



**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**

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**SCAN ME**



## Your Child's Healthcare Team

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The healthcare teams at the Dana-Farber Jimmy Fund Clinic (JFC) and Boston Children's Hospital (BCH) will work together to care for your child and support you.

**Clinic Day:** \_\_\_\_\_

**Attending Physician:** \_\_\_\_\_

**Fellow:** \_\_\_\_\_

**Nurse Practitioner/ Physician's Assistant:**

\_\_\_\_\_

**Clinical Coordinator (BCH):** \_\_\_\_\_

**Nurse Director/ Nurse Manager (JFC):**

\_\_\_\_\_

**Nursing Team (BCH):** \_\_\_\_\_

**Nursing Team (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

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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 Dana-Farber Cancer Institute's Jimmy Fund Clinic (DFCI) will care for your child.

- Inpatient care is at Boston Children's Hospital
- Outpatient care is at Dana Farber's Jimmy Fund Clinic, 3<sup>rd</sup> Floor of the Dana Building

## Your Healthcare Team

The healthcare team caring for your child includes:

- **Nurses** work closely with you and all members of the team to plan and carry out your child's care. They also teach and support you.
- The **Nurse Manager/Clinical Coordinator** oversees daily clinical and administrative needs
- The **Nurse Director** leads and manages the oncology and blood disorder programs
- **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 team of Hematology/oncology/stem cell transplant clinicians work together to manage your child's care. The team includes an **Attending Physician, Fellow, Resident, Nurse Practitioner, and Physician Assistants**. They will provide direct medical treatment and talk with you about your child's daily care.
- 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 can help you with services you may need
- **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** can help your child with physical strength during treatment
- **Occupational Therapists** can help your child maintain or return to normal daily activities

## Frequently Used 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
9 Northwest	(617) 355 8096
Hale Family Center for Families	(617) 355 6279
One Mission 6th floor Resource Room	(617) 355 5645
9 <sup>th</sup> floor Resource Room	(617) 355 7684
Child Life Services	(617) 355-6551
Blood Donor Center	(617) 355 6677
Financial Office (Billing)	(617) 355-3397
International Office	(617) 355-5209

### Brigham and Women's Hospital

Radiation Oncology	(617) 732 6310
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#### 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.

# 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

## Visiting a Patient

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

- Only 2 people (including caregivers) are allowed with a patient at a time. One of the people must be over the age of 18.
- 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 contact the security office at (617) 355-6121.

## Patient Rooms

- Do not touch the IV pump settings 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
  - Incoming calls are free
  - Phone calls made to area codes 617, 508, and 781 are free

Inpatient Care at Boston Children's Hospital (BCH)

- There is a washing machine and dryer on the 6<sup>th</sup> 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 Hematopoietic Stem Cell Transplant (HSCT) 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 delivered 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 healthcare 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

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This family education 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/demolition sites

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

Your child only needs testing if your healthcare 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 healthcare team if you have any questions about your child's infection risk or about these guidelines.

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

<b>Children considered <i>high risk</i> are not allowed to go to outdoor spaces at Boston Children's</b>	
<b>Children with cancer</b>	<ul style="list-style-type: none"><li>• Acute lymphoblastic leukemia (ALL) patients in all phases of therapy except continuation</li><li>• Acute myeloid leukemia (AML) patients in all phases of therapy except acute promyelocytic leukemia (APML) post-induction</li><li>• Relapsed ALL and relapsed AML patients in all phases of therapy</li><li>• Advanced stage non-Hodgkin's lymphoma (NHL), recurrent NHL, or recurrent Hodgkin lymphoma treated with intensively myelosuppressive chemotherapy</li></ul>
<b>Children with immunodeficiency</b>	<ul style="list-style-type: none"><li>• Severe combined immunodeficiency (SCID) patients</li></ul>
<b>Children with a hematopoietic stem cell transplant (HSCT)</b>	<ul style="list-style-type: none"><li>• All allogeneic HSCT patients (regardless of ANC)</li><li>• Autologous HSCT patients less than 60 days after their transplant</li></ul>
<b>Children with bone marrow failure</b>	<ul style="list-style-type: none"><li>• Severe aplastic anemia children getting ATG/cyclosporine treatment</li></ul>
<b>Children with solid organ transplant</b>	<ul style="list-style-type: none"><li>• No restrictions unless they are severely immunosuppressed and neutropenic</li></ul>

**Who to Call for Patient Care**

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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.

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

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## 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

- 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 late or very early for your appointment, you will be seen when a healthcare provider is available
- If you are going to be late for your child's appointment, call the front desk at (617) 632-3270
- If told to do so, please apply a topical anesthetic (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
  - Things that your child may need for the day (change of clothes, diapers, formula or special food)

## At the Clinic

- Check in at the Jimmy Fund Clinic (JFC) front desk
  - If your child seems unwell, let the front desk staff know right away
- Your child will be given an identification wristband to wear. Please make sure your child wears 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 healthcare team.
- After check-in, please stay in the waiting area
  - Stem cell transplant patients should not wait in the main waiting room. You will be seen in a private isolation room or in a regular clinic room.
- 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 healthcare 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

Dana-Farber/Boston Children's Cancer and Blood Disorders Center  
Pediatric Oncology Teaching Sheet

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

- 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 while in the clinic
- Children under 18 need to be watched by their caregiver at all times. If you must leave the clinic for at most 15-30 minutes 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.

## Checking Out of the Jimmy Fund Clinic

- When your healthcare team has cleared you to leave clinic for the day:
  - Go to the front desk to schedule any future appointments
  - Look carefully at the dates and times of all scheduled appointments
  - Return the RTLS badge to a frog drop box in the clinic when you leave →



## Who Can Come to Clinic

- Two adult caregivers may come with a child to clinic
- Anyone who is sick cannot come to clinic
- When possible, only bring to clinic your child receiving treatment
  - All children under 18 must be watched by their caregiver at all times. There is no childcare available for siblings in clinic.
  - There is not a lot of extra space at the clinic. Please think about that as you decide who comes with you.
- If your child is on precautions in a private infusion room:
  - All visitors must stay in the patient room
  - Caregivers may leave the patient room but must wash their hands before and after entering common areas such as the hallway, resource room, activity room, and kitchen.

## Clinic Areas

- The Playroom is where you can find toys, games, and other activities
- The Teen Area is where teens and young adults can spend time together while in clinic
- The Blum Pediatric Resource Room is where you can find books and information. There is also art, music, and other activities there for your family.
- Nourishment Centers (for snacks and drinks) are in the waiting area and infusion area

### 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.
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## Clinical Trials

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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 determine 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 healthcare team will talk with you about different options and any concerns you may have.

- You will be asked to sign an informed consent that gives a full explanation of 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 healthcare team would talk with you about a new treatment plan
- At any point you may choose to stop your child's participation in a clinical trial

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## When to Call Your Healthcare 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:

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

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 healthcare team if it is ok

### If your child's temperature is:

- **Lower than 96.8 F (36.0 C)** →
- **101.3 F (38.5 C) or higher** →
- **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  
healthcare team  
right away.**



- **Weekdays 8 a.m. to 5 p.m.**  
**(617) 632-3270**
- **After 5 p.m. and on  
weekends and holidays:**
  - ◇ **call page operator**  
**(617) 632-3352**
  - ◇ **ask for the pediatric  
oncology or stem cell  
transplant provider on  
call**
- **For life threatening  
emergencies 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

°C	°F
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

## **Diagnostic Tests, Scans, and Procedures**

Before any test or procedure, your healthcare team will explain what to expect and answer any questions you may have. During some tests, caregivers can be there to comfort their child. Some procedures may require sedation or general anesthesia.

For more information about diagnostic tests, scans, and procedures, please visit: <https://www.childrenshospital.org/conditions-treatments>

### **Audiogram**

A simple test in which a child wears headphones and listens for sounds, measuring how well they hear. This test may be given before and after certain treatments.

### **Biopsy**

The collection of 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, the liquid in the center of bones that produces white blood cells, red blood cells, and platelets. 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 nuclear medicine imaging test to look at the bones for disease, fractures, or infection. A small amount of radioactive dye is given through an intravenous (IV) line before the scan. Several hours later, the image is taken. To take the image, the 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 healthcare team with diagnosis and treatment. Your child will have to lie still on a table. In many cases, children have to swallow a contrast dye or receive one by IV. The contrast helps the healthcare team see more in the images.

### **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). A child lies still on their back for this test.

Diagnostic Tests, Scans, and Procedures

**Electrocardiogram (EKG or ECG)**

A test that measures heart rhythm and the rate of the heartbeat. Small stickers will be placed on the child's arms, legs, and chest. The stickers are connected to clips and wires on a machine that will record heart rhythm and rate. A child must lie still during the test.

**Gallium Scan**

A test in which a child is given an IV injection of a radioactive isotope that is only absorbed by certain tissue types. There is no risk from the radioactive isotope. After about 3 days, pictures will show where possible cancer cells are in the body. More pictures are often needed 2-4 days later.

**Glomerular Filtration Rate (GFR)**

A nuclear medicine test to measure kidney function. It is done before and after some chemotherapy treatments. A radioactive dye is given by IV and then followed by timed blood collections to measure how much dye stays in the blood. Because the kidneys remove waste from the blood, the test can tell how well the kidneys are working by measuring how quickly the dye is removed from the blood.

**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)**

A diagnostic imaging test to identify and measure if there are abnormal cells throughout the body. 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. A contrast dye is often given by IV. It helps the healthcare team see more in the images.

**MIBG Study**

A test that uses images and a tiny amount of radioactive liquid to help find certain types of cells in the body. After about 24 hours, pictures will be 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. During the scan, the child lies still on a table.

**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 your child's body using high frequency sound waves. Ultrasound does not use radiation. Your child will lie still for this test.

Diagnostic Tests, Scans, and Procedures

**X-Rays**

An x-ray takes a picture of your child's bones and organs using a small amount of radiation. Your child may be asked to sit or lie on a table or stand and stay still for the time needed to take the picture.

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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.

## Tips for 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 there to help.

### Before Medical Care

- Work with the healthcare 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.
- Give your child simple, honest information about what is going to happen. Tell them what they can expect to see, hear, smell, taste, and feel. Being honest lets them know they can trust you.
- Give lots of praise for any effort they make to try
- Give your child choices and control when possible, like letting them choose which arm to use for an injection

### 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.
- Hold their hand or rub their arms, legs, or head. Touch is comforting for some children.
- Comfort items help some children, like blankets, stuffed animals, a toy, or a 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 how they feel. Assure them that they are safe ("It's ok to be scared, but you are safe.")
- 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
- Have your child try blowing bubbles 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. For distraction:

- 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

Helping Your Child with Medical Care

## 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 can talk about it, ask what went well for them and what could be done in a different way in the future

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# Complete Blood Counts

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

When blood counts are at a normal level, your child's body can effectively fight infection, maintain normal energy, and prevent bleeding. Having lower than normal blood counts may affect your child's ability to participate in regular activities. If you have questions, ask your healthcare team.

Blood counts often drop 7-14 days after the start of each treatment cycle. This is called bone marrow suppression (or **myelosuppression**). The lowest point the blood cell counts reach after chemotherapy is called the **nadir**. Low blood counts may delay treatment and may require blood and/or platelet transfusions. These transfusions are given at the hospital or clinic.

Talk to your healthcare team about any questions or symptoms your child may have.

## 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**. There are 2 laboratory tests that are done to measure the number and function of RBCs.

- **Hemoglobin** shows how much oxygen the red blood cells are able to carry to different parts of the body
- **Hematocrit** is the percentage of red blood cells in the blood
- If the red blood cells drop below a certain level or your child has symptoms of anemia, your child may need a red blood cell transfusion

Signs and symptoms of anemia:

- Feeling tired
- Pale skin
- Shortness 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.

## Complete Blood Counts

### 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)

Your child may bruise more easily during normal activities when their platelet count is low.

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

- Do not give your child medications that contain aspirin or ibuprofen unless ordered by the healthcare team. These drugs can make platelets less effective.
- Try to avoid nicks (small cuts), cuts, and tears in the skin
- Be very careful when cutting nails to avoid nicks
- If you shave, use an electric razor
- If riding a bike, wear a helmet

### White Blood Cells

When your child's white blood cell (WBC) count is low, your child is less able to fight infections. Several types of WBCs help the body fight infections. A test called a **differential** looks at the different types of white blood cells in your child's blood count.

- WBCs that fight germs that can cause an infection are called *Neutrophils*, *Bands*, *Monocytes* and *Lymphocytes*. Certain types of lymphocytes make antibodies to help fight infection.
- WBCs that respond during an allergic reaction are called *Basophils* and *Eosinophils*.

The **absolute neutrophil count (ANC)** is the total number of neutrophils and bands 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 is an important number for two reasons:

- The ANC often determines when chemotherapy can be given
- The ANC determines when your child is neutropenic and at greater risk for infections

Your child may be told to avoid certain activities that would put them at greater risk for infection.

#### To help protect against infection:



- Clean hands often with hand sanitizer or soap and water. Always wash hands before eating and after using the bathroom. Always wash hands with soap and water if you can see they are dirty.
- Avoid crowds and indoor places such as shopping malls, movie theaters, airplanes, and houses of worship
- 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.
- Wear gloves when doing any activity that might dry or damage your skin by causing cuts of any kind, even small ones
- 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



Complete Blood Counts

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

The normal ranges listed below are for people who are healthy. The range for your child depends on their age and their disease.

Cell Type	Normal (in healthy people) 	Low (may need attention) 
White blood cells (WBC)	5,000 – 10,000	ANC <500
Red blood cells (RBC)	Hemoglobin (Hgb) 11 – 14 Hematocrit (Hct) 31% – 43%	<7  <20%
Platelets	150,000 – 450,000	10,000 – 20,000

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- For life threatening emergencies call 911.

## Giving Your Child Medication

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When giving your child medicine, always follow the directions given to you by your child's healthcare team.

### Medication Types

There are some medications that you may be asked to give your child at home. Ways to give these medications are described below. Medicines are 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 with head turned for 2 minutes so the medicine will be absorbed

#### 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 eye ointments before bedtime or at naptime since the child's vision will be blurred for a while

To give your child eye medications:

1. Place the 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 apply 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 healthcare 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 your pharmacy or hospital. Do not use a regular spoon. Pour the exact amount listed on the prescription.

#### 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.

## Giving Your Child Medication

### 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.

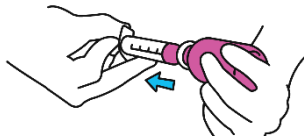
### Tablets/Capsules/Pills

- If your child cannot swallow pills, talk to your healthcare team about other options
  - Always check with your healthcare team or pharmacist before you crush, cut, or dissolve pills
  - If you are going to crush a pill, it is easiest to use a pill crusher
  - Use a pill cutter to break a pill in half, or into smaller pieces if that is easier for your child to swallow
- 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 healthcare team to see if you should give the medication again
- If your child will not take the medicine, call your child's healthcare team

## Giving Medication by Mouth

### For babies (under 1 year old)

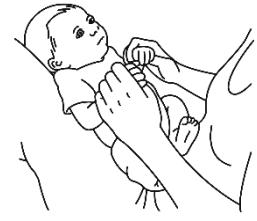
Give your baby liquid medicine using a medicine dropper, syringe, or baby bottle nipple:



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

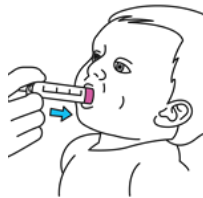


2. Screw the cap back on the bottle. Put it out of your baby's reach.



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.



## Giving Your Child Medication

### 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 Medication 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 Medication 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.
- 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.
- 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!"
- Be careful that 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.

## Giving Your Child Medication

### General Information

- If your child has a life-threatening allergy, they should always wear allergy identification
- Keep all medicine out of the reach of children and pets
- Many medications interact with other medications. Keep with you a list of all your child's medicines (prescription, herbal medicines, natural products, supplements, vitamins, over-the-counter). Give this list to your child's healthcare team.
- Talk with your child's healthcare team before giving them any new medicine, including over-the-counter, herbal medicines, natural products, or vitamins
- All patients are strongly encouraged to use birth control if sexually active. Talk to your healthcare team as some chemotherapy medications may cause birth defects or decrease your ability to have children (infertility).
- Unless you are told otherwise, an oral dose of medication should be repeated only if your child vomits within 30 minutes of taking the drug. If they vomit more than once in the 30 minutes after taking the drug, call your healthcare team.

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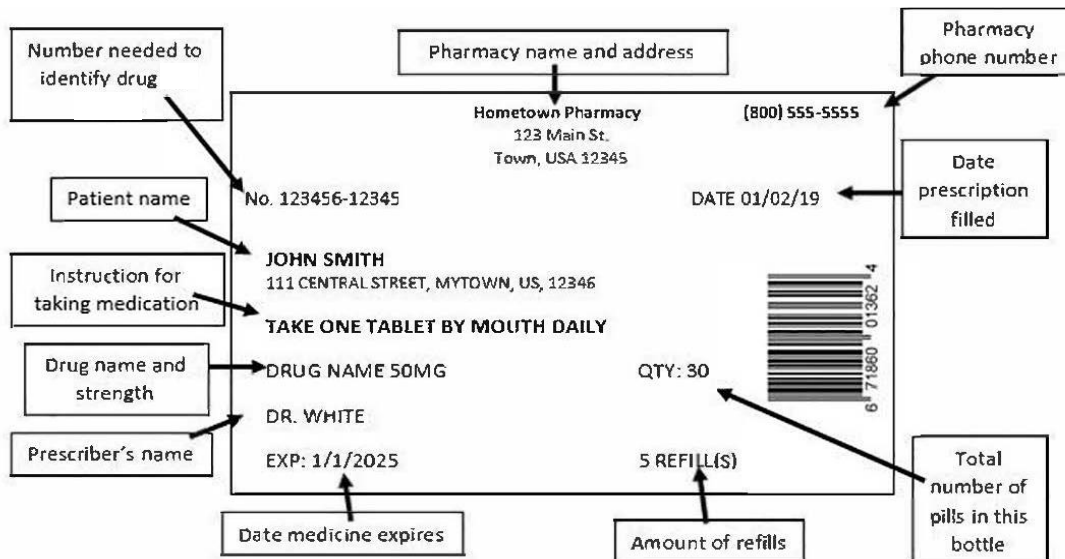
## Refilling Your Medication

When you need a refill, please call your pharmacy **before** a medication runs out, even if you have a scheduled clinic appointment. Refills may take 48 hours to be filled.

- If you do not have refills of a medication you need, call the Jimmy Fund Clinic at (617) 632-3270 during clinic hours at least 48 hours before the medication runs out. Ask to reach the prescription refill line. Leave a message with:
  - Your name
  - Your child's name
  - Your phone number
  - Name of the medication to be refilled
  - Location and phone number of your pharmacy
- 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

## 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

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It is important for everyone to take precautions (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:

- Always read the label on the bottle and follow the directions
- 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
- Anyone preparing or giving chemotherapy medications must first wash their hands and put on medical gloves. Always wear medical gloves when handling chemotherapy.
- Before you mix any oral chemotherapy medication, empty a capsule, or crush or cut tablets, put a disposable cloth or paper towels on the table or counter
- When opening a capsule to mix with food or liquid, wear a mask
- 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.
- If you have unused oral chemotherapy pills (tablets or capsules), please return them to the pharmacy where the prescription was filled. Do not flush them down the toilet, dump them in the sink, or throw them 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 healthcare team or the homecare 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 healthcare team if the eye gets red or irritated

Chemotherapy Safety at Home

**If chemotherapy gets on the skin:**

- Wash the skin thoroughly with soap and water for 15 minutes
- Call your healthcare 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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## Ondansetron (on DAN se tron)

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**Other Name:** Zofran®

**Uses:** Ondansetron is used to prevent or lessen nausea. It is given by mouth or through an IV.

### Common Side Effects

- Headache
- Dizziness
- Drowsiness
- Diarrhea (more common when taken by mouth)
- Constipation
- Weakness or twitching
- Dry Mouth

### Rare Side Effect

- Faster or irregular heartbeat (when given by IV)

### Important Things to Know About This Drug

- Dose should be given 30 minutes before starting chemotherapy or 60 minutes before radiation to help lessen nausea
- Unless you are told otherwise, an oral dose of medication should be repeated only if your child vomits within 30 minutes of taking the drug. If they vomit more than once in the 30 minutes after taking the drug, call your healthcare team.

### General Information

- If your child has a life-threatening allergy, they should always wear allergy identification
- Keep all medicine out of the reach of children and pets
- Many medications interact with other medications. Keep with you a list of all your child's medicines (prescription, herbal medicines, natural products, supplements, vitamins, over-the-counter). Give this list to your child's healthcare team.
- Talk with your child's healthcare team before giving them any new medicine, including over-the-counter, herbal medicines, natural products, or vitamins

#### 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.

# Trimethoprim and Sulfamethoxazole

## (trye METH oh prim and sul fa meth OKS a zole)

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**Other names:** Bactrim™, Septra™

**Uses:** Trimethoprim and Sulfamethoxazole are antibiotics that treat many different types of infections caused by bacteria. The combination is used to prevent lung infections/pneumonia in immune-compromised patients. It may be given by mouth, or by IV injection.

It is likely that your child will continue to take this until they are 6 months off of therapy.

### Common Side Effects

- Skin sensitivity to light
- Low blood counts (white blood count, red blood count, platelets)
- Platelets and white blood cells may take longer to recover
- Skin rash, hives, itching

### Less Common Side Effects

- Abnormal kidney function tests
- Abdominal (belly) pain
- Diarrhea
- Nausea and vomiting

## Important Things to Know About This Drug

- Drink more fluids than usual while taking this medication and take with small amounts of food
- If you see any signs of allergic reaction (rash, itching, hives), stop the medication right away and call your healthcare team
- If giving the liquid form, shake well before giving it to your child
- Use sunscreen (SPF 30 or higher) and wear sun-protective clothing when outdoors
- Unless you are told otherwise, an oral dose of medication should be repeated only if your child vomits within 30 minutes of taking the drug. If they vomit more than once in the 30 minutes after taking the drug, call your healthcare team.

## General Information

- If your child has a life-threatening allergy, they should always wear allergy identification
- Keep all medicine out of the reach of children and pets
- Many medications interact with other medications. Keep with you a list of all your child's medicines (prescription, herbal medicines, natural products, supplements, vitamins, over-the-counter). Give this list to your child's healthcare team.
- Talk with your child's healthcare team before giving them any new medicine, including over-the-counter, herbal medicines, natural products, or vitamins

Trimethoprim and Sulfamethoxazole

**Who to Call for Patient Care**

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## Allergic Reactions

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An allergic reaction may include itching, rash, hives (one or more small red bumps that appear on the skin), difficulty breathing, 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 several doses
- Right away during an infusion or several 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 healthcare 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 healthcare team
- They should wear an allergy identification 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 develops itching, a rash, or hives, call your healthcare team

### Who to Call for Patient Care

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  - Solid tumor, neuro oncology, hematologic malignancy patients: Call (617) 632-3352 and ask for the pediatric oncology provider on call.
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- For life threatening emergencies call 911.

## Constipation

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Constipation is when stool becomes hard and bowel movements become difficult or less frequent. Certain foods and medicines, especially pain medications, may cause constipation.

### Things That May Help

- Drink plenty of fluids, such as water, sports drinks, or juice
- Eat food with fiber, such as shredded wheat, oatmeal, bran, whole wheat breads and cereals, beans, nuts, dried fruit, vegetables, and fresh fruit
- Try to be active
- Take stool medications as ordered by your healthcare team

### When to Call

Call your healthcare team if your child has:

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

#### Who to Call for Patient Care

- Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270
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  - 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.
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## Diarrhea

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Diarrhea is having loose stool or more bowel movements more often. There are many causes of diarrhea, including some medications or infection. Diarrhea may cause dehydration or skin breakdown in the rectal area.

**Before giving your child any medication to treat diarrhea, talk to your healthcare team.**

### Things That May Help

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

### When to Call

- If your child has a change in their normal stooling or has loose stools more than 4 times in 8 hours
- 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 less than 1 year old and has not had anything to eat or drink for 6 hours while awake
  - If your child is more than 1 year old and has not had anything to eat or drink for 8 hours while awake

#### Who to Call for Patient Care

- Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270
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## Fatigue

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Fatigue is a feeling of being more tired than usual. 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 for your child to focus, think, or make decisions.

### Causes of Fatigue

- Treatments such as chemotherapy, other medications, radiation, or surgery
- Changes in bloodwork results
- Disruption of sleep routines or daily activities
- Stress, anxiety, worry, sadness, or fears

### Things That May Help

- Regular short rests
- Allowing flexibility in your child's routine
- Regular 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
- Discuss concerns with your healthcare team

#### 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.
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## Fever and Neutropenia

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Fever and neutropenia are common side effects of some types of treatment. Because of your child's high risk of infection, it is very important to call your healthcare team right away if your child has a fever.

If your child has **Neutropenia**, this means they have less white blood cells (*neutrophils*). Neutrophils are important to fight infection. If your child has an absolute neutrophil count (**ANC**) of less than 500 and a fever, they will need IV antibiotics to treat a possible infection.

### When your child is neutropenic, the following may be signs of infection:

- Skin feels warm to touch
- Feeling tired
- Body ache
- Cough or difficulty breathing
- Redness, swelling, or warmth where there is an injury, wound, or IV site
- Stomach pain
- Mouth sores
- Diarrhea or rectal pain with bowel movement
- Feeling dizzy, confused, or weak

### Who to Call for Patient Care

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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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## **Fever and Non-Neutropenia**

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Your child was seen for a fever on \_\_\_\_\_ and does **not** have neutropenia. This means that they have enough white blood cells now to fight infection.

You may give acetaminophen (Tylenol) every **4-6 hours** as needed until \_\_\_\_am/pm on\_\_\_\_\_.

**If your child has another fever of 38.0 C (100.4 F) or higher more than 24 hours after being seen by the healthcare team, please call the Jimmy Fund Clinic right away at (617) 632-3270.**

If you have a new concern or see a change in your child that worries you, call the Jimmy Fund Clinic. For life threatening emergencies call 911.

### **Who to Call for Patient Care**

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## Hair Loss

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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 healthcare 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 healthcare team.

#### Friends' Place

1<sup>st</sup> floor, Yawkey Building, Dana-Farber  
Weekdays 9 a.m.-5 p.m.  
(617) 632-2211

### Who to Call for Patient Care

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## Mouth Care

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

- Children under 6 years old should have their mouth care done by an adult caregiver
- Children over 6 years old should brush their teeth with a soft toothbrush after each meal and before bed
- Electric soft toothbrushes can be used
- Rinse your child's mouth with water often to keep it moist
- How much toothpaste to use:
  - Children 3 and under, put a small smear of fluoride toothpaste on the brush
  - Children ages 3-6, put a pea size drop of fluoride toothpaste on the brush
  - Children over 6 years old, put about 1 inch of toothpaste on brush
- Do not use a mouthwash that contains alcohol. They are very drying to the mouth.

## Dental Visits

Patients should see a dentist regularly. Scheduling a dental appointment depends on blood counts and treatment, and an antibiotic may be needed. Speak to your healthcare 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). If mouth sores are painful or make it hard for your child to eat or drink, call your healthcare team.

Your child's mouth or tongue may look red or have white spots. Please let your healthcare team know if you see this. White plaques (small raised areas) can develop, an infection known as *thrush*. Your healthcare team will prescribe medicine to treat it.

## 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

## When to Call

Call your healthcare team if your child:

- Cannot drink fluids
- Has white spots (plaques) in their mouth
- Cannot swallow
- Is in pain

### Who to Call for Patient Care

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## Nausea and Vomiting

Chemotherapy and radiation therapy can cause nausea and vomiting. How much nausea and vomiting your child may experience depends on the treatment they are receiving. Nausea and vomiting can be helped by medications called **antiemetics** (anti-nausea medications).

- Acute nausea may start right away after treatment
- Delayed nausea may start hours or days after completing chemotherapy
- Some chemotherapy medications can cause both acute and delayed nausea
- Anticipatory nausea (before treatment) can develop for some children and adolescents when they think about coming to the hospital or clinic

### 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.
- Sea-bands are wristbands with a small button that puts pressure at a point on the wrist, which may help control nausea
- Try relaxation and distraction methods like deep breathing and imagery. You can find relaxation apps on a phone or tablet.

### 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 healthcare 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 less than 1 year old and has not had anything to eat or drink for 6 hours while awake
  - If your child is more 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

#### Who to Call for Patient Care

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  - Solid tumor, neuro oncology, hematologic malignancy patients: Call (617) 632-3352 and ask for the pediatric oncology provider on call.
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# Nutrition Therapy During Treatment

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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 healthcare 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 healthcare team or dietitian.

## 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. In addition to growth, we want to use nutrition to help them:

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

## 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 that can be given to help increase appetite. These medications are not right for everyone and your healthcare 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 you examples and help you find ones that 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 healthcare team and dietitian will work with you to develop a plan that meets your child's needs.

Nutrition Therapy During Treatment

- **Parenteral Nutrition Support or IV Nutrition**

For children in the hospital who may have symptoms like diarrhea (loose stools), mucositis (sores along the gastrointestinal tract), or severe nausea or vomiting, your healthcare 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 receiving care 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

### Who to Call for Patient Care

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## Managing Nutrition-Related Side Effects

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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
- taste changes
- vomiting
- weight gain
- weight loss

### General Tips

- If you have questions or concerns about your child's eating, drinking, or growth, please ask your healthcare 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
- 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 healthcare team will talk about these options with you if they might be right for your child.

### Not Hungry or No Appetite

- Give 5 or 6 small meals or snacks throughout the day
- Encourage higher calorie and protein-rich foods, like nuts and seeds (without shells), lean meats, eggs, and full-fat dairy
- Keep nutrient-dense snacks like nuts and seeds (without shells), protein bars, and nut or seed butters with crackers easily available. Give a snack before bedtime.
- At meal and snack times, have your child eat solid foods first. Filling up on fluids before eating can make your child feel full and less interested in eating solid foods.
- Give sips of high-calorie drinks like whole milk, smoothies, shakes, frappes, or fortified non-dairy alternatives (like soy milk) after meals and snacks throughout the day.
  - **Note:** Your child may develop lactose intolerance. This is temporary (it will not last). If they do, try giving them Lactaid® milk and/or Lactaid® tablets when eating dairy products like milk, ice cream, and cheese. Ask your dietitian about fortified non-dairy products if needed.
- Set times for your child to eat meals and snacks, with family or friends when possible. Try setting an alarm as a reminder that it is time to eat.
- 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.

### 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

### Managing Nutrition-Related Side Effects

- 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 healthcare 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 fortified 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 potassium, such as coconut water, bananas, and peeled potatoes
- Offer foods high in sodium, such as 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
- Add butter, gravy, sauces, or dressings to moisten foods
- Avoid hard, rough, acidic, salty, and spicy foods
- Offer nutrient-dense liquids such as whole milk, shakes, smoothies, or whole milk drinkable smoothies for extra nutrition when your child is eating less solid food

## Taste 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 mask "metallic" tastes
- Encourage good, regular, gentle tooth brushing

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

### 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:
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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.



## 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)
- Irritability (getting annoyed, upset, or frustrated) over small things
- Verbal aggression (yelling)
- Physical aggression (hitting, slamming doors)
- Child not acting like themselves
- Hard time making decisions
- Attention difficulties
- Hyperactivity
- Confusion or hallucinations

Tell your healthcare team right away if while taking steroids your child seems confused, has hallucinations, has unbearable insomnia (cannot sleep), hurts themselves or others, or is doing things that get in the way of their medical 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 around you to reduce unnecessary stressors
- 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
- Avoid trying to reason with your child while they are having a tantrum
- Hold and comfort your child to prevent them from hurting themselves
- 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

#### Who to Call for Patient Care

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## Pain

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Pain has many causes, and it can be short term (acute), long term (chronic), or related to procedures (procedural). Your healthcare team will try to lessen pain during treatment and procedures. Most pain can be helped with coping methods and medications.

### How Children Show Pain

Children show pain in different ways. Many will say when they are in pain. Others will get tense, squirm, make a face, make fists with their hands, pull up their legs, moan, cry, or scream. It can be hard to comfort them.

### 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 them.

- Talk to your child using simple, everyday language, giving them as much information as you feel they can handle and that is right for them
- If you know how your child shows they are uncomfortable, share that with the healthcare team
- Help your child get in a comfortable position
- Help your child think about other things by singing softly, telling stories, counting, or playing on a tablet
- Use breathing exercises such as blowing bubbles 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
- Ask for help from Child Life staff who can work with you and your child to find what works best for them

For more help with pain management that does not include medications, ask your healthcare team about a Psychology Pain Consultation.

If your child will be having orthopedic surgery as part of their treatment, ask about a COPE consult before surgery to help manage pain after surgery.

### Medications

Your healthcare team will work with you to figure out what is causing your child's pain and the best medical treatment plan for it. The pain treatment plan will be made for your child's age, weight, tolerance, and what seems best for your family.

For more help with medications for pain, ask your healthcare team about a consultation with PACT (Pediatric Advanced Care Team) or the Acute Pain Service.

## Common Questions About Pain

- **Can babies feel pain?** Yes, babies and even newborns feel pain.
- **Can children describe pain?** Children as young as 18 months old have words for pain. Children as young as 3 years old can usually describe how much it hurts by answering "a little" or "a lot."
- **Is pain medicine dangerous?** Before prescribing any medications, your healthcare team will discuss the risks and benefits with you. Taking pain medication can help children sleep better, heal, and prevent complications. However, pain medicine can sometimes cause constipation, nausea, or drowsiness.
- **Should I worry that my child or teenager could become addicted to pain medicine?** Pain medication is often a necessary part of treatment because many diseases cause pain, and the treatment can also cause painful side effects. Many children and teens may need opioids during treatment and are not at risk for addiction when the medicine is taken as prescribed. Our bodies recognize the need for the medication, and it will be safely weaned off or stopped if no longer needed. Ask your healthcare team if you have questions.
- **What should I do if my child's pain continues?** Ask the healthcare team for help if your child continues to have pain.

### 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.

## Skin Care During Treatment

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

Some common skin changes during treatment are:

- Dryness or peeling
- Increased sensitivity to sunburns
- Rashes or open areas that may be slow to heal
- Irritation in the area around the anus, vagina, or penis
- Dry, chapped lips
- Redness or darkening of the skin
- Risk of skin infections

### Things That May Help With Side Effects

- Take a bath every day with a gentle, scent-free soap
- Always check with your healthcare team before using any kind of medicated cream, ointment, or lotion
- If your child is receiving radiation therapy 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 areas of broken skin
- Drink a lot of fluids

### Sun Protection

Protection from the sun is very important when receiving chemotherapy, radiation, after hematopoietic stem cell transplant (HSCT), or when taking certain medications.

**Use sunscreen** even on cloudy days and when around 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 and 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 exposed skin 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

### Skin Care

#### Outdoor Activities

- Limit time in the direct sun, especially between 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 choose to use self tanners, remember they are NOT sunscreens, unless the product says that it contains SPF

#### 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, which is a tiny tube or needle that is put into a vein, usually in the arm.

Your child may get a blood transfusion if they don't have enough red blood cells or platelets. Donated blood is divided into parts (red cells, platelets, and plasma) to help as many children as possible.

- **Red blood cells** carry oxygen and are given to treat anemia, or if there is a lot of bleeding
- **Platelets** help stop bleeding by plugging holes in blood vessels
- **Plasma** is the clear liquid part of blood that also helps stop bleeding

### Possible Risks of a Blood Transfusion

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

#### Transfusion reactions

The most common side effects (these happen in 1-5% of people who get transfusions) are mild rashes, hives, itching, and sometimes a fever. These usually get better without treatment. Rarely, someone has a more serious reaction. This can be either a severe allergic reaction (trouble breathing) or red blood cells breaking down too fast (*hemolysis*).

#### Infectious risks

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 becoming infected with one of these viruses is extremely small.

#### Metabolic problems

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

#### Immunologic problems

White cells in a blood transfusion may cause a rare complication called transfusion-associated graft-versus-host disease (GVHD). Since blood from someone else is different than your child's own blood, your child's body may respond by making antibodies against the transfused red cells or platelets. This may lead to a need for more transfusions.

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## Immunizations

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### Talk to your provider before your child receives any vaccines.

While your child is on treatment, they should receive vaccines for flu and Covid if eligible. Other routine vaccines are not recommended. This is because they are not likely to be effective. Your child should never receive live vaccines while undergoing treatment.

Examples of live vaccines are:

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

### Flu (Influenza) Shots

- All patients and others they live with should get a flu shot each year
- Parents, siblings, and caregivers can get flu shots from their own healthcare provider or at flu shot clinics
- 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.

### Immunizations for Siblings

In general, brothers and sisters of patients can get all the routine vaccines required for healthy children.

Until 60 days after autologous stem cell transplant, or until 3 months after all immunosuppressive medications have been stopped for allogenic stem cell transplant 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 chicken pox

**Hematopoietic stem cell transplant (HSCT) patients** must tell their healthcare team if anyone in their household recently got the chickenpox vaccine and developed a rash from it.

#### Who to Call for Patient Care

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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.

- Chickenpox usually starts with a fever and feeling very tired (similar to flu symptoms)
- 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 another 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 caregiver recently got the shingles vaccine, or plan to get the shingles vaccine, please talk to your child's healthcare team.

Shingles can be painful and cause a deep burning feeling. This usually 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 healthcare team right away if your child has been around someone with chickenpox or shingles, even if they got the vaccine.

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

### Treatment

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

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

#### Who to Call for Patient Care

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## Infection Control

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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 or affect the body's ability to make more of those cells. Below are ways to help your child avoid infections.

### Hand Washing

Washing your hands is the best way 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 blow your nose, cough, or sneeze
  - After you go outdoors
  - After you touch produce (fruits and vegetables)
  - 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
  - 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
- 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 within 2 hours
  - 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
- Let the school nurse know that your child may be at an 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 healthcare team right away
- If your child has been exposed to someone with a contagious illness, call the healthcare team right away

Infection Control

- 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 may not come into the house
  - Your child should not bathe, brush, or clean up after their pet
  - Cats may not sleep on your child's bed
  - Litter boxes should not be 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, 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
- 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 in the hospital at all times.

### Who to Call for Patient Care

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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.

## 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* are most at risk since it is hard for the body to fight infections. Neutropenia means they have less white blood cells (neutrophils).

### 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
- Check the internal temperature of cooked dishes in several places with a food thermometer to make sure the food is cooked completely:
  - 160 F (71.1 C) for beef, lamb, veal, pork, and egg dishes
  - 170 F (76.6 C) for stuffing and casserole
  - 180 F (82.2 C) for chicken and turkey
- 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 no more than 2 days and reheat until hotter than 165 F (73.8 C)

### 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

### Who to Call for Patient Care

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## Emotional Support for the Whole Family: Pediatric Psychosocial Oncology

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A serious illness can be hard for the whole family. Patients, parents, siblings, and other caregivers may feel all kinds of emotions. Our experts in Pediatric Psychosocial Oncology are 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 Cancer and Blood Disorders Center, a clinical social worker or psychologist will meet with your family to get to know you and to talk about what psychosocial services may be useful. You may also meet with a resource specialist about eligibility for financial resource assistance programs. Psychiatrists are also available if needed.

### We can help your family:

- Adjust to the illness
- Talk about the diagnosis
- Cope with treatment and its side effects
- Manage mood changes and behavioral challenges
- Learn to ease stress and anxiety
- Address school concerns
- Support siblings
- Connect to support groups or other psychosocial programs
- Make 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 financial concerns about your child's care at Dana-Farber/Boston Children's, 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 [www.danafarberbostonchildrens.org/psychosocial](http://www.danafarberbostonchildrens.org/psychosocial) for more information.

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## Integrative Therapy

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Integrative therapy (also known as *complementary therapy*) includes healing options and therapies 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.

### Tips

- Anyone who offers integrative therapy should be licensed or certified
- Ask your healthcare team about integrative therapies you are interested in trying
- Integrative therapies are often not covered by insurance companies. If you may want to do integrative therapies in the community, ask your insurance provider what they cover.

### For Patients

- When outpatient at Dana-Farber, the Zakim Center for Integrative Therapies and Healthy Living at Dana-Farber offers a variety of therapies, including acupuncture and massage. The Zakim Center's group programs (movement classes, creative arts workshops, music programs, and mindfulness meditation) are free for Dana-Farber patients ages 15 and up and their family members and caregivers. You can see the monthly group program calendar at [www.dana-farber.org/zakimcalendar](http://www.dana-farber.org/zakimcalendar). For more information or to schedule an appointment, call (617) 632-3322 or email [zakim\\_center@dfci.harvard.edu](mailto:zakim_center@dfci.harvard.edu).
- Your child may be able to get free, short massage therapy sessions while in the Jimmy Fund Clinic (JFC). Ask your healthcare team for information. Music therapy is available in the JFC Resource Room.
- When inpatient at Boston Children's Hospital (BCH), please have your healthcare team contact the Hematology/Oncology/Hematopoietic Stem Cell Transplant Integrative Therapies team with a referral. Free services for BCH patients include reiki, relaxation massage, yoga, and meditation. Music therapy is also available. Ask Resource Room staff or your Child Life specialist for information.

### For Caregivers

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

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## The Sibling Program

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Siblings of children with serious medical illnesses face many challenges. It is important to care for them and address their needs as part of care for the whole family. Dana-Farber's Sibling Program is committed to helping siblings and to creating a better experience for all affected by a child's illness.

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 connect 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 are available 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 everything 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 difficult, such as spending 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 suggestions 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
- Have times of extreme productivity (over-achievement)
- 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.
- Provide as much positive feedback as possible
- 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 the parent(s) or guardian(s)

To learn more about the Sibling Program, or to access any of the above supports, please [fill out the online registration form](#) and visit our website [www.dana-farber.org/sibling-program](http://www.dana-farber.org/sibling-program).

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## Spiritual Care

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Spirituality is an important source of strength, comfort, and hope for patients and families. Interfaith chaplains are available for spiritual and emotional support at both Dana-Farber and Boston Children's Hospital. Patients and their families guide chaplains to support their spiritual needs.

### Chaplains

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 a variety of 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](http://www.childrenshospital.org)

### Center for Spiritual Care at Dana-Farber/Jimmy Fund Clinic (JFC)

- 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.
- See the Dana-Farber website for more information: [www.dana-farber.org/spirituality](http://www.dana-farber.org/spirituality)

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