



**Dana-Farber**  
Cancer Institute



**Boston**  
**Children's**

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

# **Educational Guide for Oncology Patients and Families**

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## Your Child's Medical Team

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

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

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

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

\_\_\_\_\_

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

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

**Psychosocial Clinician (BCH):** \_\_\_\_\_

**Psychosocial Clinician (JFC):** \_\_\_\_\_

**Nurse Manager/Clinical Coordinator (BCH):**

\_\_\_\_\_

**Nurse Director (JFC):** \_\_\_\_\_

### Contact Us

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

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

# Guide for Hematology/Oncology Patients and Families

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## WRITING AND EDITING COMMITTEE

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**Carole Atkinson, MS, PNP-BC, CNRN**

Neuroscience Clinical Nurse Specialist  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Caroline A. Costello, MBA, BSN, RN, CPON®, BMTCN®**

Education Coordinator, Hematopoietic Stem Cell Transplant Program  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Colleen Gerrity, MSN, RN, CPHON®**

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

**Colleen Nixon, MSN, RN, CPHON®**

Hematology/Oncology Clinical Educator  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Daniel Wallace, RN, BSN, BA**

Jimmy Fund Clinical Case Manager  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Deborah Bond Berk, LICSW**

Senior Clinical Social Worker, Sibling Program Director  
Division of Pediatric Psychosocial Services Department of Psychosocial Oncology and Palliative Care  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Elizabeth Mullen, MD**

Attending Physician, Assistant Professor of Medicine  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Kristin Barton, MA, CHES**

Program Administration Manager II  
Patient & Family Education | Health Literacy | Communications  
Clinical Education & Informatics  
Boston Children's Hospital

**Martha Young, MS, CCLS**

Program Manager, Patient and Family Education  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Molly Shanahan, RN, BSN, CPHON®**

Staff Nurse I, Hematology/Oncology  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

**Robyn Blacken, BSN, RN, CPHON®, BMTCN®**

Program Nurse, Hematopoietic Stem Cell Transplant Program  
Dana-Farber/Boston Children's Cancer and Blood Disorders Center

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

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

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

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

Outpatient care is provided at Dana-Farber Cancer Institute:

- Jimmy Fund Clinic, 3<sup>rd</sup> floor of the Dana Building 617-632-3270

## Health Care Team

**The specialized health care team caring for your child includes:**

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

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

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

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# Inpatient Care at Boston Children's Hospital (BCH)

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## Information for Caregivers

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

## Visiting a Patient

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

## Visiting a Stem Cell Transplant Patient

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

## Patient Rooms

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

## Patient and Family Common Areas

### Activity Room & Family Resource Centers

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

### Food Service

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

### Nourishment Center

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

### **Interpreter Services**

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

### **Pastoral Care**

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

## **Contact Us**

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Business Hours 8 a.m. to 5 p.m., Monday through Friday
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Page pediatric hematology/oncology fellow on call
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## Outpatient Care in the Jimmy Fund Clinic at Dana-Farber Cancer Institute

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

### Clinic Hours:

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

### Before you arrive to clinic:

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

### While in the clinic:

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

### Outpatient Care at the Jimmy Fund Clinic

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

#### Checking out of the Jimmy Fund Clinic:

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

#### Visiting a Patient

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

#### Clinic Areas

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

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## **Inpatient Chemotherapy Admissions at Boston Children's Hospital (BCH)**

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All patients that are scheduled for inpatient chemotherapy at BCH will first be seen in the Jimmy Fund Clinic (JFC) for an evaluation by their healthcare provider. Once your provider approves the start of chemotherapy, the JFC charge nurse communicates with the BCH coordinator of patient placement (COPP) to confirm bed availability.

It is important to be aware that even though your child's admission has been scheduled, there may not be a room available if the hospital is full. If a room is not available, your clinic nurse will keep in frequent contact with BCH and keep you updated throughout the day. If a room is not available by late afternoon, there will be a plan given to you recognizing the importance of your child's treatment.

When a room is available:

- the nurse caring for your child in the JFC will inform you and arrange for transfer to BCH
- your child's nurse at the JFC will provide a report to the BCH nurse regarding what treatment your child has received in clinic
- chemotherapy will be started in the JFC depending on the time of day, the length and type of treatment

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## Family Centered Rounds

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

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

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

During Family Centered Rounds:

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

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

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## 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. New trials are planned based on the results of past trials and what we know about the disease and treatment.

Clinical trials have different phases. Each phase 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 revised treatment plan with standard treatment.

As with all treatment options, your healthcare team will speak with you about different options or any concerns you may have.

- You will be asked to sign an informed consent; this document gives you a full explanation of the clinical trial.
- If for any reason the treatment plan is found not to be the best for your child, the plan will be changed.
- At any point you may choose to end your child's participation in a clinical trial.

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## When And How To Call Your Healthcare Team

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### Call the Jimmy Fund Clinic if your child has:

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

## Emergencies:

**Call 911** immediately if your child has

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

## Monday – Friday, 8:00am to 5:00 pm:

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

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

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

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

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

## Less urgent medical questions

### 1. Prescription refills:

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

### 2. Home health or VNA services:

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

### 3. Tests and studies:

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

### 4. Health care and supply company services:

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

### 5. Division of Psychosocial Oncology and Palliative Care:

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

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

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

## **Frequently Used Numbers at Boston Children's Hospital**

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

## Diagnostic Tests, Scans and Procedures

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Your healthcare team will always explain the procedure to you and answer any questions you may have prior to any test. Parents are able to comfort their child during some tests. Some procedures may require sedation, general anesthesia or an operation.

### **Audiogram**

A test that measures hearing at different volumes of sound. This test may be given before and after certain treatments.

### **Biopsy**

A collected sample of tissue which is later examined for abnormal cells. There are three types of biopsies used to collect tissue samples:

#### **1. Needle Biopsy**

- A method used to diagnose whether abnormal cells are present by inserting a needle through the skin. Your child may feel pressure or discomfort when the needle is inserted. We usually use sedation or general anesthesia to help relax your child and use a local anesthetic to numb the needle insertion site.

#### **2. Minimally Invasive Surgery**

- A method of collecting a sample of the tissue through a small incision. It usually requires sedation or general anesthesia to make your child more comfortable.

#### **3. Surgical Biopsy**

- A method of collecting tissue performed in the operating room. General anesthesia will be used during the procedure.

### **Bone Marrow Aspiration and Biopsy**

A method 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 your child's hip bone. The sample is then examined for abnormalities or to monitor your child's response to treatment. This procedure is usually performed in the clinic, treatment room of the hospital, or the operating room. Your child will receive sedation or general anesthesia.

- For an aspiration, a needle is placed in the hip and a syringe is used to withdraw a sample of the bone marrow.
- If a biopsy is done, a small sliver of bone is taken from the same insertion site.

### **Bone Scan**

A nuclear medicine imaging test to look at the bones for disease, fractures or infection. Your child will receive a small amount of radioactive dye through an intravenous (IV) line before the scan. Several hours later, you will return for the image. Your child will lie on the table below a large camera that will move slowly around your child's body. Your child may be

asked to move into different positions but will have to remain still during the image for the best picture.

### **Computerized Axial Tomography (CAT Scan or CT Scan)**

A CAT or CT scan is a radiology test that uses a type of x-ray equipment and computers to take pictures of the body. The detailed images from a CT scan helps healthcare providers diagnose and treat your child. Your child will have to lie still on a moveable table. In many cases, children will have to swallow and/or receive a contrast by IV to help the healthcare provider better see certain body areas.

### **24-hour Urine Test**

A test to measure how well the kidneys are working by collecting all of your child's urine in a container. You will need to save all of your child's urine for exactly 24 hours. The lab can calculate your child's creatinine clearance using the collected urine to measure your child's kidney function.

### **Echocardiogram (echo)**

An echo is a test that uses sound waves (ultrasound) to make pictures of your child's heart and its chambers, veins and arteries (blood vessels). Your child will lie on his or her back and will need to remain still.

### **Electrocardiogram (EKG or ECG)**

An EKG or ECG is a test that can measure electrical activity of the heart. It will record the heart rhythm and the rate of the heartbeat. Small stickers will be placed on your child's arms, legs, and chest. These are connected to clips and wires leading to a machine that will record your child's heart rhythm and rate. Your child will be asked to remain still.

### **Gallium Scan**

Your child will receive a radioactive isotope injected by IV that is only absorbed by certain tissue types. After about 72 hours, pictures will show where these cells are present within the body. There is no risk to your child from the radioactive isotope. Often, more pictures are needed 2-4 days later.

### **Glomerular Filtration Rate (GFR)**

A GFR is a nuclear medicine test which measures kidney function. It is done before and after some chemotherapy treatments. Your child will receive a radioactive dye by IV and then have a series of timed blood collections to measure how much radioactive dye remains in the blood. Because the kidneys remove waste from the blood, the test helps understand how well the kidneys are working by measuring how quickly the radioactive dye is removed from the blood.

### **Lumbar Puncture (LP)**

An LP, also called a spinal tap, is a procedure that collects a sample of cerebrospinal fluid (CSF), which surrounds the brain and spinal cord to determine the presence of cancer cells or progress of treatment. A special needle will be inserted between the bones (vertebra) of your child's lower back into the space that has the cerebrospinal fluid. If your child needs chemotherapy into the cerebrospinal fluid, it will be injected slowly through the needle that is already in place. The procedure is usually done in the clinic, the treatment room of the

Diagnostic Tests, Scans and Procedures

hospital, or operating room, and your child will receive procedural sedation or general anesthesia.

**Magnetic Resonance Imaging (MRI)**

An MRI is a diagnostic imaging test that uses a magnet and radio waves to take pictures of organs and tissues inside the body. It can be used to identify and measure the presence of abnormal cells throughout the body. Your child will lie on a table and will be provided with hearing protection. Your child will be asked to remain still for between 20 and 90 minutes. Your child will be placed inside a tunnel-like machine. The machine is very noisy. Often, children will have to receive a contrast dye by IV to help the healthcare provider better see certain areas of the body.

**MIBG Study**

An MIBG Study (<sup>123</sup>I-MIBG study) uses images and a tiny amount of radioactive liquid to help find certain types of cells, particularly those that are found in neuroblastoma and pheochromocytoma, in the body. After about 24 hours, pictures will be taken to identify where activity is occurring within the body. During the imaging, your child lies still on a table with cameras above and below. The camera comes close to your child but doesn't touch your child. Your child will need to remain still during the study.

**Positron Emission Tomography (PET Scan)**

A PET Scan is an imaging test that produces three dimensional images of the body. This test provides information about how the body functions. During the PET Scan, your child will be asked to lie on a table and remain still.

**Pulmonary Function Tests (PFTs)**

PFTs evaluate how well the lungs work by measuring how much air the lungs can hold and how well your child can blow the air out.

**Ultrasound**

An ultrasound is a test that uses high frequency sound waves to provide images of the inside your child's body. Ultrasound does not use radiation. Your child will be asked to remain as still as possible.

**X-rays**

An X-ray takes a picture of your child's bones and organs using small doses of radiation. It can be used for many reasons. Your child may be asked to sit or lie on a table or stand and remain still for the time needed to take the x-ray.

For more information about diagnostic tests, scans and procedures, please visit:

<http://www.childrenshospital.org/conditions-and-treatments>

**Contact Us**

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## **Tips for Helping Your Child with Medical Care**

It is our goal is to make any necessary procedures your child may have, as stress free as possible. There are different strategies that parents and staff can use to help children learn to better cope with medical care. The following recommendations may be helpful.

- Make a plan ahead of time whenever possible
- Comfort your child by holding hands, rub legs, back, arms, or offer a favorite stuffed animal to hold
- Help your child feel understood by acknowledging their feelings
- Give lots of praise (for any attempt to try)
- Provide reinforcement or rewards when appropriate
- When possible, give your child choices
- Encourage your child to learn and try different techniques
- Keep your focus on your child
- If your child prefers to focus on the medical procedure rather than be distracted, give reassuring, simple information
- Share your ideas with the team on how best to support your child

### **Breathing Techniques**

- Encourage slow, deep breaths
- Blow a pinwheel, bubbles or imaginary birthday candles
- Practice types of relaxation breathing, such as belly breathing

### **Imagination**

- Develop a story using a favorite character (TV, book, pet or a favorite activity)
- Use different senses in your story – smell the flowers, hear the wind, taste the candy

### **Distraction**

- Focus on things like pop-up books, light up toys or things that make sound
- Sing along with a favorite song or TV show
- Try using an ipad (favorite show, game or new app)
- Use humor, if it does not annoy your child
- Talk with your child about recent or upcoming activities that they enjoy or are excited about.
- Remind your child that when this is over they can do something they enjoy.

### **Encouraging Statements**

- Make statements that are short, true, easy to repeat, and will comfort your child:
  - ❖ “You are doing a good job staying still”
  - ❖ “This is almost done”

Members of your healthcare team may be trained in these techniques and can teach you ways to help your child cope with medical care. If you would like additional suggestions, reach out to your Psychosocial Provider or a member of the Child Life/Music Therapy Team.

Tips for Helping Your Child with Medical Care

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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 and are checked frequently during treatment.

When blood counts are at a normal level, your child's body can effectively fight infection, maintain normal energy, and prevent bleeding. Please discuss any questions you may have about your child's participation in activities with your healthcare provider.

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

## Blood Cells

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

## Red Blood Cells

Red blood cells (RBCs) are the cells which carry oxygen through the body and give us energy. If you have a low number of red blood cells, it is called **anemia**. There are two laboratory tests that are done to measure the number and function of red blood cells.

- Hemoglobin shows how much oxygen the red blood cells are able to carry to the organs and tissues.
- 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 require a red blood cell transfusion.

Signs and symptoms of anemia:

- feeling tired- It may make your child feel better to take short rest periods between activities when your child's red blood cell count is low.
- pale skin
- shortness of breath
- headache
- fast heart rate

## Platelets

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

Signs and symptoms of low platelets may include:

- bruising
- bleeding
- small purple dots called petechiae (pah-teek-e-i)

## White Blood Cells

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

- Neutrophils, Bands, Monocytes and Lymphocytes-fight germs, like bacteria, that can cause an infection. Certain types of lymphocytes make antibodies to help fight infection
- Other types of WBCs respond during an allergic reaction. These WBCs 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:

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

## 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. If hands are visibly soiled, they must be washed with soap and water.
- Avoid crowds and enclosed places such as shopping malls, movie theaters, airplanes, and houses of worship.
- Avoid sick people.
- Shower or bathe daily.
- Wash skin immediately with soap and water if there is a nick, cut or burn. Bandage the cut if necessary. Change bandage daily until cut is healed.
- Wear gloves when doing any physical activity that might dry or damage your skin by causing cuts or nicks or tears.
- Avoid going barefoot.
- Use cuticle cream remover instead of picking, tearing or cutting cuticles.
- Never use rectal thermometers/medications.
- Do not clean out litter boxes, birdcages or fish tanks. Avoid all contact with animal urine or stool.
- Women should not use tampons or douche.
- Use sunscreen (SPF 30 or higher) and wear protective clothing when outdoors.

## To Help Minimize Risk of Bleeding when Platelet Count is Low:

- Do not take medications containing aspirin or ibuprofen unless ordered by the healthcare provider. These drugs can make the platelets less effective
- Try to avoid nicks, cuts, and tears in the skin.
- Be very careful when cutting nails to avoid nicks.
- If you shave, use an electric razor.
- wear helmet if riding a bike.

Be sure to talk to your healthcare provider about any questions or symptoms your child may have.

## CBC Summary

The normal ranges listed below are approximate. The normal range for your child will vary by the age of your child.

<u>Cell Type</u>	<u>Normal</u>	<u>Decreased Level</u>
White blood cells (WBC)	5,000 – 10,000	<500=neutropenia
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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# Medications

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## Medication Types

### Liquids

- Liquid medicine should be measured exactly using an oral syringe, medicine cup or measuring spoon from your pharmacy or hospital, not a regular spoon.

### Tablets/Capsules/Pills

- Always check with your healthcare provider or pharmacist before crushing or dissolving pills.
- It is easiest to use a pill crusher when crushing a pill.
- Use a pill cutter to break a pill in half, or if smaller pieces are easier for your child to swallow.

### Intravenous Medications (IV)

- An IV medication is given directly into a vein through a Central Venous Catheter line (CVC). Some patients require medication to be given this way in the home setting. If needed, your healthcare team will help to coordinate and teach you proper technique for this administration.

### Eye Medications: Drops and Ointments

- Place the infant or small child lying down on his/her back. The older child may sit up with head tilted back.
- Ask the child to look up.
- Use one hand to pull the lower lid down, making a little "cup" and apply the solution or ointment into the "cup".
- Keep the medication clean. Do not touch the tip of the bottle or tube with your hands or touch to the child's eyes.
- If possible, give eye ointments before bedtime or at naptime, since the child's vision will be blurred for a while.

### 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 getting their ear drops.
- Keep your child lying flat with head turned for approximately 1-2 minutes so the medicine will be absorbed.

### Subcutaneous Injection

- A subcutaneous injection is given using a small needle placed under the skin. If your child requires a subcutaneous injection, you may be taught the technique so that you can give them to your child.

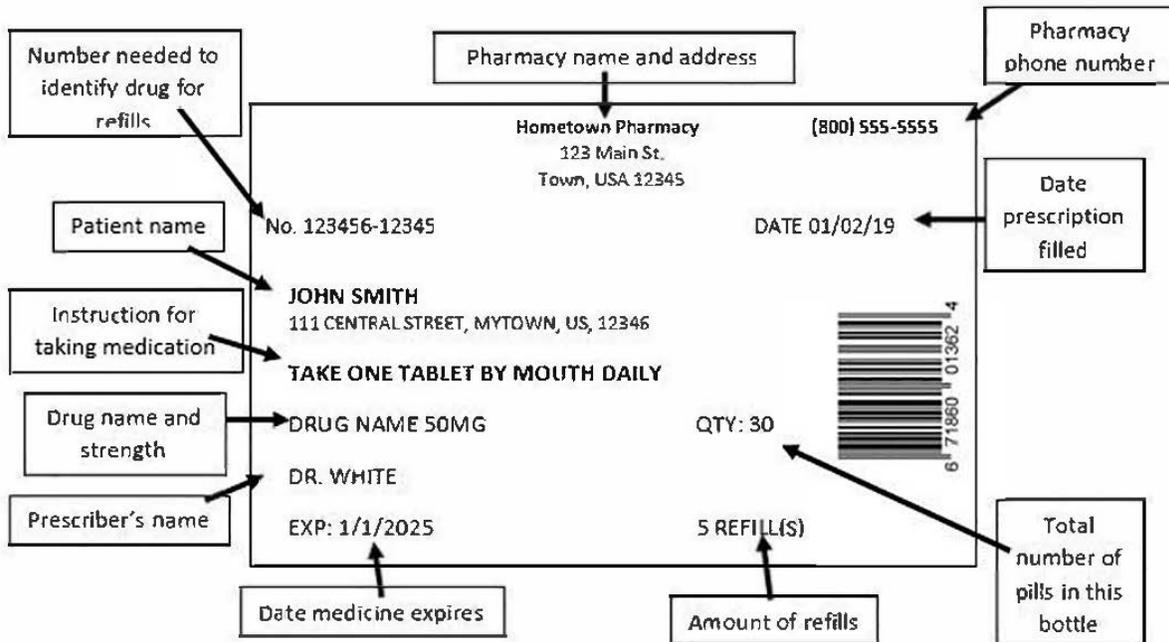
Medications

**Rectal Medications**

Medicines are not given rectally during treatment.

**Reading a Prescription Label**

It is important to always read the prescription label carefully every time you pick up your medications from the pharmacy. If you have any questions or concerns, ask your pharmacist.



**GUIDE ON HOW TO READ A PRESCRIPTION LABEL**

## Medications

### Refilling your Medication

- Ask about refills during regular appointments.
- If refills are available and you need more medication, call your pharmacy.
- Remember to call for a refill before the medication runs out. Refills may take 48 hours to be filled.
- If you do not have refills of a medication you need during regular clinic hours, call the Jimmy Fund Clinic at least 48 hours before your child will need to have their medication refilled and ask to be transferred to the prescription refill line. Leave a message with:
  - your name
  - your child's name
  - a call back number
  - which medication needs to be refilled
  - the location and phone number of your pharmacy
- If you do not have refills of a medication, and you have an urgent need after clinic hours, page the pediatric hematology/oncology fellow on call.
- Always read a prescription label each time you pick up a refill from the pharmacy.

### General Information:

- If your child has a life-threatening allergy, he/she should wear allergy identification at all times.
- Keep all medicine out of the reach of children and pets.
- Many medications interact with other medications. Keep a list of all your child's medicines (prescription, herbal medicines, natural products, supplements, vitamins, over-the-counter) with you. Give this list to your child's healthcare provider.
- Talk with your child's healthcare provider before giving him/her any new medicine, including over-the-counter, herbal medicines, natural products, or vitamins.
- All patients are strongly urged to use birth control if engaging in sexual activity. Talk to your health care provider as some chemotherapy medications may cause birth defects or decrease your ability to have children.
- An oral dose of medication should be repeated only if a patient vomits within 30 minutes of taking the drug. If your child vomits more than once during the 30 minutes after taking the medication, call your child's healthcare provider.

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## Chemotherapy Safety

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It is important for everyone to take precautions when storing, preparing or giving chemotherapy. Once chemotherapy medications are given, they pass through the body and are in blood, urine, stool, and vomit. Safety precautions should be followed when your child is receiving chemotherapy and for 48 hours after the last dose.

### To safely prepare oral chemotherapy medications, follow these precautions:

- Always read the label on the outside of the bottle and follow the directions.
- When handling or preparing these medications and take precautions to minimize contact with your child's bodily fluids during the time the medicine is being given and for 48 hours after.
- Anyone handling chemotherapy medications must wash their hands and put on disposable gloves to prepare and/or give oral chemotherapy medications.
- Place disposable cloth or paper towels on work surface (counter/table) when mixing any oral chemotherapy medication, emptying a capsule, or crushing or cutting tablets.
- When opening the capsule to be mixed with food or liquid, wear a mask and protective eyewear. Find a place that is free of air flow, away from a window or fan to prevent blowing the powder.
- Crush or cut the tablet with a pill crusher or cutter.
- Wash the surface and pill crusher or cutter with soap and water.
- Keep these medications away from areas where food is prepared and 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 down the toilet, dump in the sink, or throw away in the trash.

### Chemotherapy (intravenous) medications that are given through an IV:

When at home follow these precautions:

- A new pair of medical gloves should always be worn when touching IV chemotherapy medicines, infusion pumps and equipment for flushing IV lines.
- If IV tubing becomes loose or disconnected, put on a pair of gloves and clamp the IV tubing. A call should be placed to your healthcare provider and/or the homecare company.
- Gloves, bags and tubing containing chemotherapy should always be placed in a plastic chemotherapy waste bag or container provided by the company who supplied the infusion pump.
- All expired and/or unused chemotherapy should be placed in a sealed plastic bag and be returned.

## Chemotherapy Safety

### **Everyone caring for your child while he/she is receiving chemotherapy should take the following precautions for 48 hours after the last dose of chemotherapy:**

- Wear gloves when disposing of stool and urine.
- Close the lid and flush the toilet twice to prevent possible spray/splash of chemotherapy.
- Wear gloves when handling diapers. Diapers should be placed in a separate bag and thrown away with regular trash.
- Wash hands with soap and water after removal of gloves.
- Pregnant caregivers should avoid handling patient body waste.

### **Eye contact with chemotherapy medication**

If chemotherapy comes in contact with the eye, irritation may occur.

- Rinse the eye with large amounts of water for 15 minutes.
- Contact your doctor if irritation or redness develops.

### **Skin contact with chemotherapy medication**

If chemotherapy comes in contact with the skin, irritation or rash may occur.

- Put on medical gloves.
- Wash the skin thoroughly with soap and water for 15 minutes.
- Contact your doctor if irritation or redness develops.

### **Clothing or bedding that comes in contact with chemotherapy medication or body fluids**

- Put on medical gloves.
- Remove all clothing.
- Immediately place the items in the washer separate from other laundry. If you do not have a washer, place the laundry in a plastic bag until it can be washed.
- Consider using a plastic cover to protect your mattress.

### **Chemotherapy medication spills on the floor or other surfaces**

- Put on medical gloves.
- Keep people and pets away from the spill until the clean up is finished.
- Use wet (with water) paper towels for cleaning powder spills.
- Use a dry paper towel for liquids.
- Wash the area thoroughly with soap or other household cleaner.
- Place all paper towels used to clean up the spill and any additional supplies used to wash the area in a plastic bag. It can be disposed of with regular trash once in separate bag.
- Remove gloves while avoiding contact with the skin and place in a plastic bag.
- Wash hands with soap and water.

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## **Giving Your Child Medication by Mouth**

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When giving your child medication, always follow the directions given to you by your child's prescriber, such as a doctor or nurse practitioner.

### **Quick tips**

- Be calm and use positive words when giving the medication. Praise your child for being cooperative or helpful.
- Never call the medicine "candy." This can make it seem like a desirable treat.
- Always store medication out of your child's reach.

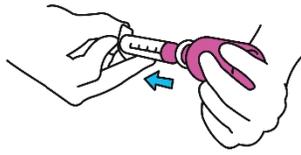
### **What if I have problems giving my child medication?**

- If your child cannot swallow pills and the medicine does not come in a liquid, ask your child's pharmacist if the pills can be crushed. **Not all pills can be safely crushed or cut.**
- If the pharmacist says your pills can be crushed, **ask your pharmacist what food to mix the crushed pill with.** It's important to ask your pharmacist about this because some foods may change the medication's effect.
  - If your pharmacist says it's OK, crush 1 dose in a bowl with the back of a spoon and mix with a small amount (such as 1 to 2 Tbsp.) of the recommended food. Give the mixture right away.
- If your child throws up right after taking the medication, read the medication information sheet you were given or call your child's prescriber to see if you should give the medication again.
- If your child will not take the medicine, call your child's prescriber.

### **Giving medication to babies (under 1 year old)**

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

Giving Your Child Medication by Mouth



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



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



5. 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 the mouth and repeat.



6. 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.

## Using a nipple:

1. Follow steps 1 through 3 for "How to give medication using a dropper or syringe" (see first page).
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 or swallow all the medicine.

## Giving medication to children (ages 1-3 years)

- **Just before giving your child the medicine, 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 household 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 to keep your child from choking.

### Giving Your Child Medication by Mouth

- **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. Let your child choose a drink.
- **Children 2 years or older can also take oral-disintegrating tablets.** 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 taking the medicine?"

## Giving medication to children (ages 4–6 years)

- **Ask your pharmacist what drinks your child can take the medicine with. Let your child choose a drink.** Give your child choices such as, "Do you want to take your medicine with water or juice?"
- **Explain to your child why this medicine is needed** and how it will help him or her feel better.
- Children this age can usually take liquid medication or a chewable medication 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 cupcake sprinkles) toward the back of the tongue and let it melt.
- Have your child take sips of water with the candy on the back of the tongue and swallow it.
- Slowly work up to having your child swallow larger pieces of food or candy. Then try a small pill.
- Try mixing the pill with a small amount (such as 1 to 2 Tbsp.) of food that your pharmacist recommends. Give the mixture 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 throughout the process. 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.

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## Ondansetron (on DAN se tron)

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**Other name:** Zofran®

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

**Your child may experience the following common side effects:**

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

**Your Child may experience the following rare side effect:**

- Faster and/or irregular heartbeat (IV)

### Special Instructions:

- Dose should be administered 30 minutes before starting chemotherapy or 60 minutes prior to radiation to help lessen nausea.

### General Statements:

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

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# 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. It is used to prevent lung infections/pneumonia in immune compromised patients. It may be given by mouth, or by IV injection.

**Your child may experience the following 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

**Your child may experience the following less common side effects:**

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

### Special Instructions:

- Drink increased amounts of fluids while taking this medication and take with small amounts of food
- If any signs of allergic reaction are present: rash, itching and/or hives, stop the medication immediately and notify your health care provider
- If giving the liquid form, shake well before administering
- Use sunscreen (SPF 30 or higher) and wear protective clothing when outdoors

### General Statements:

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

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

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

## Contact Us

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

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

## 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 and/or facial swelling. Medications, blood products, latex, food or things in the environment may cause allergic reactions. Your child will be observed for any symptoms of an allergic reaction when in the clinic or hospital.

### **An allergic reaction may happen:**

- During the first dose of medication or after several doses.
- Immediately or after several hours.

### **If your child has an allergic reaction:**

- Medications can be given to prevent a reaction or lessen symptoms.
- If your child has a reaction, he/she may be given medicines to prevent similar reactions in the future.
- The medicine that caused the reaction may be changed or given in a different way.

### **If your child has a life-threatening allergy:**

- They should wear an allergy identification band at all times.
- Keep a record of your child's allergies and previous reactions (including medications and blood products).
- Inform your child's health care provider of your child's allergies.

## When to call

- If you are at home and notice any difficulty breathing or facial swelling, **call 911.**
- If your child develops itching, a rash, or hives, call your healthcare provider.

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## Constipation

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

### Some things that may help:

- Drink plenty of fluids.
- 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 exercise and stay active.
- Take stool medications as ordered.

### When to call us:

- If your child has no stool for 2 days.
- If your child has abdominal pain that disrupts normal activity.
- If your child has pain when trying to stool (have a bowel movement).

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## Diarrhea

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Diarrhea is an increase in the frequency of bowel movements or a decrease in the form of stool (greater looseness of stool). Diarrhea can occur for many reasons and may be caused by certain medications or infection. Diarrhea may lead to dehydration or skin breakdown.

**Before giving your child any medications to treat diarrhea, talk to your healthcare provider.**

### What may help:

- Offer small amounts of fluids at least every 2 hours.
- Avoid milk or dairy, apple or grape juice, spicy-hot foods, and fried or fatty foods.
- Clean rectal area well after each stool and apply ointment.
- If your child is breast-feeding, you may continue nursing.

### When to call:

- If your child has a change in their stooling routine or has more than 4 diarrhea stools within 8 hours.
- If your child has signs of **dehydration**, such as:
  - A decrease in urination (peeing) or no urination for 6-8 hours
  - Fewer than 4-6 wet diapers a day
  - If your child is younger than 1 year old and has not had anything to eat or drink for 6 hours while awake.
  - If your child is older than 1 year and has not had anything to eat or drink for 8 hours while awake.

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## Fatigue

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Fatigue can be described as feeling more tired than usual. The fatigue that comes with cancer and treatment is different from the fatigue of daily life because it might last longer and rest does not always help.

At times your child may not have the energy to attend school or participate in activities with family and friends. It may also be difficult for your child to concentrate or make decisions.

### **Fatigue may be caused by:**

- Treatments such as chemotherapy and other medicines, radiation, and /or surgery
- Physical factors such as change of routines in sleeping or daily activities
- Mental or emotional factors such as stress, anxiety, worry, sadness, or fears

### **What may help:**

- Frequent short rest periods
- Allow changes to your child's routine
- Regular light exercise
- Developing a normal sleep routine
- Eating a well balanced diet
- Sometimes medications are used to help relieve symptoms of fatigue
- Discuss concerns with your healthcare team

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## Fever and Neutropenia

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Fever and neutropenia is a common complication of cancer treatment. Because of your child's increased risk of infection, it is very important to call your healthcare provider right away if your child has a fever.

**Fever** is considered a temperature of 101.3°F (38.5°C) or higher, or 100.4°F (38.0°C) or higher twice within a 24-hour period.

**Neutropenia** is a decrease in the infection-fighting white blood cells called neutrophils. If your child has an absolute neutrophil count (ANC) of less than 500 and a fever, treatment with IV antibiotics will be started.

When your child is neutropenic, the following **signs and symptoms** may indicate infection:

- Increased skin temperature
- Feeling tired
- Body aches
- Cough or shortness of breath
- Redness, swelling, or warmth at the site of an injury, surgical wound or IV site
- Abdominal pain
- Mouth sores
- Diarrhea/rectal discomfort with bowel movement
- Feeling dizzy, confused or weak

### What to do:

- Check your child's temperature but never rectally.
- **Do not give any fever reducing medicine until you have spoken to your healthcare provider.**
- If your child has a temperature of **101.3 F (38.5C)** or higher, call the Jimmy Fund Clinic immediately.
- If your child has a temperature between **100.4 F (38 C)** and **101.2 F (38.4C)** recheck the temperature in one hour.
- In one hour, if your child's temperature is greater than or equal to **100.4 F (38 C)**, call immediately.
- If your child's temperature is greater than **100.4 F (38 C)** after that one hour or again within 24 hours, call immediately.
- If your child has a port-a-cath, it will be accessed for blood work and antibiotics upon arrival to clinic or ED. If your child uses a topical anesthetic prior to port-a-cath accesses, please apply at home prior to arrival to clinic or ED.

## Fever and Neutropenia

During clinic hours, call the Jimmy Fund Clinic and ask to speak to the triage nurse for further instructions. After clinic hours, page the on call pediatric oncology fellow by calling the page operator.

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## Hair Loss

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Hair loss (Alopecia) can be caused by chemotherapy and radiation treatment. Hair loss may begin about 14-21 days after receiving chemotherapy. Hair loss can range from slight thinning to complete baldness and may occur anywhere on the body. For most patients hair will grow back; sometimes the texture or color may be different.

Some people may choose to wear scarves, hats or a wig. If your child wants a wig, it is helpful to choose one before their hair falls out. Insurance companies or other resources may help cover the cost.

If you are interested in a wig, please make an appointment with the Friend's Place at Dana Farber. Please note that fitting wigs is by appointment only.

Friends Place

1<sup>st</sup> floor, Yawkey Building at DFCI- Monday through Friday 9am-5pm

(617) 632-2211

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## Mouth Care

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

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

## Dental Visits

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

## Mouth Sores

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

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

## Some things that may help:

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

## When to call:

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

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## Nausea and Vomiting

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Chemotherapy and radiation therapy can cause nausea and vomiting. The amount of nausea and vomiting your child may experience depends on the treatment they are receiving. Nausea and vomiting can be eased by medicines called *antiemetics* (anti-nausea medications).

- Acute nausea may occur right away
- Delayed nausea may occur hours or days after completing chemotherapy
- Some chemotherapy medications may cause both to occur
- Anticipatory nausea may occur for some children/adolescents when thinking about coming to the hospital or clinic

### Some things that may help

- Try giving small sips of cold, clear liquids
- Try to eat small meals throughout the day
- Avoid strong odors or spicy foods. The smell of food and perfumes may make your child feel sick
- Sea-bands are wristbands with a small button, which put pressure at a point on the wrist, which may help control nausea
- Relaxation techniques and distraction methods can include: deep breathing, imagery, phone/tablet relaxation apps

### When to call

- Nausea or vomiting does not stop after taking antiemetics
- If your child has signs of dehydration such as:
  - ❖ a decrease in urine or no urination for 6-8 hours
  - ❖ for a baby or toddler, fewer than 4-6 wet diapers a day
  - ❖ not able to eat or drink for 6-8 hours while awake
- If you see blood in the vomit

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## Nutrition Therapy During Cancer Treatment

Nutrition is an important part of your child's cancer treatment. But eating might be hard for your child because of the side effects of medications, chemotherapy, or radiation therapy. These side effects may include:

- constipation (difficulty pooping)
- diarrhea (loose poop)
- mouth sores
- nausea
- taste changes
- vomiting (throwing up)
- weight gain
- weight loss

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 - low levels of a type of white blood cell (ANC less than 500) - are especially at risk since it is hard for the body to fight infections.

### Food Safety Guidelines

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

- **Wash your 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** longer than two hours.
- **Throw away milk or formula that has been at room temperature longer** than one hour.
- **Check the internal temperature of cooked dishes in several places** with a food thermometer to make sure the food is cooked completely.
  - **We recommend:**
    - 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
- Use a cooler with ice or ice packs to keep food cold when you're traveling.
- **Keep refrigerated foods at 40°F (4.4°C) or lower.**
- Thaw frozen food in the refrigerator or by running under cold water. Do not thaw at room temperature.
- **Keep refrigerated leftovers for no more than two days** and reheat them until they're hotter than 165°F (73.8°C).

## **Foods to Avoid**

### **Don't give your child:**

- Food from street vendors, salad bars or shared bins
- Raw meat
- Raw poultry (like chicken, turkey, duck, or geese)
- Raw eggs
- Raw fish, seaweed, and sushi
- Raw seed sprouts (like alfalfa 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) or **raw meat, fish or poultry.**
- **Eat food that has fallen on the floor.**

## **How to optimize nutrition during treatment**

### **General tips**

- Discuss any questions or concerns you may have with your child's eating, drinking or growth with your medical team.
- Meet with a dietitian regularly throughout treatment to help manage symptoms and to monitor growth.
- Bring preferred foods, drinks, and/or formula with you during inpatient admissions and to clinic visits in case your child is hungry or thirsty.
- Many patients struggle with poor appetite during treatment and require nutrition support. A Nasogastric Tube (NGT) is the preferred way to feed your child when possible. If your child is experiencing frequent vomiting or diarrhea, they may require parenteral nutrition (PN). Your medical team, nurse, and dietitian can discuss these options with you.

### **If your child loses their appetite**

- Give your child 5 to 6 small meals or snacks throughout the day.
- Encourage higher calorie and protein-rich foods, like nuts, lean meats, eggs and full-fat dairy.
- Keep snacks readily available. Give a snack before bedtime.
- At meal and snack time, encourage eating solids first as fluids can make your child feel full.
- Give your child sips of high-calorie drinks like whole milk, smoothies, shakes/frappes or fortified dairy alternative kinds of milk (like soy milk) throughout the day.
  - Please note: Your child may develop lactose intolerance. This is only temporary. If this happens, try giving your child lactaid milk and/or lactaid tablets when eating dairy products, like milk, ice cream and cheese.
- Notice the time of day when your child's appetite is best. Have them eat more then.
- Schedule times for your child to eat instead of going by when their hungry. Try setting an alarm as a reminder that it's time to eat.

### **If your child has nausea or vomits**

- Give your child the prescribed anti-nausea medications 30 to 60 minutes before eating.
- Keep your child upright/sitting up for at least 2 hours after eating.
- Try feeding your child dry, salty foods, such as crackers, potato chips or pretzels.
- Avoid giving your child foods with strong odors or that are deep-fried.
- Give your child cool liquids between meals. Have your child use a straw.

### Nutrition Therapy During Cancer Treatment

- Offer your child ginger tea or plain cookies.
- Have your child smell lemon or orange slices.

### If your child has diarrhea or constipation

- Have your child drink extra liquids.
- Give your child foods with fiber, such as whole grains, fruits and vegetables.
- Do not give your child a lot of sweet drinks, such as juice, soda and sports drinks.

### If your child has mouth sores

- Give your child soft, bland foods and liquids.
- Add butter, gravy, sauce or salad dressing to moisten foods.
- Avoid hard, rough, salty or spicy foods.

### If your child has taste changes

- Try new spices and flavors, like roasted red pepper hummus or chicken with garlic.
- Try salty or highly flavored foods, like soy sauce and curry sauces.
- Avoid extremely sweet foods. Taste changes frequently happen with sweets, and they can taste "like cardboard" or "just not right."
- Sour/tart candies may help if your child says they have a "metallic taste" in their mouth.

### When should I call my doctor?

- Call your doctor if you have questions about your child's nutrition.
- You can also arrange a consultation with a registered, licensed dietitian at the Jimmy Fund Clinic (617-632-3270) or Boston Children's Hospital (617-355-4677).

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## **Steroids: Mood and Behavior Changes**

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

- Sadness and crying
- Yelling
- Hitting
- Name calling
- Mood swings
- Demanding behavior
- Irritability
- Not acting like themselves
- Being overly active or energetic
- Extreme hunger
- Difficulty sleeping

If while taking steroids your child seems confused, is not sleeping, hurting themselves or others, or is in significant emotional distress, these are **urgent symptoms** that should be discussed with your healthcare team immediately.

### **Some things that may help:**

- Prioritize safety for your child and others
- Do not focus on minor issues
- Adjust the environment to reduce unnecessary stressors or routines
- Encourage your child to express how they are feeling
- Speak clearly and calmly
- Avoid trying to reason with your child while tantrums are occurring
- Hold and comfort your child to prevent self-destructive behavior
- Praise and reward positive behavior with attention, activities, and/or special time
- Avoid new situations and changes in routine when possible
- Snacks and frequent small meals may be helpful

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## Pain

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Your healthcare providers will try to keep your child as pain free as possible during all treatment and procedures. Pain in children can be from many causes. Children may not be able to express how much discomfort or pain they have. Pain can be short term (acute), long term (chronic), or surrounding procedures (procedural).

### How do I know when my child is in pain?

A child may express pain in different ways. Often children can tell you when they have pain. If a child has difficulty or is unable to verbalize how they feel, they may express pain through their behavior.

- **Face:** A child in pain may grimace or frown. Your child may have a clenched jaw or wrinkled nose.
- **Arms/Fingers:** A child in pain may have tense clenched fists.
- **Legs:** A child in pain may act uneasy, restless, and/or tense. Your child may kick up or draw up their legs.
- **Cry:** A child in pain may moan or whimper. In severe pain, your child may cry, scream or sob. Your child may be difficult to comfort.
- **Activity:** A child in pain may squirm, shift back and forth or arch their back.

### How is pain managed?

Most pain is best managed with a combination of non-medication coping techniques and medications.

#### Coping Strategies

There are different strategies that may help your child cope with pain.

- Help your child get in a comfortable position
- Distract your child by singing softly, telling stories or counting
- Breathing exercises such as blowing bubbles, may help your child to relax
- Have your child imagine going to a favorite place or doing their favorite activity
- Child life services can work with you and your child around techniques that work best for your child

#### Medications

The type and amount of pain medication and how it is given will depend on the type of pain, weight of your child and whether or not your child can take medicine by mouth. The healthcare team will work with you to find out what is causing your child's pain and will work with you to make a plan. There are many options that can be used to help your child be as comfortable as possible.

## Pain

### How you can help your Child in Pain?

Parents know about comforting their own children better than anyone else.

- **Ask your child about the pain.** By acknowledging their pain, you are giving your child the message that you believe that they are in pain and you want to help them.
- **Use words that work for you and your child.** Talk to your child using simple, everyday language. Provide your child with as much information as you feel he/she can handle.
- **You know your child best, if you know signs your child displays when uncomfortable, you can help by sharing those signs with the medical team.**

### Common Questions and Answers about Pain

- **Can babies feel pain?** Yes, current research shows that infants, and even newborns feel pain.
- **Can children describe pain?** Children as young as 18 months old have words for pain. Children's 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. The benefits of giving pain medication are increased comfort, improved healing, and prevention of complications. The risks of giving pain medicine may include constipation, nausea, or drowsiness.
- **Should I be concerned that my child or teenager could become addicted to pain medicine?** Pain medication is often a necessary part of treatment because many underlying diseases cause pain, and the treatment can cause side effects that are painful. Many children and teens may need to Opioids during treatment. This is usually for a short period of time and is managed by your healthcare team. Any questions or concerns that you have should be directed to your healthcare team.
- **What should I do if my child's pain is not well managed?** Call your child's healthcare provider about your concerns.

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- Life Threatening Emergencies dial 911
- Coping Clinic
- Psychologist – Kristen Uhl's program on Saturdays for children coping

## Skin Care During Treatment

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Chemotherapy, radiation, and medications may cause changes to your child's skin. Tell your healthcare provider about rashes, redness, open areas, or any other skin irritation.

Some of the common skin changes during treatment are:

- Dryness
- Increased sensitivity to sun
- Rashes or open areas which may be slow to heal
- Irritation in the area surrounding the anus and/or the vagina or penis
- Dry, chapped lips
- Redness or darkening of the skin
- Risk of skin infections

### Managing side effects

- Bathe daily with a gentle, scent-free soap
- Always Check with your health care provider before using any sort 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 plenty of fluids
- Apply lip balm with SPF 15-30

### Sun protection

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

#### Sunscreen Application

- Apply "water resistant" sunscreen with SPF 30 or greater with both UVA and UVB protection 30 minutes before going outdoors
  - *Hypoallergenic* – may lessen the risk of developing a rash or an allergic reaction
  - *Noncomedogenic* – may be better for your skin if you have acne. Gels are often preferable
- Reapply sunscreen covering all exposed areas including head and ears, at least every 1-2 hours. Reapply after swimming, sweating, or after using a towel to dry off
- Sunscreen should be applied even on cloudy days or when around reflective surfaces such as snow, sand, and water
- Apply lip balm with SPF 15-30

## Skin Care

### Protective Clothing

- Wear sunglasses and hats wide enough to cover face, neck, and ears while outside
- SPF clothing will provide extra protection

### Planning for Outdoor Activities

- Limit time spent in the direct sun, especially between the hours of 10am and 4pm
- If outside during these hours, try and find shady areas to avoid direct contact with the sun

### Artificial Tanning

- Do not use tanning salons or tanning beds
- Chemicals found 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 specifically says it contains a SPF

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# Transfusions

## What is a blood transfusion?

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's put into a vein, usually in the arm.

## How does a blood transfusion help?

Blood transfusions can be lifesaving. Your child may get a blood transfusion if they don't have enough red cells or platelets. Healthy adults can donate 1 pint of blood every 2 months. The blood is divided into parts (including red cells, platelets and plasma) so it can help as many children as possible.

**Red cells:** Red cells carry oxygen and are given to treat anemia, or if there is a lot of bleeding.

**Platelets:** Platelets help stop bleeding by plugging holes in blood vessels.

**Plasma:** Plasma is the clear liquid part of blood that also helps stop bleeding.

## What are the 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 (1-5%) 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, including those that cause hepatitis, human immunodeficiency virus (HIV), human T-cell lymphotropic virus (HTLV) and syphilis. The chance of becoming infected with one of these viruses is extremely small.

Virus	Risk per unit transfused (roughly)
HIV I	1 in 2,100,000 transfusions
HTLV I	1 in 3,000,000 transfusions
Hepatitis C	1 in 1,900,000 transfusions
Hepatitis B	1 in 200,000 transfusions
West Nile Virus	1 in 1,000,000 transfusions

## Transfusions

Other infectious agents (Chagas disease, malaria, syphilis) are not transmitted by transfusion often. The chance of it happening is less than 1 in a million. Bacterial infections of blood products are uncommon. Albumin has not been shown to have a measurable risk. Intravenous immunoglobulin (IVIG) has caused hepatitis in the past, but products are now treated in ways thought to prevent hepatitis.

**Metabolic problems:** Changes in blood salts (increased 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. Since blood from someone else is different than your child's own blood, your child's body may respond by making antibodies against red cells or platelets. This problem may lead to more transfusions.

### Are there other options?

- There are no red blood cell substitutes available.
- The risks from blood transfusion may be lowered by transfusing saltwater (saline) instead of blood products or giving a protein (albumin) that has no known infectious risks. Depending upon the nature of your child's operation and their size and age, it might be possible to have your child give blood for themselves (an autologous blood donation) or to re-use blood lost in surgery. You may want to discuss these alternatives with your child's surgeon and anesthesiologist.
- **Blood Donor Center:** Giving blood ahead of time for oneself may be arranged at your physician's request. If you have questions about blood donation, please call the Blood Donor Center at (617) 355-6677.

## Contact Us

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## Immunizations

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

Live vaccines can cause illness in children who are at increased risk of infection. Live vaccines should not be given to the child during treatment.

Examples of live vaccines are:

- Measles, mumps and rubella (MMR) vaccine
- Chicken pox vaccine
- Oral Rotovirus vaccine
- Nasal flu vaccine
- Oral Polio vaccine

Your healthcare provider may also recommend that your child should not receive other types of vaccines while on treatment. You should always check with your provider first before your child receives any vaccines while on treatment.

### **Flu (influenza) shots**

It is strongly recommended that all patients and their household contacts receive a flu shot each year. Family members and siblings can receive flu shots from their own health care provider or at special flu shot clinics. Patients, siblings, family members and contacts **SHOULD NOT** receive the nasal flu vaccine (FLUMIST) for seasonal influenza. Contacts who inadvertently received the nasal flu vaccine should not be in contact with the patient for 7 days following receipt of the nasal Flu vaccine.

### **Immunizations for siblings**

Generally, brothers and sisters of patients are allowed to be immunized with all the normal vaccines required for healthy children.

Until 60 days following autologous stem cell transplant or until three months after all immunosuppressive medications have been stopped for allogenic stem cell transplant recipients, recipient/patient should not be around:

- Anyone who has received the oral polio vaccine with the past 6 weeks
- Anyone who has received nasal Flumist within the previous 7 days
- Anyone who has not had chicken pox or the vaccine against chicken pox

**Hematopoietic stem cell transplant patients** must speak with their healthcare provider if a household contact recently received the chickenpox vaccine and develops a vaccine associated rash.

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## Chickenpox (Varicella) & Shingles (Zoster)

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

Chickenpox usually starts with:

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

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

Shingles usually starts with:

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

### Exposure

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

### Treatment

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

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## Infection Control

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Treatments such as chemotherapy, radiation and surgery can lessen your child's ability to fight infection by temporarily decreasing the number or production of the cells in your child's body that fight infection. Suggestions for preventing infections in your child are described below.

### Hand Washing

- Hand washing is the best way to avoid spreading germs to others
- Wash your hands with soap and water for 20 seconds:
  - After using the bathroom
  - After touching animals
  - When your hands look or feel dirty
  - If your child is on precautions for infections such as C-difficile (C-diff) or Norovirus, **use soap and water**, as antibacterial gels do not work
- Clean your hands with soap and water or antibacterial hand gel:
  - After blowing your nose, coughing, or sneezing
  - Before and after eating, drinking, or handling food
- When using antibacterial hand gel apply a nickel-size amount in the palm of your hand and rub hands together, covering all the surfaces, until the hand sanitizer dries

### Preventing Infections

#### At home, school or in your community

- ❖ Use good personal hygiene
  - Shower or bathe daily
  - Brush teeth at least two times a day
  - Do not share cups, eating utensils, or toothbrushes
  - Only touch your eyes, nose or mouth after you have washed your hands
- ❖ Handle, prepare, and store food safely:
  - Wash your hands
  - Clean kitchen surfaces and utensils before and after handling food, especially when preparing meat or poultry
  - Wash raw fruits and vegetables
  - Always refrigerate leftovers and 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 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 to be notified of any contagious illnesses at school
- ❖ Follow the proper directions for care of a central line or port
- ❖ Keep your pet healthy by visiting the veterinarian regularly and keeping their immunizations up to date. Generally birds and reptiles are discouraged as pets. If you have any questions or concerns contact your healthcare provider

Infection Control

- If fever or illness develops at home, contact the healthcare team right away
- If your child has been exposed to someone with a contagious illness, contact the healthcare team right away

**When in a healthcare facility like the clinic or the hospital**

- If you or your child comes to the clinic or hospital with fever, cold-like symptoms, diarrhea, vomiting or any other illness, please let a clinic assistant or front desk staff member or your child's nurse in the hospital know right away
- Do not bring siblings who are sick to the clinic or the hospital
- Some families are concerned that other patients might have an infection. Healthcare providers can explain what measures are in place to protect your child.
- Some illnesses require a private room called an isolation room
- If your child is on isolation for a contagious illness:
  - ❖ Patients, siblings and visitors must remain in the isolation room
  - ❖ Patients, siblings and visitors cannot visit common areas on the unit such as the resource room, activity room or kitchen

**When at the hospital**

- Screening is required at the information desk *daily* for all visiting children under the age of 12 years old. A GREEN dinosaur sticker is placed on children that may visit.

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## Back to School Program

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The Back to School program, is designed to ease your child's transition back to school. Treatment may involve frequent clinic visits, radiation, surgery or hospitalization, causing children to miss some school. Returning to school can be a positive experience. It can also be a challenging and emotional experience. The program provides:

- **Student and family support** - To prepare your child for the return to school, we provide individual counseling and family guidance to help support the transition back to the classroom.
- **Classmate understanding** - At the school, we provide classmates with age appropriate information about your child's treatment and encourage social support.
- **Teachers and school personnel** - We work with teachers and other school personnel to increase their understanding of health, educational and psychological issues faced by your child.

The Back to School Program may include a phone consultation with the school, an information packet which can be sent to the child's teacher or a school visit from your child's care team. The team tailors the presentation to the child's classmates and school staff.

During the presentation, we discuss disease, treatment, side effects and medical procedures, and the emotional aspects of your child's experience. We try to remove any confusion about cancer, blood disorders and stem cell transplant. Our presentations vary, depending on the age of the children. Options include:

- PowerPoint presentations
- Puppet shows
- Teaching dolls
- Written materials
- Medical play

After the presentation there is a question-and-answer period. Our goal is to encourage social support for the child who is returning to the school community. These visits may also be provided if the student is currently not in school or expected to have an extended absence from school.

## Back to School Program Contacts

**Kendal Temple**, *Oncology Community Outreach Nurse*  
Boston Children's Hospital  
Kendal.Temple@childrens.harvard.edu  
617-355-0472

**Lisa Scherber**, *Director of Patient & Family Programs*  
Dana-Farber Cancer Institute Jimmy Fund Clinic  
Lisa\_Scherber@dfci.harvard.edu  
617-632-3278

## Back to School Program

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

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The experience of a serious illness can be challenging for the whole family, and it's normal for children, parents, siblings, and other caregivers to feel a range of emotions and need support. Our experts in Pediatric Psychosocial Oncology are here to support you and your family's emotional health as you manage cancer or another serious illness.

As a part of a child'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 discuss what psychosocial services may be useful. You may also meet with a resource specialist regarding eligibility for financial resource assistance programs. Psychiatrists are available for consultation 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
- 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 individual support you need throughout treatment.

We meet with patients and families in the Jimmy Fund Clinic and in inpatient areas 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 related to your child's care at Dana-Farber/Boston Children's, including questions regarding insurance, transportation, or accommodations, please talk with your Resource Specialist. Or call 617-632-6080 and ask 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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Complementary therapy, more recently called integrative therapy, includes a range of healing options and therapies. Integrative therapies can be used along with traditional medical treatment to treat disease, reduce stress and to prevent or reduce side effects and symptoms. Integrative therapies include but are not limited to acupuncture, reiki, therapeutic touch, chiropractic, homeopathy, music therapy, massage, guided imagery, yoga, and the use of herbal remedies.

### Special Instructions

- Anyone who practices complementary or integrative medicine should be licensed or certified.
- You should always talk to your healthcare provider about any integrative therapies you are interested in trying.
- Unlike traditional treatments for cancer, integrative therapies are often not covered by insurance companies. If seeking services for therapies outside of Dana-Farber/Boston Children's, patients should check with their insurance provider to find out about coverage for these services.

### For Patients at Dana-Farber/Boston Children's

- The Zakim center for Integrative Therapies at Dana-Farber can suggest appropriate services such as acupuncture, massage, and other integrative therapies. Funding is available, for those who qualify, to support acupuncture and massage sessions at the Zakim Center. 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)
- When inpatient at Boston Children's Hospital, please have your clinical staff contact the Hematology/Oncology/Hematopoietic Stem Cell Transplant Integrative Therapies team at extension 87144 or email [IntegrativeNursing-dl@childrens.harvard.edu](mailto:IntegrativeNursing-dl@childrens.harvard.edu) with a referral. Services available for our patients at no cost include: Reiki, Relaxation Massage, Yoga, and Meditation.
- Music therapy is available in both the Jimmy Fund Clinic and at Boston Children's. Ask resource room staff or your child life specialist for more information.
- Your child may be able to receive free mini sessions of massage therapy while in the Jimmy Fund Clinic. Check with your healthcare provider in clinic for more information about this opportunity.

### For Caregivers at Dana-Farber/Boston Children's

- The One Mission Resource Room provides Yoga, Reiki and Chair Massage for inpatient caregivers. See schedule in the resource room for details. Additional caregiver relaxation programs can be found in the 9NW Resource Room 617-355-7684 and in the Hale Center for Families in lobby of BCH, 617-355-6279
- The Blum Pediatric Resource Room located in the Jimmy Fund Clinic or the One Mission Resource Room on the 6<sup>th</sup> floor at Boston Children's Hospital has books and other information available about integrative therapies.

Integrative Therapy

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## The Sibling Program

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When your child is receiving treatment, this impacts the entire family, through multiple clinic visits, frequent hospitalizations, and significant changes in normal routine. Our team will work with you to determine which services best meet your family's needs and to share suggestions and strategies for coping. Dana-Farber/Boston Children's Sibling Program provides support to siblings and their families. The following Sibling Voices video, available on YouTube and on the Dana-Farber/Boston Children's Website, was created by and for siblings who have a brother or sister with cancer. It also can help parents/guardians, educators, and others better understand the sibling experience.

### Sibling Voices Video:

<http://www.danafarberbostonchildrens.org/for-families/patient-and-family-support-services/sibling-program.aspx>

## Sibling Program Events and Activities

The Sibling Program offers comprehensive, personalized psychosocial support to the school-aged and teenaged siblings of our pediatric patients. We also offer special opportunities that may include:

- **April Sibling Week:** Each year in April, siblings are invited to this special week, which includes craft activities, interactive guest artists, and lunch for the entire family and staff, all hosted by the Sibling Program. Siblings ages 5 and older are also invited to take part in a group just for brothers and sisters lead by psychosocial clinicians.
- **"Just for Sibs" Group:** All outpatient and inpatient brothers and sisters are invited to upcoming groups. Group dates will be posted or ask your healthcare team for more information.
- **Support for Siblings in the Schools:** Psychosocial clinicians provide information to teachers and guidance counselors about how to support the sibling.
- **Parent Support:** Psychosocial staff can provide consultation to parents around sibling issues.
- **Sibling Bags:** Bags containing age-appropriate books and materials are provided to siblings ages 5 and up.
- **Sibling "BEADS" Program:** Similar to the BEADS Program (Beading Each a Different Story), BEADS for Sibs is designed to represent the unique experience of having a brother or sister on treatment. You can find more information about the BEADS for Sibs Program through the resource rooms or your psychosocial clinician.

## Tips for Teachers:

Siblings who have a brother or sister being treated at Dana-Farber/Boston Children's often experience challenges. While children may react differently, below are some reactions siblings may experience, along with some suggestions that may be helpful.

## Possible sibling reactions to a brother or sister's illness while in school

- Complaints of not feeling well
- Withdrawal such as participating less or being less social
- Change in academic performance
- Periods of extreme productivity (over-achievement)
- Frequent absences or tardiness

## Suggestions

School is often the place where a sibling can get a break from the concerns that they have. Sometimes, giving the sibling space, and not asking how the family or patient is coping, is most helpful. Check in with the student to see 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, please contact the parent(s) or guardian(s)

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## Spiritual Care

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Spirituality is an important source of strength, comfort, and hope for patients and families. Chaplains are available for spiritual and emotional support at Dana-Farber/Boston Children's Hospital Cancer and Blood Disorders Center. Interfaith Chaplains are guided by you to support your spiritual needs throughout your hospitalization.

### When to call a chaplain:

- During times of difficult waiting
- For confidential listening
- For age/developmentally appropriate spiritual, religious, and emotional support
- Prayer, religious rituals, sacraments, worship services, breathing and guided meditation
- Help with life transitions or losses
- Devotional resources in a variety of traditions and languages

### Chaplaincy at Boston Children's Hospital

- **To Contact:** Call the page operator at (617) 355-6363 and ask for a chaplain to be paged. A staff member can also page a chaplain for you. Chaplains are in the hospital 8am-5pm and are on call 5pm-8am every day of the week.
- **Chapel:** All are welcome to the multifaith chapel is located on Farley 1. The chapel is always open.
- **Website:** [www.childrenshospital.org](http://www.childrenshospital.org) Find Chaplaincy under "Family Resources."
- **Channel 28 on your TV:** Includes peaceful meditative sounds and scenes that invoke serenity like a trickling waterfall, a quiet walk through a garden.
- **Phone:** (617) 355-8095

### CHAPLAINCY AT DANA-FARBER/ JIMMY FUND CLINIC

- **To Contact:** Call Spiritual Care at 617-632-5778 or page the chaplain at (617) 632-3352 and ask the page operator for the on-call chaplain. A staff member can also contact a chaplain for you. The Spiritual Care office YC206, is located on the second floor of the Yawkey Building.
- **Chapel:** You are welcome to visit the Dana-Farber's interfaith chapel which is located on the second floor of the Yawkey Building. The chapel is open 24 hours a day.
- **Website:** [www.dana-farber.org/spirituality](http://www.dana-farber.org/spirituality)
- **Phone:** (617) 632-5778

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