- Adjust to the illness.
- Talk about the diagnosis and its effects.
- Cope with treatment and its side effects.
- Cope with loss and grief.
- Manage mood changes and behavior challenges.
- Learn to ease stress and anxiety.
- Address school concerns.
- Support siblings.
- Connect to support groups or other psychosocial programs.
    - Parents Together program: For caregivers of children treated at DF/BCH.
    - Sibling Program: For siblings ages 5-19.
- Adjust to the transition off of active treatment.

Your family's needs may change over time, and our team will work with you to make sure that you get the support you need throughout treatment.

We meet with patients and families in the Jimmy Fund Clinic and on inpatient units at Boston Children's Hospital. If you have a specific psychosocial need or just want to learn more, please talk with your social worker, psychologist, or psychiatrist. Or call (617) 632-6080 and ask to speak with a psychosocial provider.

If you have concerns about paying for your child's care, including questions about insurance, transportation, or where to stay, please talk with your Resource Specialist or call (617) 632-6080 to speak with a member of the resource team.

Visit **https://www.dana-farber.org/cancer-care/treatment/pediatric-psychosocial-oncology** to learn more.

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Integrative Therapies

Integrative therapies (also known as *complementary therapies*) include options such as acupuncture, reiki, therapeutic touch, chiropractic, homeopathy, music therapy, massage, guided imagery, yoga, and herbal remedies. Integrative therapies can be used along with traditional medical treatment to treat disease, reduce stress, and prevent or reduce side effects and symptoms.

For Patients

- The Zakim Center for Integrative Therapies and Healthy Living at Dana-Farber offers a variety of therapies for patients. To learn more, schedule an appointment, or sign up for a program, call **(617) 632-3322** or email **zakim_center@dfci.harvard.edu**. You can also get information at **myzakim.dana-farber.org**.
    - For free massage and acupuncture sessions for your child, complete a patient fund application from the Zakim Center. It takes up to 14 days for the application to be reviewed. Once approved, you can schedule an appointment.
    - For Dana-Farber patients ages 18 and up and their caregivers, the Zakim Center offers free group programs (movement classes, creative arts workshops, music programs, and mindfulness meditation). For a schedule, check the website or contact the Center.
- Ask about Music therapy in the Jimmy Fund Clinic **Blum Pediatric Resource Room**.
- When inpatient at Boston Children's Hospital (BCH), please ask your care team to contact the Integrative Therapies team with a referral. Free services for BCH patients include reiki, relaxation massage, yoga, meditation, aromatherapy, and music therapy.

For Caregivers

- A calendar of caregiver relaxation programs is available in the BCH One Mission Resource Room on the 6th floor or in the Hale Center for Families in the BCH lobby (617) 355-6279.
- The Resource Room in the JFC has books and other resources about integrative therapies.

Tips

- Ask your care team about integrative therapies you might like to try.
- Anyone who offers integrative therapies should be licensed or certified.
- Integrative therapies are often not covered by insurance companies. To find out what is covered, call your insurance provider.

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The Sibling Program

Siblings of children with serious illnesses face many challenges. It is important to care for them and their needs as part of care for the whole family.

The Dana-Farber Sibling Program:

- Connects siblings to one another.
- Has books and information for both caregivers and siblings.
- Provides tools and resources to help caregivers and schools support siblings.

Please visit the Sibling Program website to see our Sibling Voices Video:
http://www.dana-farber.org/sibling-program

Support Groups

Groups are open to siblings of patients at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. They offer siblings a place to come together to connect, have fun, and make friends. Virtual groups can make it easy to join from home. At each group meeting there is a fun activity to do together as a way to meet one another and connect. There are separate sibling groups for younger and older children.

Support for Caregivers

The Sibling Program has books and resources for caregivers to help them learn how best to support siblings and to identify when more help is needed.

Siblings at Home

Sibling Bags

School-age and teen backpacks for all siblings ages 5 and up. The bags include information, encourage children to ask questions, and can help them to cope with the changes they and their family face. In each bag there are:

- Books that offer support and help for all the changes to home life, family, and all that goes along with having a sibling who has a serious illness.
- Materials for fun, calming activities to do at home.

Sibling "BEADS" Program

Sibling BEADS is a program that gives siblings beads to mark milestones, such as special family time and celebrations, and beads to recognize things they have had to do that are hard, such as time away from parents or caregivers. To join the sibling bead program, speak with the staff in the Blum Pediatric Resource Room at the Jimmy Fund Clinic.

Siblings at School

Supporting siblings in their school is an important part of sibling care. Schools can be a place where siblings can feel like things are normal. However, the pressure of schoolwork, relationships with friends, and all the emotions that come with an illness in the family make it stressful for many. The Sibling Program offers information to schools about how best to support siblings, and to identify those in need of more support.

Tips for Teachers

Siblings of children who have a serious illness often experience challenges. Below are some reactions siblings may have, as well as some things that may be helpful.

Siblings in school may:

- Complain of not feeling well.
- Withdraw (such as participating less or being less social).
- Show change in academic performance (how they do with schoolwork).
- Have times of over-achieving.
- Often be late or absent from school.

Ways to Help

- School is often the place where a sibling can get a break from their worries. Sometimes it is best to give them space and not ask how the family or patient is doing. Check in with the student to ask what is helpful to them during this time.
- Give as much positive feedback as you can.
- View irritability as sadness rather than confrontation.
- Confirm the contact list of adult caregivers for sibling.
- Encourage peer support.
- Modify academic demands.
- If you are an educator and have concerns about a sibling in your school, contact their parent or guardian.

To learn more about the Sibling Program, or to access any of the above supports, please fill out the online form and visit our website *www.dana-farber.org/sibling-program*.

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Spiritual Care

Spirituality is an important source of strength, comfort, and hope for patients and families. There are multifaith chaplains for spiritual and emotional support at both Dana-Farber and Boston Children's Hospital.

Spiritual care brings holistic, emotional, or religious aspects of life into a patient's care. Chaplains provide support in times of change, struggle, or uncertainty. Spiritual care focuses on each patient's needs and is for all spiritual, religious, and non-religious backgrounds. A chaplain can help connect to habits, rituals, or beliefs that are supportive to you, and create space to reflect on anything you have been thinking about.

You can ask a chaplain for:

- Support during times of difficult waiting.
- Confidential listening.
- Age and developmentally appropriate spiritual, religious, and emotional support.
- Prayer, religious rituals, sacraments, worship services, breathing, and guided meditation.
- Help with life changes or losses.
- Devotional resources in many traditions and languages.

Spiritual Care at Boston Children's Hospital (BCH)

- Chaplains are in the hospital 8 a.m. to 5 p.m. and are on call at any other time.
- Call (617) 355-8095 or call the page operator at (617) 355-6363 and ask them to page a chaplain. A staff member can also page a chaplain for you.
- All are welcome to visit the multi-faith chapel on Hale 1. The chapel is always open.
- Look under *Family Resources* on the BCH website: www.childrenshospital.org**.**

Spiritual Care at Jimmy Fund Clinic (JFC) & The Center for Spiritual Care at Dana-Farber

- A chaplain is on site at the JFC Mondays and Fridays 8 a.m. to 4 p.m. and is on call during all other clinic hours.
- Call (617) 632-5778 or call the page operator at (617) 632-3352 and ask for the on-call chaplain. A staff member can also page a chaplain for you.
- All are welcome to visit Dana-Farber's multi-faith chapel on Floor 2 of the Yawkey Building. The chapel is always open.
- Learn more at www.dana-farber.org/spirituality.

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