EDUCATIONAL GUIDE FOR ONCOLOGY PATIENTS AND FAMILIES
Team Members on Your Child’s Medical Team

Clinic Day: ________________________________

Attending Physician: _______________________

Fellow: _________________________________

Nurse Practitioner: _______________________

Physician’s Assistant: _____________________

Primary Nurse (BCH): _____________________

Primary Nurse (JFC): _____________________

Psychosocial Clinician: ___________________

Nurse Manager (BCH): _____________________

Nurse Manager (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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ACKNOWLEDGEMENTS
Association of Pediatric Oncology Nurses Standards of Practice
Children’s Oncology Group Nursing Discipline – Pediatric Oncology Parent Handbook Nemours Children’s
Dana-Farber/Boston Children’s Cancer and Blood Disorders Center
Pediatric Writing and Editing Committee September 2016
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Welcome to Dana-Farber/Boston Children’s Cancer and Blood Disorders Center

The Dana-Farber/Boston Children’s Cancer and Blood Disorders Center is dedicated to the quality care of children 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 in hematology, oncology and stem cell transplant at Boston Children’s and Dana-Farber Cancer Institute’s Jimmy Fund Clinic.

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

- 6 North  617-355-8066
- 6 West  617-355-8069
- 6 East  617-355-8063
- 9 Northwest  617-355-8096

Outpatient care is provided at Dana-Farber Cancer Institute:

- Jimmy Fund Clinic, 3rd floor  617-632-3270

HEALTH CARE TEAM

The specialized health care team caring for your child includes:

- **Nurses** work closely with all members of the team to plan and carry out your child’s care, 24 hours a day, 7 days a week. They provide teaching and support. Please feel free to discuss your concerns or questions with any nurse caring for your child.

- The **Nurse Manager** oversees the unit’s daily clinical and administrative needs. He/she is available to meet with you at any time.

- The **Nurse Director** is responsible for leading and managing the various oncology and blood disorder programs. He/she is also available to meet with families.

- **Clinical Assistants** will care for your child under the direction of a nurse.

- A **Case Manager** works with the nursing staff to make sure that all home care needs and supplies are arranged before your child leaves the hospital.

- **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. **Physician Assistants** and **Nurse Practitioners** are clinicians with an advanced degree with training in pediatrics. The health care team will see your child every day and will talk with you about how your child is doing.

- A psychosocial clinician is assigned to every family. This clinician may be a **Staff Social Worker or Psychologist, or a Social Work Psychology Intern**. As members of the
Pediatric Psychosocial division, they will follow your child at Children’s Hospital Boston as well as at the Jimmy Fund Clinic, allowing for consistency of care throughout treatment. They specialize in providing counseling for the entire family, including siblings. This can include parent counseling and child guidance, play therapy, talk therapy and distraction techniques to help your child through difficult medical procedures. These clinicians will work closely with the medical team to provide you with individualized care.

- **Resource Specialists** from the Division of Psychosocial Services assist families with concrete resources, including transportation, accommodations, and financial aid. They help families in need apply for financial assistance from local, regional, and federal programs for which they may be eligible.

- **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 and programs as a diversion from hospital routines. Child Life Specialists may also visit your child at the bedside and may also organize group activities in each unit’s activity room, enabling children to socialize with their peers. Child Life Specialists can also help arrange for a tutor through your child’s school.

- **Registered Dieticians** work as part of the health care team to help patients and families with nutrition and diet concerns.

- **Administrative Assistant** works at the front desk and will 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 and treatment, and provide support programs.

- **Physical Therapists** work as part of the health care team to help patients maintain physical strength during treatment.

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Inpatient Care at Boston Children’s Hospital (BCH)

Information for Caregivers

- Parents or guardians can stay in the hospital 24 hours a day. Only one adult may sleep at the bedside overnight.
- 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, parents/caregivers must provide a photo ID. This must be worn at all times.
- All patients must wear an identification band at all times while on hospital property.
- All patients under the age of 18 must be accompanied by a parent/guardian, nursing unit staff, or volunteer when leaving the hospital floor/unit.
- Parents are responsible for siblings and other visitors.
- Electrical appliances (i.e. coffee maker, mini refrigerator) are not allowed in the hospital.

Visiting a Patient

- Only parents or caregivers are allowed to visit the hospital after 8 p.m.
- Friends and family members who are ill can not visit the hospital.
- All visitors under 12 years old must be screened 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 weapon 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 younger than 18 years old can visit in the patient room.
- Children under two years old may not visit a stem cell transplant patient unless cleared by the healthcare team.
- 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.

**INFECTION CONTROL**

- Hand washing, for at least 15 seconds, is the best way to help prevent the spread of infection.
- When you enter or leave your child’s room wash your hands. You may use the sink located in your child’s room or use Purell® in the dispensers outside the room.
- To prevent the spread of germs and diseases, do not touch any child but your own and do not visit in any other patient room.

**PATIENT ROOMS**

- When your child is inpatient at Boston Children’s Hospital every effort is made to admit your child to the unit that they are most familiar with. 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.
- Do not touch the IV pump settings. Use the nurse call light to call with 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. Laptops are available to borrow throughout the hospital stay. Patients can bring their own laptops. 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.
- To make calls outside of those areas codes, dial 9-1, then the area code and number. You must charge your calls to your home phone or a phone credit card, or make a collect call. Cell phones are allowed on the unit. Each bed space on the 6th floor includes a personal refrigerator. Please take your food items with you when your child is discharged.
- To support children and/or family members who are deaf or hard of hearing, Teletypewriters (TTYs) are available. If you would like a TTY in your child’s room, your child’s nurse can help you obtain one.
- There is a washing machine and dryer located on the 6th floor. The laundry key and detergent is at the main desk of your unit.
- If your child was admitted to the hospital unexpectedly there is a limited supply of personal care items available.
- Store your personal items in the bedside cabinet or closet in your child’s room. Valuables, money or jewelry can be locked in the safe in your closet.
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.

At BCH, cards, letters, toys, and Mylar balloons for patients are welcomed. Latex balloons are not allowed anywhere in the hospital. Due to infection concerns, plants and flowers are not allowed on the 6th 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. A child life specialist and volunteers staff the activity room. Patients and siblings of all ages are welcome if accompanied by an adult. Any visitor who is sick or is visiting another patient on precautions needs to stay in the patient’s room. 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 are welcome in the 6W activity room, **two at a time**, after screening for infections. Siblings of stem cell transplant patients may **not** walk in the hallways or be in the activity room.

**Family Resource Centers**
- Resource Room, Boston Children’s Hospital, 9th floor, (617) 355-7864
- Patient and Family Resource Room, Boston Children’s Hospital, 6th floor (617) 355-5645
- Center for Families, Boston Children’s Hospital, main lobby (617) 355-6279
- Blum Pediatric Resource Room, Dana-Farber Cancer Institute’s Jimmy Fund Clinic, Dana 3 (617) 632-3900

**Food Service**
BCH offers a food service for patients that feature a room service-style menu. 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).

**Kitchen**
The kitchen on your unit has drinks and snacks for patients. A filtered water and ice machine, coffee maker and microwave are available for use. Bottled water is available for stem cell transplant patients as they should not use the filtered water machine. Each kitchen 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
(617) 355-7198
If you need an interpreter while you are in the hospital, please ask your child’s health care provider.

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

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Outpatient Care at the Jimmy Fund Clinic

Information for Caregivers

Clinic Hours:
- Clinic hours are from 8AM to 5PM Monday through Friday
- Clinic is closed nights, Sundays and holidays
- Clinic is open on Saturdays from 8AM to 3PM for scheduled infusions or lab draws only. If you are concerned about your child, you should not call the clinic on Saturdays but follow the weekend/night procedure.

Before you arrive to clinic:
- Please arrive 15 minutes before your first scheduled appointment of the day to allow time for check-in and vital signs.
- Make every effort to arrive at your scheduled appointment time.
  - Allow extra time to valet or self-park.
  - 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 (617-632-3270).
- Arriving on time with a topical anesthetic such as EMLA in place helps keep your appointment on schedule, and minimizes wait time.
- Bring a current medication list and your child’s medications to each clinic visit.
- If you take Cyclosporine (Neoral®, Sandimmune®, Gengraf®) or Tacrolimus (FK506/Prograf®), do NOT take the morning dose until after the blood work is drawn.
- 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.

When you arrive to clinic:
- Check in at the JFC front desk. An identification bracelet will be placed on your child.
- An RTLS (Real Time Locating System) Badge will be given to you and your child. This small badge should be worn when you are in clinic and helps staff find you throughout your clinic 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.
- If your child is not feeling well, let the front desk staff know.
• A clinic assistant will measure your child’s height, weight, temperature, blood pressure, heart rate and oxygen saturation. Let the front desk staff know if you are waiting for longer than 20-30 minutes.

• If your child needs lab work, it usually takes 1–2 hours for results to be available.

• When it is time for your child to see their provider you will be taken to an exam room.

• You may order food for your child. Patient menus are available at the front desk.

• Please do not leave money, jewelry or other valuables unattended at any time while in the clinic.

If receiving treatment:

• Children need to be supervised by a guardian at all times. If something unexpected happens and you must leave the clinic for a short time during your child’s treatment, please tell clinic staff right away so that they can determine if we can safely care for your child in your absence.

• While you are waiting nurses, physicians and pharmacists 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.

Checking out of the Jimmy Fund Clinic:

• When your health care provider has cleared you to leave clinic you will be given:
  o An updated list of all your child’s medications
  o A “blue form” to schedule your next appointment at the front desk
  o A list of upcoming appointments. Please review the dates and times carefully.
  o Please return the RTLS badge for both you and your child to the RTLS 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:
  o Friends and family members who are ill can not visit.
  o Children must be supervised by parents or guardians at all time.
  o Due to limited space, be aware of the number of people who come to clinic.

• Visiting a patient on precautions in a private infusion room:
  o Siblings and visitors must remain in the patient room.
  o 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.
Infection Control

- Hand washing, for at least 15 seconds, is the best way to help prevent the spread of infection.
- When you enter or leave your child’s room wash your hands. You may use the sink located in your child’s room or use Purell® in the dispensers outside the room.
- To prevent the spread of germs and diseases, do not touch any child but your own and do not visit in any other patient room.
- If you are sick, please tell your child’s healthcare provider.
- Stem Cell Transplant patients must wear a mask when entering Dana-Farber. Patients should continue to wear a mask to clinic until they have returned to school and are allowed to go to public places.
- Until your healthcare team tells you otherwise, Stem Cell Transplant patients must ride the elevator at Dana-Farber only with their family members.
- Patients may need special precautions to prevent the spread of infection. Staff will wear gowns, gloves or masks. These precautions will be explained to you.
- If a patient is on any contact precautions:
  - 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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Scheduled Chemotherapy Admissions

Many chemotherapy treatments may be given outpatient in the Jimmy Fund Clinic (JFC) although some treatments require admission to the Boston Children’s Hospital (BCH).

Clinic Appointment—Day of Admission

- Your appointment time in the JFC is made to allow for blood work and a physical exam to be completed.
- When your healthcare provider approves the start of chemotherapy, the JFC charge nurse communicates with the BCH coordinator of patient placement (COOP) to confirm bed location.
- 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

Inpatient Room Availability

There may not be a room at BCH due to several reasons.

- Unplanned events or emergencies
- Patients waiting overnight in the emergency room
- Unexpected admissions from the JFC
- Seasonal illnesses such as flu or virus

Your clinic nurse will keep you updated throughout the day about room availability. If a room is not available by late afternoon, there will be a clear plan given to you.

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Family Centered Rounds

Dana-Farber/Boston Children’s Cancer and Blood Disorders Center practices family centered care and considers you, the caregiver, an expert on the needs and changes 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. Families can choose to have discussions at bedside or outside of the room. 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
- Patient’s nurse for the shift; charge nurse may also be present
- Pharmacist
- Medical/Nursing students
- Case Manager

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 work.
- A physical exam may be 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.

Family Centered Rounds usually takes 10 minutes per patient. Please remember that the medical team must meet with all patients. If you have any outstanding questions or concerns, please let your healthcare provider know so that additional time to meet can be arranged.

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Cancer Diagnosis and Treatment

Cancer occurs when a cell grows and divides in an abnormal way. There are many different types of cancer and these cancer cells may start in different places in the body. There is nothing you or your child could have done to prevent cancer. We do not know the underlying cause of most childhood cancers. Depending on the type of cancer, treatment may include: surgery, chemotherapy, radiation therapy, biotherapy, and hematopoietic stem cell transplant.

Treatment Decisions:

- A diagnosis is made once test results are back. This may take several days or sometimes weeks. A team of providers specializing in this disease will then meet with you to offer a recommendation for the best treatment for your child’s type of cancer.
- An oncologist will explain the treatment in detail and discuss this plan with you. This can be a difficult time as it is necessary to inform you of all the potential risks and side effects, even the very unlikely ones that may occur.
- Treatment is started after guardians or patients over 18 years old have signed a consent (a legal document).
- Some children may be treated on a protocol that is part of a clinical trial. Clinical trials evaluate specific treatments for particular types of cancer and allow new and better treatments to be determined.

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Clinical Trials and Protocols

Many children with cancer 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 cancer treatment.

Clinical trials have different phases.

- **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 cancer.
- **Phase III** clinical trials compare a new or revised treatment plan with standard treatment.

Clinical Trial Protocols

- Each clinical trial has a detailed treatment plan, which is called the "protocol". This explains different therapies, such as medicines, surgery, and radiation and tests that need to be done throughout the clinical trial.
- All therapies start with a full explanation of the recommended treatment plan and (parent/guardian/patient) consent. Speak with your healthcare team about different options or any concerns you may have.
- 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 Provider

Call your healthcare provider if your child has:

- **Fever**—call immediately if your child has:
  - A temperature of **101.3 F (38.5°C)** or higher once
  - A temperature of **100.4 F (38 C)** or higher twice in 24 hours
  - We recommend you recheck a temperature in one hour if it is 100.4 F (38 C) or higher
  - Shaking or chills
  - Do not give any fever reducing medicine until you have spoken to 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

- **Decrease in urine output** or no urination for 6-8 hours while awake

- **Exposure** to chicken pox, shingles, measles, German measles 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/is...

- 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 the name of the medication and the pharmacy phone number with the triage nurse.
   - 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:
   - Call the Jimmy Fund Clinic at 617-632-3270 for questions about scheduled radiology tests or other studies to be done at Children’s Hospital Boston.
   - 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

Jimmy Fund Clinic Main Number (617) 632 3270
Pediatric Patient Registration (617) 632 3913
Blum Pediatric Resource Room (617) 632 3900
Division of Pediatric Psychosocial Services (617) 632 5425
School Liaison Program (617) 632 5909
Resource Specialists (617) 632 3365
Activities Department (617) 632 3278
Perini Clinic (617) 632 5124
Stop & Shop Outcomes Clinic (617) 632 2680

New Patient Referrals
General Oncology (888) 733 4662
Neuro Oncology (617) 632 2680
Stem Cell Transplant (617) 632 3961
DFCI Financial Office (617) 632 3455
DFCI Page Operator (617) 632 3352

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
6th floor Resource Room (617) 355 5645
Blood Donor Center (617) 355 6677
Diagnostic Tests, Scans and Procedures

Your healthcare team will always explain the exact 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 require sedation, general anesthesia or an operation.

Audiogram
A hearing test 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:

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.

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.

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 substance 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. Please review the Bone Marrow Aspiration and Biopsy teaching sheet for additional information.

- 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 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. The bones are then examined by a special camera. Your child may need sedation or general anesthesia.
Computerized Axial Tomography
A CAT or CT scan is a radiology test that takes pictures to identify and measure the presence of abnormal cells throughout the body. Sedation or general anesthesia may be used if needed to help your child remain still. In many cases, children will have to swallow and/or receive a contrast by IV to help visualize certain body areas.

Creatinine Clearance
A test to measure how well the kidneys are working by collecting all of your child’s urine in a container for 24 hours.

Echocardiogram
An “echo” records movements of your child’s heart. It uses ultrasound waves without risk to your child. Sometimes, sedation is needed for children who have a difficult time remaining still.

Electrocardiogram
An EKG or ECG is a test that records the heart rhythm. Sticky pads will be placed on your child’s arms, legs, and chest. These are connected to wires leading to a machine that will record your child’s heart rhythm.

Gallium Scan
Your child will receive a radioactive isotope injected by IV that is only absorbed by certain tissue types. After 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
Glomerular filtration rate (GFR), is a 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
A procedure that collects a sample of cerebrospinal fluid, also called CSF, which surrounds the brain and spinal cord to determine the presence of cancer cells or progress of treatment. A needle will be inserted between the bones of your child’s lower back. If your child needs chemotherapy into the spinal 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 hospital, or operating room, and your child will receive procedural sedation or general anesthesia. Please review the Lumbar Puncture teaching sheet for additional information.

Magnetic Resonance Imaging
An MRI, is a test that provides detailed images of the inside of the body. It is used to identify and measure the presence of abnormal cells throughout the body. 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 visualize certain body areas. Your child may be given a sedative or general anesthesia to help them keep still.
MIBG scan
Your child will receive an injection of a radioactive isotope that is only absorbed by certain cells, particularly those that are found in neuroblastoma and pheochromocytoma. After 24 hours, pictures will be taken to identify where activity is occurring within the body.

Positron Emission Tomography (PET Scan)
An imaging technique that produces three dimensional images of the body. This test provides information about how the body functions. Your child may need sedation or general anesthesia if they need help to remain still.

Pulmonary Function Tests
Pulmonary Function Tests (PFT’s) 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. Young children may have a difficult time completing this test.

Ultrasound
A test that uses ultrasound waves to provide images of the inside your child’s body. Ultrasound does not use radiation.

X-rays
An X-ray takes a picture of your child’s bones and organs. It can be used for many reasons.

Contact Us
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  Page pediatric hematology/oncology fellow on call
- Life Threatening Emergencies dial 911
Tips for Helping Your Child With Medical Care

Your child’s care can often require specialized testing or treatments. These are often referred to as procedures. Our goal is to make these procedures as stress free as possible.

There are different strategies that parents and staff can use that may be helpful for your child regarding their medical care. Different strategies work for different children. We want to work with your child’s style.

The Psychosocial Team and the Child Life Specialists at Dana-Farber/Boston Children’s are specially trained in these techniques and can teach you ways to help your child cope with medical care.

These are some of the strategies that can help to relax and focus your child’s attention.

Breathing Exercises
- Blow a pinwheel, party blowers, bubbles
- Blow out imaginary birthday candles
- Practice using relaxation 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
- Help your child to focus on physical sensations he/she is experiencing, and talk about how it feels, changes, etc.

Distraction
- Focus on things like pop-up books, egg timer or color wheel
- Sing along with a favorite tape
- Hold hands, rub legs, back, arms, or offer a favorite stuffed animal to hold
- 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
Tips for Helping Your Child with Medical Care

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”

Ways to help your child:

• Share your ideas on how best to support your child.
• Encourage your child to learn and try different techniques
• Reassure your child in matter of fact way, he or she can do it
• Give lots of praise
• Help your child to practice relaxation
• When possible, give your child choices
• Keep your focus on your child
• Comfort your child by holding hands, rub legs, back, arms, or offer a favorite stuffed animal to hold
• If your child prefers to focus on the medical procedure give reassuring, simple information

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Complete Blood Counts

A complete blood count (CBC) is a laboratory test that shows the type and number of cells in the blood. Blood counts are checked frequently during cancer treatment. Your healthcare team checks the blood counts to monitor your child’s response during treatment. It is normal for people who receive cancer treatment to have low blood counts. The blood counts usually drop one week to two weeks after treatment. This is called bone marrow suppression (myelosuppression.)

Most of the time, your child’s blood counts will be at a level that allows him/her to fight infection, maintain normal energy at play, and prevent bleeding. During the times when the counts are normal, your child should be allowed to take part in play activities with other children. We will be glad to discuss any questions you may have about the safety of your child’s play and sports.

Low blood counts may cause your child the most treatment delays, therapy changes and unscheduled trips to the hospital. The lowest point the blood cell counts reach after chemotherapy is called the nadir. You will probably be at home when the blood counts reach their lowest point, so it will be necessary for you to know what to look for, what to do and when to call the treatment team. Usually, the blood counts recover on their own but sometimes transfusions are necessary. The transfusions are given in the hospital or at the clinic.

Blood Cells

Blood cells are made in the hollow cavity of the bone called bone marrow. The bone marrow is the “factory” where blood cells are made. When some types of chemotherapy and radiation are given, the factory slows down production of blood cells. There are three types of blood cells: red cells, white cells, and platelets. Each type of blood cell has a special function.

Red blood cells (RBC’s) 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. A normal hemoglobin is between 11 and 14.
- Hematocrit is the percentage of red blood cells in the blood. A normal hematocrit is between 31 and 43.
- The hemoglobin and hematocrit are used by our program to help determine transfusion needs. If the red blood cells drop below a certain level or your child has symptoms then your healthcare team may order a red blood cell transfusion.

Signs of anemia are

- feeling tired
- shortness of breath
- headache
- fast heart rate

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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. A normal platelet count is between 150,000 and 450,000. Signs and symptoms of low platelets may include:

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

When the platelet count drops below a certain level or there is active bleeding, a platelet transfusion may be ordered.

White Blood Cells
White Blood Cells (WBC’s) help the body fight infections by capturing them and destroying them. WBC’s also protect the body against certain bacteria, viruses and fungi. A normal white blood cell count is between 5,000 and 10,000. The numbers on your laboratory report may be written as 5.0 for a count of 5,000. When your child’s WBC count is low your child is less able to fight infections.

There are several types of WBC’s each having a special function. A test called the “differential” is the breakdown of the different types of white blood cells in your child’s blood count.

- Neutrophils and Bands – fight bacterial infection
- Lymphocytes- make antibodies
- Monocytes- destroy and remove bacteria
- Basophils and Eosinphils- respond during allergic reaction

The Neutrophils are the most important because they help protect the body from bacterial infections. Other names for the neutrophils are granulocytes, segs, bands or polys.

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

What you can do to protect your child when counts are low

- **Clean hands often and well** 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 churches.
- Avoid sick people
- Shower or bathe daily.
- Try to avoid nicks, cuts, and tears in the skin.
• 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.
• Avoid going barefoot.
• Be very careful when cutting nails to avoid nicks.
• Use cuticle cream remover instead of picking, tearing or cutting cuticles.
• If you shave, use an electric razor.
• Never use rectal thermometers/medications.
• Do not clean out litter boxes or birdcages. Avoid all contact with animal urine or stool or fish tanks.
• Remember to wear helmet if riding a bike.
• Women should not use tampons or douche.

Other things you should do

• Take short rest periods between activities.
• Do not take medications containing aspirin or ibuprofen (Advil®) unless ordered by the healthcare provider. These drugs can make the platelets less effective.
• Avoid long exposure to the sun and getting sunburned. Wear sunscreen of at least SPF 15.

These are general guidelines. Be sure to talk to your healthcare provider about any specific questions or unusual symptoms your child may have. For Bone Marrow Transplant patients, see Bone Marrow Transplant Discharge packet.

Contact Us

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• Life Threatening Emergencies dial 911
# CBC Summary

<table>
<thead>
<tr>
<th>Cell type</th>
<th>Function</th>
<th>Normal</th>
<th>Decreased Level</th>
<th>When decreased what to look for</th>
</tr>
</thead>
</table>
| White blood cells  | Fight infection  | 5,000-10,000 | <500=neutropenia | • Fever of 100.4°F (38°C) 2 times in 24 hours  
• Fever of 101.3°F (38.5°C) or greater once  
• Chills or sweating  
• Redness or swelling of any open areas on body  
• Any other signs of infection |
| Red blood cells    | Carry oxygen     | Hemoglobin (Hgb) 11 - 14 | <7 |
|                    |                  | Hematocrit (Hct) 31% - 43% | <20% |
| Platelets          | Control bleeding | 150,000-450,000 | 10,000 – 20,000 | • Easy bruising  
• Bleeding gums  
• Nose bleed |

For more information, please refer to the Blood Counts teaching sheet.

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Medications

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.
- To crush a pill it is easiest to use a pill crusher.
- You may try to break a pill in half. Smaller pieces may be easier for a child to swallow than a larger pill. You may use a pill cutter.

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
- Keep your child lying flat with head turned for approximately 2 minutes to allow the medicine to enter deep into the ear.
- If the child is less than 3 years old, gently pull the ear back and down while placing the drops in the ear.
- Children older than 3 years should have their ear gently pulled up and back while getting their ear drops.

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.

Rectal Medications
Medicines are not given rectally during treatment.
Medications

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.

- Make sure the patient’s name is correct
- Read directions about how to take the medication
- Check the medication name and concentration
- Check the bottle for refills
- Amount of medication to give

Refilling your Medication
Always read the label each time you refill your prescription.

- Ask about refills during your regular appointments.
- If refills are available and you need more medication, call your pharmacy.
- Remember to call for a refill before your run out of medication. Refills may take 48 hours.
- 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.

General Information:
- If your child has a life-threatening allergy, he/she should wear allergy identification at all times.
**Medications**

- 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.
- 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

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.

Intravenous Chemotherapy is given almost always at home by a visiting nurse through your child's central access tube located in the chest or arm.

Oral Chemotherapy is given by a caregiver by mouth or through a feeding tube in the form of pills, capsules, tablets or liquids. It is important to always read the label on the outside of the bottle and follow the directions for preparing the medication.

To safely prepare Oral Chemotherapy medications, follow these precautions:

- Anyone handling chemotherapy medications must wash their hands and put on disposable gloves to prepare and/or give oral chemotherapy medications.
- If you are, or may be pregnant, avoid 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.
- 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.
- All expired and/or unused oral chemotherapy should be placed in a sealed plastic bag and returned to the pharmacy in which the medication was dispensed or the Jimmy Fund Clinic.
Chemotherapy Safety

Chemotherapy (intravenous) medications that are given through an IV:
Intravenous Chemotherapy is given through an intravenous tube almost always at home by a visiting nurse.

- 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, a pair of gloves should be worn 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 to the company who supplied the infusion pump.

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 in disposing of urinal and commode waste. Wash hands with soap and water after removal of gloves.
- 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.
- Pregnant caregivers should not handle 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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Tips for Giving Your Child Medication

Taking medication can be difficult for some children. There are different ways that you can try to improve this experience for your child.

- Acknowledge that taking medicine can be difficult
- Provide information about the medicine
- Create structure and routine to medicine time
- Allow your child to have some choices when possible
- Praise your child for their efforts
- Do not hide medication in your child’s favorite food or drink
- Never refer to medicine as candy
- Always store medication locked and out of the reach of children and teens
- If your child is unable to swallow pills, but interested in learning, speak to your child’s psychosocial clinician or child life specialist
- If your child refuses to take the medicine, call a member of your child’s healthcare team for guidance

Giving Medicine to Infants (Birth-2 years)
- Give your baby liquid medicine using a medicine dropper or medicine syringe.

To give your baby medications using a medicine dropper or syringe:
1. Fill the dropper or syringe with the correct amount of medicine.
2. Hold your infant in a cradled position and gently pull down the chin while opening the child’s mouth. Swaddling in a blanket can be helpful.
3. Gently place the dropper or syringe in your baby’s mouth along the inside of the cheek and very slowly push the syringe to release the medicine.
4. Gently blowing on the face can trigger the swallow reflex in some infants.

Giving Medication to Children Ages 2-5 Years
- Give medicine to children age 2-5 years with a medicine cup or syringe.
- Gently place the dropper or syringe in your child's mouth along the inside of the cheek and slowly push the syringe to release the medicine.
- If the medicine can be crushed, mix it applesauce, pudding, or yogurt. Only use a small amount to ensure your child takes all of their medicine.
- If pills can be dissolved, use a syringe to deliver the medicine to your child by mouth when dissolved in water or liquid.
- Chewable tablets can be given to children 2 years of age or older. Make sure your child chews and swallows all the medicine.
Tips for Giving Your Child Medication

- Oral-disintegrating tablets can be given to children 2 years of age or older. Place oral-disintegrating tablet on your child's tongue or on the side of the cheek and let dissolve. Encourage your child to not chew the pill.
- For children this age, encouraging them to swallow the medicine and then gently blow out can prevent gagging.
- Make medicine time fun and playful
  - Include the child’s favorite toy
  - Encourage medical play with stuffed animals
  - Distract with movie or TV show

Giving Medication to Children Ages 5-12 Years

- At this age children can have a greater understanding about why they need to take medication.
- This may be a time when children start taking medication in pill form. If your child does not know how to swallow pills, talk to your child’s psychosocial clinician.
- It is still important to give choices and to ask supportive questions.
  - “How can I help you take your medicine?”
  - “What do you need to get this done?”

Giving Medication to Children Ages 12 Years and Up

- This age group can understand that taking their medication will help them feel better; they just don’t always want to. Resistance to taking medication is normal at this age.
- It may be helpful to remind your teenager that taking their medication is not a choice but giving them options or rewards may help the process.
- While many teenagers want the independence of taking their medications, many still need parents to have oversight of the medicines.
- Creating a sense of teamwork with your teen can help minimize power struggles
  - Include your teenager in their care plan
  - Encourage choices and a sense of control. Your teenager can pick a pill box, for example, and you fill the pill box together.
- Having to take medicines makes teens “feel different” from their peers. Do what you can to eliminate the possibility that taking medicines interferes with social engagements/activities.

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- Life Threatening Emergencies dial 911

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 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.
Ondansetron (on DAN se tron)

Other name: Zofran®

Used for: Controlling nausea.

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 heartbeat (IV)

Special instructions:

- This drug can be administered in many different ways (IV or orally [liquid, tablet, disintegrating tablet, or dissolvable film]) ask your health care provider or pharmacist for the best way to administer each
- Dose should be administered 30 minutes before starting chemotherapy or 60 minutes prior to radiation to help prevent 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.
- 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.

Contact Us

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

Other names: Bactrim™, Septra™

Used for: 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 orally or by injection.

Your child may experience the following common side effects:

- Skin sensitivity to light
- Platelets and white blood counts: prolonged suppression/longer recovery time following discontinuation
- Skin rash, hives, itching

Your child may experience the following less common side effects:

- Kidney toxicity
- Abdominal pain
- Diarrhea
- Nausea/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

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) (sul fa meth OKS a zole)

- Use sunscreen with SPF higher than 15 with any exposure to the sun and wear protective clothing, including a hat, when outdoors to avoid sunburn

**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.
- 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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Transfusion

Blood transfusions can be lifesaving. Transfusions are the administration of blood or blood products through a peripheral IV or central venous access device. They are given for many reasons. Donated blood is divided into parts including red cells, platelets and plasma, so it may benefit as many children as possible.

- **Red cells:** Red cells carry oxygen through the body and give us energy. If your child has a low red blood cell count, called anemia, your child may receive a red blood cell transfusion.
- **Platelets:** Platelets help stop bleeding by plugging holes in blood vessels. If your child has a low platelet count, called thrombocytopenia, your child may receive a platelet transfusion.
- **Fresh Frozen Plasma (FFP):** Plasma is the clear liquid portion of blood that also helps stop bleeding.
- **Intravenous Immunoglobulin (IVIG):** IVIG is a part of plasma that contains antibodies that help fight infection.
- **Albumin:** Albumin is a blood protein that may be given to treat low blood pressure or excessive blood protein loss.

Receiving a Transfusion

Red blood cells and platelets must be **typed** to match with your child’s blood. You may have to wait several hours for the blood product to be ready.

The amount of blood product your child will receive depends upon his/her weight. A signed consent is necessary prior to receiving a blood product transfusion. The consent is good for one year.

Your child will be closely watched during the transfusion. The nurse or clinic assistant will check the temperature, pulse, respirations, and blood pressure throughout the transfusion. The nurse will also watch for any side effects or reactions. A red blood cell transfusion will require two to four hours to complete; platelets require 30 to 60 minutes to infuse, but may take longer.

Risks of Transfusion

Receiving donated blood is now safer than ever because of improved testing. However, all blood transfusions carry a small risk.

**Transfusion Reactions:** Common signs of reactions include: fever, chills, muscle aches, nausea, and back pain. Your child may have hives, itching red face, vomiting, dizziness and noisy breathing. The nurse will stop the transfusion if these reactions occur and medication may be given. Your child may then need these medications before each transfusion.

**Infectious Risks:** All blood is screened for viruses and other infections including those that cause hepatitis, human immunodeficiency virus (HIV), human T-cell
Transfusions

lymphotropic virus (HTLV) and syphilis. The chance of becoming infected with one of these viruses is extremely small.

<table>
<thead>
<tr>
<th>Virus</th>
<th>Approximate risk per unit transfused</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV I</td>
<td>1 in 2,100,000 transfusions</td>
</tr>
<tr>
<td>HTLV I</td>
<td>1 in 3,000,000 transfusions</td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>1 in 1,900,000 transfusions</td>
</tr>
<tr>
<td>Hepatitis B</td>
<td>1 in 200,000 transfusions</td>
</tr>
<tr>
<td>West Nile Virus</td>
<td>1 in 1,000,000</td>
</tr>
</tbody>
</table>

Other infectious agents (Chagas, malaria, syphilis) are rarely transmitted by transfusion (less than 1 in a million). Bacterial infection of blood products may uncommonly occur. Albumin has not been shown to have a measurable risk of viral transmission. IVIG has caused hepatitis in the past, but current products are now treated in ways thought to prevent hepatitis.

Talk to your healthcare provider about any concerns you have about blood product transfusions.

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Fever and Neutropenia

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 health care provider right away if your child has a fever.

**Fever** is considered a temperature of 38.5° C (101.3 F) or higher, or 38.0° C (100.4° F) 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
- Shaking chills
- 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 temperature orally, in the ear or under the arm, **never rectally**!  
- **Do not give any fever reducing medicine until you have spoken to your health care provider.**
- If your child’s temperature is 38.5° C (101.3° F) or higher, or 38.0° C (100.4° F) twice in 24 hours, call the clinic or on call MD immediately. Your child needs to be seen by a health care provider as soon as possible.
- If your child has a port-a-cath, put EMLA cream on the port before leaving for the clinic or ED. Your child will be accessed for blood work and antibiotics. Our goal is that your child will receive IV antibiotics within one hour of contact in the clinic or ED (90 minutes if we are waiting for blood work to confirm neutropenia). Therefore, IV access as quickly as possible will be a priority.
Fever and Neutropenia

During clinic hours, call the Jimmy Fund Clinic and ask to speak to the triage nurse. You must arrive by 3pm to be seen in clinic. After 3 pm you will be sent directly to the Emergency Department (ED). After clinic hours, page the on call pediatric oncology fellow by calling the page operator.

**What happens if my child develops fever and neutropenia?**

If your child develops a fever when the ANC is less than 500, your child will be admitted to the hospital for IV antibiotics. In the emergency room or clinic, blood will be drawn to check for bacteria and your child will be evaluated for infection. While in the hospital, your child will receive IV antibiotics until the ANC increases (even if the fever goes away).

**When can we go home?**

The antibiotics are discontinued, and discharge from the hospital is possible when:

- Your child has had no fever for 24 hours
- The ANC is steadily rising
- There are no other signs of infection and your child appears well

Other factors, such as pain or being unable to eat or drink, may keep your child in the hospital longer, even if the blood counts have recovered. When you go home after a hospital stay for fever and neutropenia, please continue to follow these precautions:

- Avoid contact with people who are sick
- Use good hand washing
- Call your health care provider if a fever or any other signs of infection return

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Allergic Reactions

An allergic reaction may include itching, rash, hives (one or more small red bumps that appear on the skin), difficulty breathing, 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 have or 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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Hair Loss

Hair loss (Alopecia) can be caused by chemotherapy and radiation treatment. Hair usually begins to fall out about 14-21 days after receiving chemotherapy. Hair loss will occur over a period of days to weeks. Hair loss can range from slight thinning to complete baldness and may occur anywhere on the body.

Depending on the type of therapy, hair re-growth may start during treatment. In most cases it begins three to four weeks after therapy ends and may grow back a different color or texture. For most patients, hair will grow back after radiation. High doses of radiation therapy can cause permanent hair loss in the area being treated.

Some people 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
1st floor, Yawkey Building at DFCI- Monday through Friday 9a-5p
(617) 632-2211

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Constipation

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

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 helps:

- Offer small amounts of fluids at least every 2 hours.
- If your child is breast-feeding, you may continue nursing.
- 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.

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
  - No eating or drinking for 6 hours while awake if your child is younger than 1 year old
  - No eating or drinking for 8 hours while awake if your child is older than 1 year

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Fatigue

Fatigue can be described as feeling more tired than usual. The fatigue that comes with cancer 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 helps?

- 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
- Accept help from friends and family
- Discuss concerns with your health care team

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Skin Care During Treatment

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
- Use a scent-free moisturizing lotion after bathing
  - Always check with your health care provider before using any sort of medicated cream, ointment or lotion
  - Do not use any lotions, creams, or ointments if your child is receiving radiation or total body irradiation
- 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. They are NOT sunscreens, unless the product specifically says it contains a SPF

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Mouth Care

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

- Brush your teeth with a soft toothbrush after each meal and before bed.
- Electric soft toothbrushes can be used.
- Children under six years old should have their mouth care provided by an adult caregiver.
- 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.
- Patients who have fluoridated water do not need fluoride supplements.

Dental Visits

Patients should see a dentist regularly. Scheduling this appointment is depending on 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).

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:

- Drinking cold or room temperature fluids through a straw
- Avoiding hot, spicy or acidic foods
- Eating foods that are soft, tender or pureed (beaten or blended)
- Cutting food into small pieces
- Taking pain medication

When to call:

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

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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 and radiation therapy. These side effects may include:

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

If your child’s immune system is not working as well as it should, he’s at risk of food borne infections, especially if he’s has neutropenia, which means having low levels of a type of white blood cell (ANC less than 500). This makes it hard for the body to fight infections.

What are guidelines for food safety?

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

- **Wash your and your child’s hands well** before and after preparing, cooking and eating meals.
- **Clean all cooking tools very well** before and after each use.
- **Use water and a clean brush to scrub fresh fruits and vegetables** before eating or cooking them.
- **Heat sliced deli meats** to a steaming temperature before eating.
- **Throw away leftovers that have been at room temperature** longer than two hours.
- **Check the internal temperature of cooked dishes in several places** with a food thermometer to make sure they’re cooked long enough. We recommend:
  - 160°F degrees for beef, lamb, veal, pork and egg dishes
  - 170°F degrees for stuffing and casserole
  - 180°F degrees 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 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 165º F.

What are foods that I should not give my child?

Don’t give your child:

- food from street vendors, salad bars or shared bins
- raw eggs
- raw fish
- raw shellfish
- soft French-style cheeses (such as brie)
- pates
- uncooked hot dogs
- raw seed sprouts (like alfalfa sprouts)
- 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 (like chicken, turkey, duck or geese).
- **drink directly from cans** - Wash the can before opening it and pour into a clean cup.
What can help my child get better nutrition during treatment?

**General tips**
Give your child five to six small meals or snacks throughout the day.
Keep healthy snacks available.
Give a snack before bedtime.
Give high-calorie drinks, like chocolate milk, whole milk, smoothies, shakes/frappes or full-fat soy milk.
Notice the time of day when your child’s appetite is best. Have him eat more then.

**If your child has nausea or vomits (throw up)**
Give him the prescribed anti-nausea medications 30 to 60 minutes before eating.
Keep him upright/sitting up for at least two hours after eating.
Try feeding him dry, salty foods, such as crackers, potato chips or pretzels.
Avoid giving him foods with strong odors or that are deep-fried.
Give him cool liquids between meals, like lemonade or juice diluted with water. Have him use a straw.
Offer him ginger tea or cookies.
Have him smell cut lemon or orange.

**If your child has mouth sores**
Give him 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 pizza and curry sauce.
Avoid extremely sweet foods. Taste changes happen frequently with sweets and they can taste “like cardboard” or “just not right.”
Sour/tart candies may help with metallic taste.

**If your child has high blood pressure**
Avoid salty foods, like canned soups, pickles, processed meats and cheeses.
Do not add salt to foods.
If you need to limit the amount of salt your child eats, ask your dietitian for information about the No Added Salt Diet.

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What are some high-calorie foods?

Pick your favorite recipe from this list, or mix and match. Simply mix the ingredients in a blender and enjoy.

**Vanilla Shake**
1 1/2 cups ice cream (3-4 scoops)
1/2 cup whole milk
3 tablespoons nonfat milk powder (or 2 tablespoons chocolate, strawberry or coffee syrup)

**Strawberry Shake**
2 cups whole milk
2/3 cup nonfat dry milk powder or 1 package vanilla Carnation Instant Breakfast
2 1/2 cups strawberry ice cream
2 tablespoons heavy cream

**Strawberry Banana Smoothie**
1 cup whole milk
1/2 cup yogurt
1 banana
1/2 cup strawberries

**Banana Orange Shake**
1/2 cup whole milk
1/2 cup orange juice
1 cup vanilla ice cream
2 whole bananas

**Peanut Butter Shake**
1 cup whole milk
3 tablespoons smooth peanut butter
3 tablespoons chocolate syrup

**Fortified Milk**
Add 2-4 tablespoons powdered nonfat milk to 8 ounces of whole milk

**Super Pudding**
1 cup fortified milk
1 cup heavy cream
1 package (4 1/2 oz) instant pudding
❖ Prepare according to package directions and divide into 1/2 cup servings.

**Super Grilled Cheese**
Dip cheese sandwich into egg and fortified milk mixture before grilling with lots of butter or margarine. This will be like French toast with cheese in the middle.

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 at Boston Children’s Hospital (617-355-4677).

For other questions, please call the following phone numbers:

- **Monday-Friday 8:00am-5:00pm:** Call the Jimmy Fund Clinic at 617-632-3270.
- **Weekdays after 5:00pm, holidays and weekends:** Call the page operator at 617-632-3352 and page the pediatric hematology/oncology or stem cell transplant fellow on call.

Please note: This Family Education Sheet is for educational purposes only. For specific medical advice, diagnoses and treatment, talk with your doctor and/or dietitian.

This Family Education Sheet is available in Spanish.
Nausea and Vomiting

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.

- 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

Suggestions to lessen nausea and vomiting

- Nausea and vomiting can be eased by medicines called antiemetics (anti-nausea medications).
- 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 such as deep breathing, telling a story, or watching a movie may also help relieve nausea.
- 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.

When to call

- Nausea or vomiting that does not stop after taking anti-emetics
- 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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Peripheral Neuropathy

Cancer or cancer treatments such as chemotherapy may cause injury to the peripheral nerves (nerves outside the brain and spinal cord). This is called Peripheral Neuropathy.

Symptoms of Peripheral Neuropathy
- Most often occurs in the hands or feet.
- Weakness.
- Unsteadiness or tripping when walking.
- Muscle cramps.
- Numbness or tingling. These symptoms may be worse at night.
- Sensitivity to touch.
- Change in sensation, for example loss of temperature sensation.

Treatment
Most often these symptoms are temporary and will get better over time. Treatment may include stopping or changing the dose of the medication that may have caused the peripheral neuropathy. Additional treatment is aimed at relieving the symptoms:
- **Medication** – There are effective medications for nerve pain. Speak to your healthcare provider about what is the best option for your child.
- **Physical therapy** – may help strengthen muscles and relieve symptoms.
- **Integrative therapies** – Meditation, relaxation, guided imagery, self-hypnosis, acupuncture and massage can be helpful. Ask your healthcare provider to request this consultation.

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Pain

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 say how much discomfort or pain they have.

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 cannot tell you directly, 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 pain is managed?
Pain is best managed with a combination of different medicines as well as coping techniques.

**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.

**Coping Strategies**
There are different ways 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
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.

Common Questions and Answers about Pain

- **Can babies feel pain?** Yes, research has now shown that infants can 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 to provide comfort, improve healing, and prevent complications. The risks of giving pain medicine may include constipation, sleepiness or slow breathing.

- **Should I be concerned that my child or teenager could become addicted to pain medicine?** Pain medication is often a necessary part of treatment. Some children and teens may need to take Opioids (often called narcotics) during their 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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Fever Information and Temperature Conversion

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

Call your healthcare provider right away if your child has:
- A temperature of 38.5°C (101.3°F) or higher
- A temperature of 100.4°F (38°C) or higher twice in 24 hours

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

Please refer to chart on the following page

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Infection Control

Chemotherapy, radiation and surgery can lessen your child’s ability to fight infection. Some suggestions for preventing infections in your child are described in the following sections.

Hand Washing

- Hand washing is the best way to prevent infection.
- When using soap and water rub your hands together for 10-15 seconds.
- 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.
- If your child is on precautions for an infection called “C-diff”, use soap and water, as antibacterial gels do not work against “C-diff”.
- Wash your hands:
  - After using the bathroom, blowing your nose, coughing, or sneezing
  - Before and after eating, drinking, or handling food
  - After touching animals
  - When your hands look or feel dirty

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
  - 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
    - Keep hot foods hot and cold food cold
    - Always refrigerate leftovers and items that spoil
    - Do not drink unpasteurized milk
    - Do not eat uncooked or raw meat, poultry, clams, fish, or eggs
  - When your child’s 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
Infection Control

- 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.
- If fever or illness develops at home, contact the treatment team right away for further instructions.

When at the hospital
- If you or your child come to the hospital with fever, cold like symptoms, diarrhea, vomiting or any other illness, please let a nurse know right away.
- Screening is required at the information desk daily for all visiting children under the age of 12. A GREEN dinosaur sticker is placed on children that may visit.
- 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:
  - 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 clinic
- If you or your child come to the clinic with fever, cold like symptoms, diarrhea, vomiting or any other illness, please let a clinic assistant or front desk staff know right away.
- Do not bring siblings who are sick to the clinic.
- 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:
  - 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.

Contact Us

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Home Hydration after Chemotherapy

Intravenous (IV) fluids for hydration after chemotherapy can be given at home. When IV fluids are given at home, it is important for you to know what to do and who to call for medical help.

When Receiving IV Fluids at Home:

1. Periodically check the pump to be sure the IV fluids are infusing.
2. If your child is receiving hydration overnight, check the access site and/or tube connections before bedtime and when your child wakes up. If your child is receiving hydration during the day, check the access site and/or tube connections every 2 hours.
3. If your child has a port-a-cath:
   a. The needle should be in place
   b. The dressing should be dry
   c. There should not be redness, leakage or swelling around the access site
4. If your child has a central line or PICC line:
   a. Be sure the tubing is connected
   b. Check to make sure there is no leakage
5. If the IV tubing becomes disconnected:
   - Clamp the IV tubing
   - Turn off the pump

Who should I call for help?

Call your infusion company if the pump alarms and you are not able to fix the problem.

During Clinic hours call the Jimmy Fund Clinic (617-632-3270). During Evenings (after 5:00pm), Weekends, Holidays call the Pediatric Oncology Fellow on call (617-632-3352) if your child has any of the following problems:

- Vomiting more than twice in 8 hours
- Not urinating at least every 4-6 hours
- IV line comes apart
- Implanted port site looks puffy or the needle comes out
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Immunizations

Talk to your oncologist before your child receives any vaccines.
Immunizations (vaccines) are an important part of your child’s health care. However, your child should not receive any live vaccines while on treatment. Examples of live vaccines are: the measles, mumps and rubella (MMR), chicken pox vaccine, and the intranasal flu vaccine. Live vaccines can cause illness in children who are at increased risk of infection. Your 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.

Can my other children receive immunizations?
Yes! Brothers and sisters (siblings) of patients are allowed to be immunized with all the normal vaccines required for healthy children. Always call your provider if a sibling develops symptoms after receiving any vaccine.

Please note the following: Hematopoietic stem cell transplant patients must speak with his/her provider before any family member gets the chicken pox vaccine. (Refer to Chickenpox and Shingles after Transplant teaching sheet.)

What about Flu (influenza) shots?
It is strongly recommended that all patients and their household contacts receive a flu shot each year. Patients may receive their flu shot in the clinic. Family members and siblings can receive flu shots from their 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 or for the H1N1 virus.

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Chicken Pox (Varicella)

Chicken pox is an infection caused by the varicella virus. People who have had chicken pox or the vaccine should be protected from getting this infection. Chemotherapy can take away this protection. Ask your health care provider if your child is at risk for getting chicken pox.

Symptoms of chicken pox include:
- Rash with small red spots anywhere on the skin
  - These spots often have a clear, fluid filled center
  - New spots can develop for several days
  - The rash is usually very itchy
  - The spots will become dry and crusted as they heal
- Fever

Exposure
- Chicken pox is usually spread through close contact, through droplets in the air
- Exposure to chicken pox means being around a person who:
  - breaks out with the spots within 1 to 2 days
  OR
  - has chicken pox
- A contact of five or more minutes is considered an exposure
- The virus can also be spread by contact with zoster blisters

Treatment
- **If your child is exposed to chicken pox or develops chicken pox, call your care provider immediately.**
  - Your child may need to receive an injection of varicella zoster immunoglobulin (VZIG) to help protect against this virus.
  - If they develop chicken pox they may need antiviral treatment.
How long are people contagious?

- People with varicella are most contagious for 1 to 2 days before and after the onset of the rash, until the spots are all crusted.
- Your child may develop chickenpox between 10 and 21 days after being exposed.
- If your child received Varicella-Zoster Immune Globulin (VZIG) as a treatment, they will need to be in isolation for 28 days since this can delay the development of chicken pox.

Special Instructions

- If family members or others in close contact with your child have NOT had the chicken pox, please inform your healthcare providers.
- Talk with your healthcare provider before your child or any family members receive the vaccine.

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Shingles

Shingles, also called zoster, is caused by the varicella virus, which also causes chicken pox. Shingles may occur in anyone who has already had varicella (chicken pox) or the chicken pox vaccine. The chicken pox virus stays in the body long after the disease goes away in an inactive form. If the immune system is not working well, the virus can become active again.

Shingles usually occur as a patch of red blisters along a line of the skin on the back or chest or other part of the body. The blisters usually occur on one side of the body. It can be very painful, with a deep burning feeling along the nerves affected by the infection. There can also be fever, chills, and flu-like symptoms as the rash develops.

Exposure

- If you have never had chicken pox or the chicken pox vaccine and are exposed to someone with shingles, you can get chicken pox. This most often occurs by touching the rash.
- If your child is admitted to the hospital or seen in clinic, they will need to be in an isolation room to prevent exposing other children.

Treatment

- Antiviral medications are given in some cases.
- Medications for pain and itch may also be given.
- Your child may need to be admitted to the hospital for treatment.

Special Instructions

- Antiviral medications are most effective when given early, so call your care provider right away.

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### Weekly Medication Schedule

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Emotional Support for the Whole Family: Pediatric Psychosocial Oncology

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 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.

www.danafarberbostonchildrens.org/psychosocial
Contact Us

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Back to School Program

The Back to School program, sponsored by Dana-Farber/Children’s Hospital Cancer Center, is designed to ease your child’s transition back to school. Cancer treatment and stem cell transplant care 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 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

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Sibling Program

When your child is receiving treatment, this impacts the entire family, through multiple doctor 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 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, also available on YouTube, 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:

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 these special opportunities:

- **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 ages 5 to 12 years are invited to attend this weekly group.

- **Support for Siblings in the Schools Program**: The program provides information to teachers and guidance counselors about how to support the sibling.

- **Teen Sibling Program**: Several times a year special group activities for teen siblings are provided.

- **Parent Support**: Psychosocial staff and the Sibling Specialist 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**: Like 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.
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**Tips for Teachers: The Sibling Experience**

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

Please contact the parent(s) or guardian(s) if you have any concerns.

**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
Integrative Therapy

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 also help guide you to services such as acupuncture, massage, Reiki and yoga. There may be funding for free sessions at the Zakim Center for pediatric patients. For more information or to schedule an appointment, call 617-632-3322 or email zakim_center@dfci.harvard.edu.
- When inpatient at Boston Children’s Hospital, please have your clinical staff contact 617-355-7684 with a referral. Services available for our patients at no cost include: Massage Therapy, Acupuncture, Reiki, Yoga, Meditation, and Aromatherapy.
- 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 6th floor at Boston Children’s Hospital has books and other information available about integrative therapies.
Contact Us

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Spiritual Care

Spirituality can be an important source of strength, comfort, and hope for patients and families. Chaplains are available for spiritual and emotional support at Dana-Farber/Children’s Hospital Cancer Center. Chaplains represent a broad range of religious and spiritual traditions. Chaplains can provide a comforting presence and be a resource for helping you meet your own unique spiritual needs.

Services chaplains provide:

- Support around spiritual, religious, and emotional issues
- Prayer request at any time during your treatment
- Religious rituals, sacraments, or worship services
- Help with life transitions or losses
- Scripture or other devotional resources in a variety of traditions and languages

CHAPLAINCY AT CHILDREN’S HOSPITAL BOSTON

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.

Chapel: Children’s interfaith chapel is located on Farley 1 near the Center for Families. The chapel is open 24 hours a day.

Website: [www.childrenshospital.org](http://www.childrenshospital.org) (find chaplaincy under "For Patient and Families"). The website has links to prayer times, places of worship in the Boston area, dietary, and bereavement resources.

Channel 28 on Your TV: Includes sounds of a trickling waterfall, a quiet walk through a garden, music and sacred images, and prayers.

Phone: (617) 355-6664

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
Contact Us
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