

A Handbook About Your Care



DANA-FARBER/BRIGHAM AND WOMEN'S



CANCER CENTER



Welcome

Our interpreters can help patients communicate across languages and cultures. Services are available in many different languages, either in person or by telephone.

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If you need an interpreter, call:

617-632-3673 Dana-Farber

617-732-6639 Brigham and Women's

Si necesita un intérprete, llame al:

617-632-3673 Dana-Farber

617-732-6639 Brigham and Women's

Se precisar de um intérprete, ligue ao:

617-632-3673 Dana-Farber

617-732-6639 Brigham and Women's

Если Вам требуется помощь переводчика, звоните

617-632-3673 Dana-Farber

617-732-6639 Brigham and Women's

For a Spanish copy of this handbook, call 617-632-3673.

Para pedir una copia de esta guía en español, llame al

617-632-3673 o visite <http://espanol.dana-farber.org>.

In an Emergency

If you have a medical emergency, dial 911. For non-emergency situations, ask your care team what number you should call during regular business hours, and keep this phone number handy. After hours and on weekends, you can page your doctor or an on-call doctor by dialing 617-632-3352 (Dana-Farber)

or 617-732-5500 (Brigham and Women's).

My important phone numbers:

From the Adult Patient and Family Advisory Council

A Note to New Patients

Welcome.

As current or former patients and family members who serve you through the Adult Patient and Family Advisory Council, we, too, have experienced cancer care. We are volunteers who contribute the “voice of the patient and family” to your health care providers.

Dana-Farber/Brigham and Women’s Cancer Center is a leader in the practice of patient- and family-centered care, which means that you are an active member in your care and you play a central role in all decision-making, ensuring that you receive the medical treatment, information, and support you need. Strengthening these efforts is Dana-Farber’s new Yawkey Center for Cancer Care, a state-of-the-art facility designed with the careful guidance of our patients and families to improve your experience here.



We work diligently to help ease the burden of cancer treatment for patients and their families, and we hope that this handbook is useful to you. We wish you well and are here to help.

Sincerely,

The Adult Patient and Family Advisory Council
 Dana-Farber/Brigham and Women’s Cancer Center
 617-632-4319
www.dana-farber.org/pfac

Reminder for Families and Friends

A diagnosis of cancer or another serious illness often has a ripple effect on family and friends. You may find yourself devoting a great deal of your time and attention to the person who is sick. This is important, but you also need to take care of yourself.

Accept offers for help, and tap the many resources here at Dana-Farber/Brigham and Women’s Cancer Center. You can find practical tips and suggestions online at www.dana-farber.org/caregivers.

Here for You

You're welcome to bring a friend or family member along to your appointments at DF/BWCC.



Getting Started

About Dana-Farber/Brigham and Women's Cancer Center

Dana-Farber/Brigham and Women's Cancer Center (DF/BWCC) is a collaboration between Dana-Farber Cancer Institute and Brigham and Women's Hospital to provide the best possible care to adults with cancer or certain blood diseases. Dana-Farber provides most outpatient services, while inpatient care is provided by Brigham and Women's Hospital.

We also offer services and care at DF/BWCC satellite centers in Boston and beyond. These centers, which are listed on the back of this handbook, allow patients to benefit from our expertise and services in the convenience of their own communities.

Tips for Patients

You and your family are important members of your health care team. These tips can help you get the most out of each appointment.

- **Communicate with your health care team.** Always feel free to ask questions or have something explained again. Consider bringing a friend or family member when you meet with your health care team.
- **Listen carefully.** Take notes when your doctor or nurse explains something, or ask a loved one to do so. Ask if it's okay to use a portable tape recorder or digital voice recorder, so you can record conversations and listen to them again at home.
- **Write it down.** If you have questions before an appointment, write them down and ask them when you meet with your health care team.
- **Bring your ID cards.** Keep your insurance card and hospital cards with you at all times. If you have insurance questions, visit www.dana-farber.org/insurance.
- **Know what medications you take.** Make a list of the medications you take and any allergies you have. Update this list often, and carry it with you so you can share it with your health care team.

Choose Your Health Care Proxy

A health care proxy form is a document that can ensure your beliefs and values will be heard and followed if you cannot communicate them yourself. Any adult can fill out and sign a health care proxy. It requires only the presence of two witnesses, who also sign the form. It does not cost money or require a lawyer.

To get the health care proxy form, call 617-632-3417 or find it at www.dana-farber.org/healthcareproxy.

Manage Your Care Online

Patient Gateway is a secure website at www.patientgateway.org designed to help you manage and maintain your care. You can use the site to privately and securely:

- Schedule appointments
- Request routine prescriptions
- Check your lab results
- View parts of your medical record
- Get timely news and updates
- E-mail your doctor

To learn more about the secure Patient Gateway website, visit www.patientgateway.org.

Healthy Tips

Many cancer patients have weakened immune systems, so it's important to practice good hygiene at DF/BWCC:

- Wash your hands often.
- Cover your nose and mouth when you cough, using a tissue or your arm or shoulder.
- Avoid close contact with people who have a cold or flu-like illness.
- If you are sick with cold or flu when you are scheduled for an appointment, call your clinic to ask about rescheduling.
- If friends or family members are sick, ask them to stay home.

Finding Your Way

Dana-Farber Cancer Institute and Brigham and Women's Hospital are located in Boston's Longwood Medical Area, which offers access to public transportation, shuttle service, and a number of parking options.

AT RIGHT: DF/BWCC
IN THE LONGWOOD
MEDICAL AREA

Getting Directions

To hear a recording of directions, call 617-632-3400 (Dana-Farber) or 617-732-6000 (Brigham and Women's).

Parking

- At Dana-Farber, valet and self-service parking are available in the garage located under the Yawkey Center for Cancer Care. The garage entrance is on Jimmy Fund Way. To learn more, call 617-632-3134 or visit www.dana-farber.org/directions and click on "Parking."
- At Brigham and Women's Hospital, valet parking for patients is available at every entrance. Visitors can park in the garage at 70 Francis St., near the corner of Brookline Avenue and Francis Street. To learn more, call 617-732-5877 or visit us at www.brighamandwomens.org/parking.

Public Transportation

DF/BWCC is accessible by buses and subways operated by the Massachusetts Bay Transit Authority (MBTA). To get travel information and schedules from the MBTA, call 800-392-6100 or visit

www.mbta.com. People with hearing problems can call the TTY line at 617-222-5146.

The nearest subway stops are:







- Green Line (**Heath Street "E" branch**): The Brigham Circle stop is closer to Brigham and Women's Hospital.
- Green Line (**Riverside "D" branch**): The Longwood stop is closer to Dana-Farber.

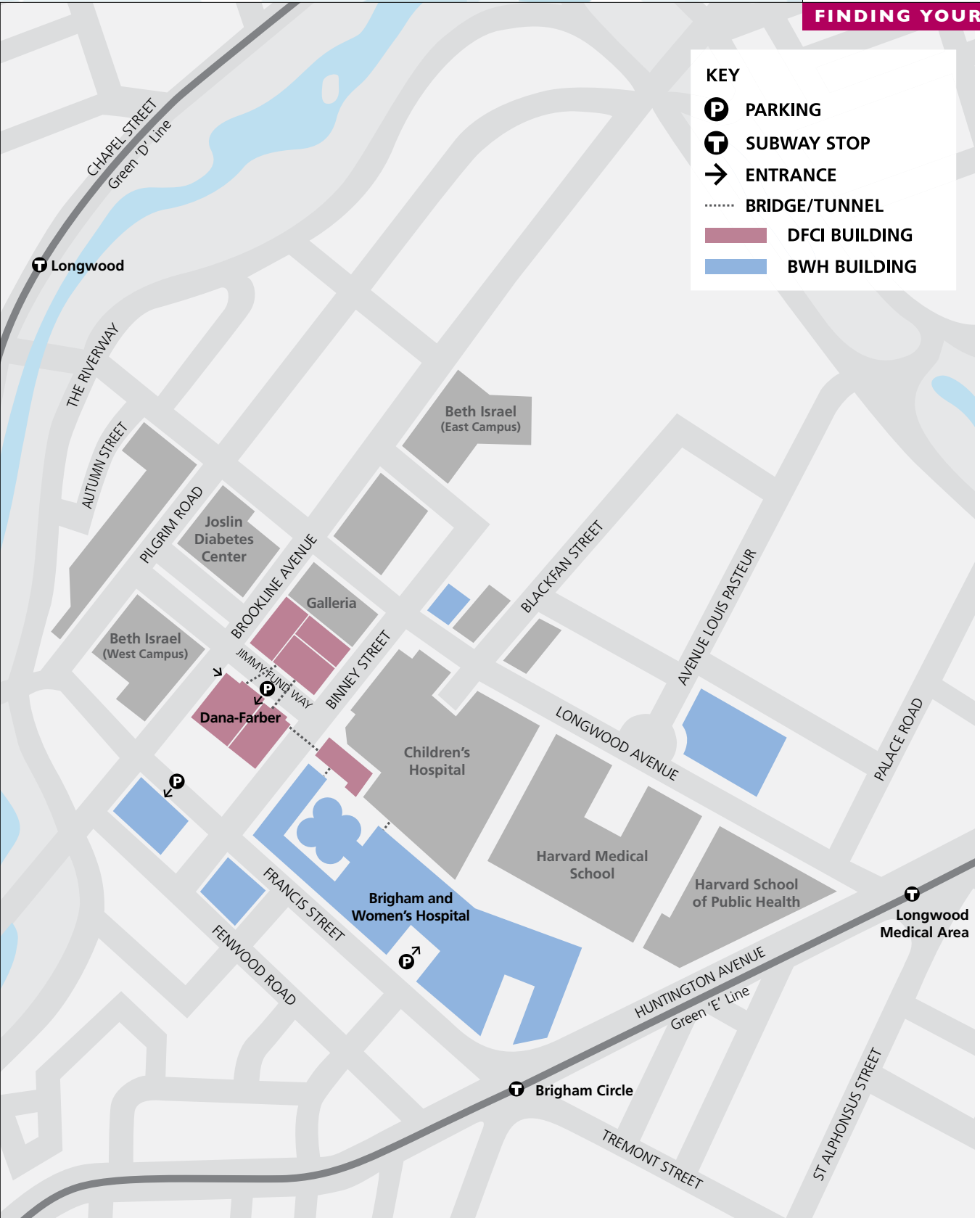
Partners HealthCare Shuttles

Partners HealthCare offers free shuttles between DF/BWCC (picking up and dropping off at Brigham and Women's Hospital) and other affiliated institutions, including Faulkner Hospital. To find schedules and a list of destinations, please visit www.partners.org, select "Our Hospitals and Affiliates," and then click on "Shuttle Schedules."

For more details, visit us at www.dana-farber.org/directions or www.brighamandwomens.org/directions.

KEY

-  PARKING
-  SUBWAY STOP
-  ENTRANCE
-  BRIDGE/TUNNEL
-  DFCI BUILDING
-  BWH BUILDING



Your Health Care Team

From your first appointment at Dana-Farber/Brigham and Women's Cancer Center (DF/BWCC), our specialists will work with you as a team to evaluate and treat your cancer. They will answer any questions and discuss treatment options, including the possibility of participating in clinical trials of innovative new treatments. Our goal is to provide an expert evaluation and the most advanced care possible.



Working for You

No matter your diagnosis, our specialists work together as a team for you. Depending on your needs, you can expect to see some of the health care experts listed here, and perhaps others as well.

Doctors

- **Attending physician:** Supervises your care when you need treatment as an inpatient (in the hospital).
- **Medical oncologist:** Specializes in cancer and oversees your chemotherapy and/or other medical treatment.

- **Surgical oncologist:** A surgeon who specializes in cancer surgery, creating your operative plan, performing the procedure, and supervising your post-operative care.
- **Radiation oncologist:** A physician who specializes in the treatment of cancer using radiation.
- **Psychiatrist:** A physician who helps you manage the psychological and emotional issues you may experience. A psychiatrist can prescribe medications.
- **Psychologist:** A clinician who helps you manage psychological and emotional issues using psychotherapy. A psychologist does not prescribe medications.
- **Oncology fellow:** A physician in training who cares for patients, under the supervision of oncologists.
- **Intern and resident:** A physician in training who may provide some of your care.

Nurses and Physician Assistants

- **Nurse practitioner:** Works with your doctors or independently to provide your care.
- **Oncology nurse:** A nurse who specializes in the care of cancer patients and their families.
- **Physician assistant:** Works with your doctors to provide care.

Professional Support

- **Clinical social worker:** Provides emotional support and counseling.
- **Chaplain:** Offers spiritual support to patients and families of all beliefs.
- **Resource specialist:** Helps you find community services and programs.

Other Members of Your Team

- **Administrative staff:** A new patient coordinator arranges your first outpatient visit. A clinic administrator schedules your outpatient appointments and tests. An inpatient unit coordinator organizes care in the hospital unit.
- **Pharmacist:** Prepares and dispenses your medications and chemotherapy.
- **Physical or occupational therapist:** Assists with physical difficulties that may result from illness or treatments.
- **Registered dietitian:** Helps you create a plan for healthy foods and meals.
- **Respiratory therapist:** Provides care and assistance to patients with cardiopulmonary (breathing) problems.

Learn more about DF/BWCC's cancer expertise online at www.brighamandwomens.org/cancer.

Treatment Centers

You will be seen in one of our specialized treatment centers, each of which is devoted to fighting a particular type of disease.

- Breast cancer**
- Cutaneous cancer** (skin)
- Endocrine cancer** (thyroid, adrenal, gland)
- Gastrointestinal cancer** (colon, liver, stomach, esophageal, pancreatic, rectal, anal)
- Genitourinary cancer** (bladder, prostate, kidney, testicular)
- Gynecologic cancer** (cervical, ovarian, uterine, vaginal)
- Head and neck cancer**
- Hematologic malignancies** (blood cancers, such as leukemia, lymphoma, and multiple myeloma)
- Hematology** (blood diseases)
- Melanoma** (skin cancer)
- Neuro-oncology cancer** (brain and spinal cord)
- Sarcoma** (soft tissue and bone cancer)
- Thoracic cancer** (cancers in the chest, such as lung cancer)



Your Cancer Treatment

After your care team determines your diagnosis, they will work with you to choose the best course of treatment. This may involve chemotherapy, radiation therapy, stem cell transplant, surgery, or other options. Here's a closer look at some common ways to track and treat cancer.

Chemotherapy

Chemotherapy uses anti-cancer medications to kill cancer cells and help prevent them from multiplying in your body. The two most common ways to receive chemotherapy are:

- **Infusion**, which delivers medications or other fluids into the body through a needle or device inserted into a vein. Depending on your treatment plan, you may need to have chemotherapy via

infusion while you are an outpatient or as an inpatient.

- **Oral chemotherapy**, in which your doctor prescribes anti-cancer pills or capsules that you can take at home.

Radiation Therapy

Radiation therapy uses high-energy X-rays or beams to kill cancer cells or keep them from growing and dividing.

- **Where it happens:** Radiation

therapy units are at Dana-Farber on the lower levels of the Dana building and on Lower Level 2 of the Ambulatory Services building at Brigham and Women's.

- **How long it takes:** Radiation treatments generally take only a few minutes and are given every day. These daily treatments generally last from one to six weeks.
- **Learn more:** Visit us online at www.brighamandwomens.org/cancer and click on the "Radiation Oncology" link.

Inpatient Care and Surgery

If you need surgery or need to be hospitalized for cancer-related

services at DF/BWCC, your care will most likely take place in the Brigham and Women's Hospital Surgical Units or Medical Oncology Unit at 75 Francis St.

- **Getting ready:** If you are scheduled for surgery, you will receive instructions on how to prepare. If you have questions about your inpatient admission, call the Sharf Admitting Center at 617-732-7450.
- **Handy tip:** In most cases, a family member can stay overnight in your room if you are an inpatient. To learn more, visit www.brighamandwomens.org/cancer and click on "Inpatient Care."

What to Expect at Your Outpatient Appointment

If you are scheduled for an outpatient visit at DF/BWCC, the following tips may help:

- **Please arrive and check in at your appointment on time.** Be sure to allow adequate time for travel and parking.
- **Be prepared to visit several areas.** If you're scheduled for chemotherapy infusion, your appointment may start with a blood test. Then, you might visit with a nurse practitioner or oncologist on your clinic floor. Next, you'll move on to infusion. All of these steps take time, and there may be a wait between each step.
- **Why the wait?** We are constantly trying to reduce waiting times, but sometimes waits are a normal part

of the process. For example, we may need to wait for your blood test results, which are needed before your chemotherapy can begin. It also takes time to safely prepare your medication for infusion.

- **Before you leave:** Be sure to make your next appointment before you leave for the day. You may also want to visit the Dana-Farber retail pharmacy to pick up prescriptions.

We welcome your feedback and suggestions on how to make your visits more comfortable or efficient. Talk with a member of your care team if you have questions or ideas.

Tips about Infusion

If you need chemotherapy via infusion in one of Dana-Farber's outpatient clinics:

- Feel free to bring books, magazines, a laptop computer, or portable music (with earphones) to help pass the time.
- To avoid our busiest times, schedule your infusion appointment before 10 a.m. or after 2 p.m.
- You can bring drinks or snacks, or purchase items in one of our dining areas. Volunteers may also deliver snacks in certain areas.
- You can bring one adult family member or friend to your appointment. Children are welcome in the adult clinic areas if accompanied by another adult.

YOUR CANCER TREATMENT

Stem Cell Transplants

A stem cell transplant is the infusion of healthy stem cells into your body. It is used to treat certain blood diseases and blood cancers, such as leukemia, lymphoma, and multiple myeloma.

- **Where it happens:** Your care before and after a stem cell transplant will take place in Dana-Farber's outpatient clinic, and your procedure will take place at Brigham and Women's Hospital.
- **Getting ready:** If you need a stem cell transplant, you will be given a comprehensive guide for patients and caregivers to help you prepare.

Clinical Trials

A clinical trial (also called a research study) seeks answers to questions about new treatments. Clinical trials test

new therapies, look at new ways to give treatment, find out how lifestyle changes can help cancer patients, and explore ways to keep cancer from recurring. These trials ultimately allow us to bring the latest and most effective therapies to patients.

- **Getting ready:** If you are able to participate in a clinical trial, your doctor, nurse, and members of the study team will explain the purpose of the trial, and discuss the benefits and risks with you.
- **Wondering whether a clinical trial might be right for you?** Visit www.dana-farber.org/clinicaltrials or call toll-free 866-790-4500.

Tracking Your Progress

You may need one or more imaging tests to see where your cancer is



Pharmacy

Our experienced pharmacists prepare and dispense chemotherapy and other medications for both inpatients and outpatients at DF/BWCC. As members of your health care team, they also participate in the physicians' daily work rounds.

- **Where to pick up a prescription:** At Dana-Farber, the outpatient pharmacy is located on the 2nd floor of the Yawkey Center. At Brigham and Women's, the outpatient pharmacy is on the 2nd floor,

along "The Pike" (a long hallway that connects many departments).

- **Handy tip:** If your doctor gives you a prescription during your visit to DF/BWCC, you can request that the prescription be forwarded to the outpatient pharmacy while you're still in the building. You'll be able to pick it up before you leave – or have it mailed to your home.



located and what progress you've made during treatment. These tests include: radiography, mammography, ultrasonography, computed tomography (CT), magnetic resonance imaging (MRI), single photon emission tomography (SPECT), positron emission tomography (PET), and more.

In DF/BWCC's many pathology laboratories, physicians, scientists, and technologists diagnose and classify tumors and other illnesses through biopsies, blood tests, or other specimens. They provide reports that can help you and your doctor choose the best therapy for your type of cancer and genetic make-up. Periodic examination of new specimens can also help

doctors measure your body's response to treatment.

- **Where it happens:** Diagnostic services are located throughout DF/BWCC. If you need a scan or test, we'll give you instructions on where to go.
- **Getting ready:** If a test or scan comes with special requirements, such as not eating or drinking certain items, a member of your care team will let you know in advance.

Learn more about some of the diagnostic tools used to track treatment at www.dana-farber.org.

Our Expertise in Clinical Research

Dana-Farber and Brigham and Women's Hospital are founding members of Dana-Farber/Harvard Cancer Center, a research collaborative that brings together leading cancer institutions, including Dana-Farber; Harvard Medical School, Harvard School of Public Health, Brigham and Women's Hospital, and three other Harvard-affiliated hospitals, to form the largest comprehensive cancer center in the world. Each year, our research efforts and collaborations give patients access to hundreds of clinical research trials that offer the most advanced treatment protocols, before they are available to patients at other institutions.

Treating the Whole Patient

DF/BWCC offers programs and services designed to address the wide range of needs that can result from cancer treatment. Our experts will work with you to promote the wellness of both your mind and body.

Integrative Therapies

The Leonard P. Zakim Center for Integrative Therapies at Dana-Farber gives patients access to services that are designed to complement traditional cancer treatments. The center offers services such as acupuncture, massage, nutritional counseling, music therapy, and meditation to help promote well-being and ease the side effects of cancer and cancer treatment. Other services at the Zakim Center include Reiki, Qigong, and yoga.

Clinicians from the Zakim Center work with you and your health care team to incorporate these approaches into your treatment plan. To learn more, call 617-632-3322, or visit www.dana-farber.org/zakim.

Pain and Symptom Management

The Adult Palliative Care Program helps patients live as comfortably as possible while facing a serious or life-threatening illness. Through all stages of illness, our team can help make medical treatments more tolerable, assist in planning for medical care,

and provide support that helps enhance your quality of life.

Ask your oncologist for a consultation from Palliative Care, which includes specially trained physicians, nurses, social workers, pharmacists, and chaplains. To learn more, call 617-632-6464 or visit us online at www.dana-farber.org/palliative.

Nutrition

Balanced nutrition is an important part of cancer treatment and survivorship. A healthful diet can help rebuild your body's cells and energy level, especially if you are receiving chemotherapy or radiation.

Our registered dietitians, who have special training in oncology and integrative nutrition, will work with you and other members of your health care team to:

- Tailor an eating plan that fits with your diagnosis and treatment plan
- Address changes in appetite or weight
- Manage the side effects of cancer



treatment, such as nausea, vomiting, taste changes, and bowel irregularities

- Learn more about foods, vitamins, herbs, and supplements

To ask about seeing a registered dietitian while you are an outpatient, speak with a member of your health care team. You can also call 617-632-3006. To learn more, visit www.dana-farber.org/nutrition.

Hats, Wigs, Books, and More

Friends Place is a store on the first floor of Dana-Farber's Yawkey Center that offers items and services that can help you adjust to changes in your appearance during or after cancer treatment. Our experienced

staff, which offers consultations for men and women, can suggest a variety of ways to help you minimize the physical effects of cancer therapy.

Friends Place sells a diverse range of specialty products, including: items to help with post breast surgery needs, head coverings (wigs, hats, scarves, sleep caps), sexual health books and aids, products for lymphedema patients (compression sleeves and Medic Alert bracelets), non-metallic deodorants, skincare products, books, videos, and more.

For more about Friends Place, call 617-632-2211 or visit www.dana-farber.org/friendsplace.

Visit the Healing Garden

When you need a place to relax and enjoy nature, visit the Stoneman Healing Garden on the third floor of Dana-Farber's Yawkey Center for Cancer Care. This indoor sanctuary features stone walls, seasonal flowers, and a canopy of greenery. Overlooking the garden is the Morse Conservatory, which offers a plant-free environment ideal for patients with allergies and other health concerns.

Support and Counseling

Social Workers

Licensed clinical social workers provide consultation, guidance, and supportive counseling to you and your family as you cope with the impact of illness on your life, work, and relationships. These services are available by request or by referral from your doctor or nurse. To learn more, call 617-632-3301 (Dana-Farber) or 617-732-6469 (Brigham and Women's).

Mental Health Services

Because your illness affects more than just your body, you may find yourself dealing with difficult emotions or feelings of sadness, depression, or anxiety. Working with your other health care team, psychologists and psychiatrists can help you identify your goals and cope with illness. To learn more, call the Adult Psychosocial Oncology program at 617-632-6181 or visit www.dana-farber.org/psychosocial.

Spiritual Care (Chaplains)

Our chapels provide a place for quiet reflection for persons of any belief, and



our chaplains can offer worship services, spiritual counseling, prayer, sacraments, or a sympathetic ear.

Dana-Farber's chapel is on the second floor of the Yawkey Center. The chapel at Brigham and Women's is in the hospital's main lobby. To contact Spiritual Care, call 617-632-3908 (Dana-Farber) or 617-732-7480 (Brigham and Women's). To learn more, visit www.dana-farber.org/spirituality.

One-to-One: Connecting with Someone Who's Been There

Trained volunteers who can talk with you through the One-to-One program have already been through a cancer experience. They can help ease your concerns, share information, and offer reassurance and hope. To learn more, call 617-632-4020 or visit www.dana-farber.org/onetoone.

Support for Caregivers

If you are a family member or friend who is helping another person with the challenges of a cancer diagnosis, you are a caregiver. We offer support and

resources for you, including practical tips for dealing with stresses often related to caregiving. Call 617-632-4235 or visit www.dana-farber.org/caregivers.

Help for Parents

If you are a parent with cancer, the Family Connections program offers resources to help you and your children feel more prepared for the challenges of living with cancer. The program provides age-appropriate information and resources for children and teens, including special binders with guidance to help parents talk with children. Call 617-632-4020 or visit www.dana-farber.org/familyconnections.

Facing a Difficult Decision?

When you face a complicated issue, Dana-Farber's Ethics Consult Service may be able to help. The service can help everyone involved in a patient's care talk about and come to agreement about ethical concerns such as:

- Resolving conflicts
- Deciding whether to stop anticancer treatment
- Planning for a time when a patient may no longer be able to make medical decisions

To request a consult, call the ethics hotline at 617-632-5713. Learn more on our website at www.dana-farber.org/ethics.

Let Us Help You

DF/BWCC's centers for patients and families can help you find answers to questions, get support, and find the services you need.

- At Dana-Farber, the **Ruth and Carl J. Shapiro Center for Patients and Families** serves as an information hub, where you can go to learn anything ranging from supportive resources and daily events to finding your way around DF/BWCC and Boston. Visit the Shapiro Center on the first floor of Dana-Farber's Yawkey Center or call 617-632-3750.
- At Brigham and Women's, the **Robert and Ronnie Bretholtz Center for Patients and Families** offers support and information services, including patient/family relations staff and an area for families and friends. Find it in the Schuster lobby, near the 75 Francis St. entrance. To learn more, call 617-732-7440.

Whenever you have a question, call the Shapiro Center for Patients and Families at **617-632-3750**.



Support Groups

DF/BWCC offers many support groups for patients and families. We can also help you find such programs in your community. To get a schedule of the latest groups and programs, call 617-632-4235 or visit www.dana-farber.org/supportgroups.

Patient Resources and Education

DF/BWCC offers a number of resources and programs designed to help you and your loved ones address the challenges of living with cancer.



Places to Learn and Explore

Resource centers help you learn more about your diagnosis, find programs that may interest you, and get answers to your questions about cancer. The centers offer Internet access, brochures on cancer-related topics, books, DVDs, and educational workshops.

- The **Eleanor and Maxwell Blum Patient and Family Resource Center** is located on the first floor of Dana-Farber's Yawkey Center. To

learn more about the Blum Center, call 617-632-5570 or visit www.dana-farber.org/resourcecenter.

- The **Michele and Howard Kessler Health Education Library** is located in the Schuster lobby at Brigham and Women's Hospital, near the entrance at 75 Francis St. To learn more, call 617-732-8103 or visit www.brighamandwomens.org and enter "Kessler library" in the search box.

Financial Assistance or Coaching

If you or a family member have problems managing cancer's economic impact, Dana-Farber's Office of Patient and Family Assistance may be able to help. Eligibility requirements apply. Assistance programs include help paying for parking, financial coaching from volunteer financial planners, and legal assistance from outside attorneys. To learn more, contact your social worker or call Dana-Farber's Office of Patient and Family Assistance at 617-632-4494. Or visit us at www.dana-farber.org/financial.

Addressing Your Concerns

If you have an issue related to your care at DF/BWCC that you cannot resolve with your doctor, nurse, or other member of your health care team, or if you have suggestions for improved services, please call the Patient/Family Relations office. They listen, provide general information about DF/BWCC, and help you get answers to your questions. Call 617-632-3417 (Dana-Farber) or 617-732-6636 (Brigham and Women's).

Hospice Care

If your illness progresses, you and your caregivers may want to consider hospice care. This

service can help you enhance your quality of life, manage symptoms, address emotional and spiritual concerns, cherish your time with loved ones, and live with dignity. Your care team can refer you to a hospice that is affiliated with Dana-Farber, or to another program of your choice. To learn whether a hospice might be right for you, talk with a member of your health care team.

Patient Navigators

Patient navigators provide information and support to patients whose language, income, and life circumstances can make it difficult for them to access health care. The navigators work with persons being screened or treated for cervical, breast, or colon cancer. Call 617-632-3301 to learn more.

For People with Disabilities

DF/BWCC is accessible to people with disabilities and complies with the provisions of the Americans with Disabilities Act (ADA). For example:

- Wheelchairs and assistance from security staff are available at the main entrances.
- You can receive help parking, and can navigate all our buildings by wheelchair.

Put Survivorship in Your Sights

The Perini Family Survivors' Center at Dana-Farber serves as an umbrella for three programs for cancer survivors:

- **David P. Perini, Jr. Quality of Life Clinic**, for survivors of childhood cancers
- **Lance Armstrong Foundation Adult Survivorship Program**, for adult cancer survivors
- **Stop & Shop Family Pediatric Neuro-Oncology Outcomes Clinic**, for survivors of childhood brain tumors

To learn more, call the Perini Family Survivors' Center at 617-632-5100 or visit us at www.dana-farber.org/survivor.

- If you need to be escorted from one building to another, arrangements will be made for you.

If you have questions, or need an accommodation, call an ADA coordinator at 617-582-7100 (Dana-Farber).

Connect with Others Online

CaringBridge is a nonprofit website that allows you to set up a free, secure Web page that you can use to write journal entries, provide updates, and post photos. To learn more, visit the site at www.caringbridge.org.

Bereavement Program

DF/BWCC offers a program for families who lose a loved one, which includes a guide, resources, and support groups. To learn more, visit www.dana-farber.org/bereavement.

Help Make Your Care Safer

DF/BWCC has many systems in place to protect your safety, such as ID bands that help ensure you get the right medication. One of the most important things you can do to make your experi-

ence safe is to speak up if something doesn't seem right. You can help us care for you by following the "Check, Ask, Notify" (CAN) rules:

Check to make sure things look right.

- Is your chemotherapy the same color as usual? Do your pills have the same shape and color that they usually have?

Ask questions about your care.

- Ask your doctor or nurse to repeat important instructions. Ask members of your health care team if they washed their hands.

Notify us if you have any problems or changes.

- Have you had any side effects since your last visit?

DF/BWCC's Center for Patient Safety is especially interested in

learning how patients and families can work together with clinicians to help prevent medical errors. For information, call 617-632-4935.

Learn more about our patient safety efforts online at www.dana-farber.org/patientsafety.



Your Rights and Responsibilities

At DF/BWCC, we encourage you to be an active member of your health care team. We also want you to know your rights as a patient, friend, or family member during your visit.

Your Rights

As a patient of DF/BWCC, you have certain rights under federal and Massachusetts state law.

You have the right to:

Respect

- **receive health care that respects** your cultural, psychosocial, and personal values and beliefs, including the right to request pastoral and other spiritual services. DF/BWCC is committed to serving all patients, without regard to race, color, religion, national origin, sex, age, marital status, sexual orientation, gender identity or expression, disability, political affiliation, veteran status, or other non-medically relevant factors.
- **obtain a copy** of any rules or regulations that relate to the conduct of patients, as provided below.
- **have a family member, friend, or other individual** be present with you for support during your visits.

Privacy and Confidentiality

- **know that your records** and communications are confidential

to the extent provided by law.

- **expect privacy** during medical treatment and care, within the capacity of DF/BWCC.

Participation

- **refuse to be** examined, observed, or treated by students or other staff, without jeopardizing access to psychiatric, psychological, or other medical care.
- **refuse to serve** as a research subject or receive any care or examination that is primarily for educational or informational purposes, rather than for treatment; and to participate in any consideration of ethical issues that arise in your care, such as resolving conflict, withholding resuscitation, forgoing or withdrawing life-sustaining treatment, or taking part in research studies.

Pain Management

- **receive assessment** and treatment for physical and psychological pain.

Information and Treatment

- **obtain an explanation** of any relationship (including financial) that DF/

About Your Medical Record

You have the right to request copies of your medical records by calling 617-632-2955 (Dana-Farber) or 617-732-6071 (Brigham and Women's). Copies may be available in electronic form sent through secure e-mail or on CD, depending on the type of request.

You can also enroll in Patient Gateway (www.patientgateway.org) to securely view many parts of your medical record.

YOUR RIGHTS AND RESPONSIBILITIES

To get a copy of the "Patients Rights Law" (Mass. General Laws, Chapter 111, Sec. 70E), call Patient/Family Relations at **617-632-3417** (Dana-Farber) or **617-732-6636** (Brigham and Women's).

BWCC or your physician has with any other health care facility or educational institution, to the extent that the relationship relates to your care.

- **receive information** regarding financial assistance or free health care.
- **receive information**, as needed and available, if you have a vision, speech, hearing, or cognitive impairment.
- **obtain the name and specialty** of the physician or other health care providers caring for you.
- **have all reasonable requests** responded to promptly and adequately, within capacity.
- **receive enough information** to give an informed consent to treatment, to the extent provided by law, including an explanation of your condition, proposed treatments, and alternative therapies, with their respective benefits and risks.
- **make decisions** regarding your health care, including the decision to refuse or discontinue treatment, to the extent permitted by law.
- **fill out advance care directives**, such as a health care proxy form, to designate someone who can make decisions for you if you become incapable of understanding a proposed treatment or procedure, or are unable to communicate your wishes regarding your care.
- **receive a complete copy** of the Massachusetts Patient Rights law (M.G.L., chapter 111, sec. 70E), available from Patient/Family Relations, or on the Internet at www.mass.gov/legis/laws/mgl/111-70e.htm.
- **if you have** breast cancer, receive complete information from your physician on medically viable alternative treatments.
- **have an interpreter** or other assistance, as needed and available, when there is a language, communication, or hearing barrier.
- **inspect your medical record** and receive a copy of it. If you request a copy, you may be charged a fee, unless you show that your request supports a claim or appeal under any provision of the Social Security Act in any federal or state needs-based benefit program.
- **receive prompt, life-saving treatment** in an emergency, without discrimination or delay based on economic or payment concerns.
- **receive a prompt and safe** transfer to the care of others if DF/BWCC is unable to meet your request or need for treatment or service. For example, if we are unable to offer the type and quality of care, based on available resources, required by your specific condition or disease, we will make sure that you can receive care elsewhere.
- **receive an itemized list** of charges submitted to your insurer or another third party regarding your care, including

the amounts covered by the third-party payer, and a copy of itemized charges sent to the attending physician.

- **register complaints** or grievances, and seek solutions to problems, through Patient/Family Relations. You have the right to file a grievance if you have concerns regarding your care and treatment.

Your Responsibilities

By taking an active role in your health care, you can help your health care team meet your needs as a patient. That is why we ask you and your family to share certain responsibilities with us.

We ask that you:

- **provide, to the best of your ability,** accurate and complete information about your present condition, past illnesses, hospitalizations, medications, and other matters related to your health, including information about home and/or work that may impact your ability to follow the proposed treatment.

- **follow the treatment plan** developed with your provider. You should express any concerns about your ability to comply with a proposed course of treatment. You are responsible for the outcomes if you refuse treatment or do not follow your care provider's instructions.
- **be considerate of other** patients and DF/BWCC staff and their property. Abusive, threatening, or inappropriate language or behavior will not be tolerated.
- **keep appointments,** or call us when you are unable to do so.
- **be honest** about your financial needs, so that we may connect you to appropriate resources.
- **give us any health care proxy** or other legal document, such as a power of attorney or court order, that may affect your decision-making ability or care.
- **notify us** if you object to students or researchers participating in your care.

Please direct your concerns to:

Dana-Farber Cancer Institute

Patient/Family Relations
450 Brookline Ave.
Boston, MA 02215
Phone: 617-632-3417
Fax: 617-582-7914
TDD: 617-632-5330

Brigham and Women's Hospital

Patient/Family Relations
75 Francis St.
Boston, MA 02115
Phone: 617-732-6636
Fax: 617-582-6130
TDD: 617-732-6458

Massachusetts Department of Public Health

Division of Health Care Quality
99 Chauncy St., 2nd Floor
Boston, MA 02111
Phone: 800-462-5540
Fax: 617-753-8165

Massachusetts Board of Registration in Medicine

200 Harvard Mill Square,
Suite 330
Wakefield, MA 01880
Phone: 800-377-0550
Fax: 781-876-8383

The Joint Commission

Office of Quality Monitoring
1 Renaissance Blvd.
Oakbrook Terrace, IL 60181
Phone: 630-792-5000
www.jointcommission.org

We Value Your Privacy

We create a medical record when you visit DF/BWCC as a patient. Portions of your medical record can be viewed by members of your health care team at all DF/BWCC sites. This information is treated as confidential and is protected under federal and state laws, which require us to maintain the privacy of your health information. For example, federal laws

known as HIPAA (Health Insurance Portability and Accountability Act) give you control over, and knowledge about, who is using your health information, and for what purpose.



Learn more about our privacy efforts at www.dana-farber.org/privacy.

Basics

Where to eat, stay, get cash, and more

Resources for Newcomers

Patients, families, and visitors new to the Boston area can speak with volunteers at DF/BWCC to get helpful information.

- The **Ruth and Carl J. Shapiro Center for Patients and Families** on the first floor of Dana-Farber's Yawkey Center offers self-service touch screens and a Concierge Desk staffed by volunteers who can provide advice, maps, and brochures. To learn more, call 617-632-3750.
- The **Newcomers Resource Center** at Brigham and Women's Hospital is located in the Friends of BWH office, in Room 309 of the Peter Bent Brigham building. It offers books, pamphlets, and advice.

Dining Options

The area around DF/BWCC offers many options for meals. The Longwood Galleria next to Dana-Farber features a food court and restaurant. Other restaurants and coffee shops are nearby on Longwood Avenue.

You can also find inexpensive dining areas, including the dining pavilion on the third floor of Dana-Farber's Yawkey Center and food outlets in the Brigham and Women's Hospital lobby.

Internet Access

Free wireless Internet access is available in most patient care areas at Dana-Farber and Brigham and Women's. If you need to access a computer workstation, visit the Shapiro Center for Patients and Families or one of our resource centers.

Where to Stay

If you and your family need a place to stay while you are receiving care, there are several housing programs and hotels that provide a "home away from home." It's a good idea to plan ahead, since rooms can book quickly.

For a list of local hotels, private housing, and group housing, call the Center for Patients and Families at 617-632-3750 or visit us at www.dana-farber.org/placestostay.

Where to Get Cash

Banks and ATMs are located throughout the medical area, including:

- On Brookline Avenue, next to Dana-Farber's Mayer building
- On Longwood Avenue, next to the Harvard Coop Bookstore
- In the first-floor lobby of the Tower building at Brigham and Women's Hospital

- In the Ambulatory Services building at Brigham and Women's Hospital
- In the Longwood Galleria, next to Dana-Farber

Where to Shop

Our gift shops offer magazines, books, stamps, greeting cards, and more. At Dana-Farber, the Friends Corner Gift Shop is located on the first floor of the Yawkey Center. At Brigham and Women's Hospital, The Shop on the Pike gift shop is on the 2nd floor, near the 75 Francis St. entrance. In addition, the Harvard Coop Bookstore on Longwood Avenue sells books, clothing, cards, office supplies, household goods, and more.

Find Local Activities and Events

The Recreational Resources program at Dana-Farber helps patients and family members learn about current and upcoming events and activities in the Boston area. Call Volunteer Services at 617-632-3307 or visit the Shapiro Center for Patients and Families to learn how you may be able to find tickets for live theater shows, special

events, musical performances, sporting events, and more.

Backup Child Care

The Brigham and Women's Hospital Backup Child Care Center provides emergency backup child care services to DF/BWCC patients with children ages 8 weeks to 12 years old. Patients are eligible to use the program only while attending an appointment at Dana-Farber or Brigham and Women's. To learn more, call 617-732-9543.

Notary Public

A notary public can authorize important documents, including power of attorney, banking statements, and absentee voting forms. To make an appointment with a notary public, call Patient/Family Relations at 617-632-3417 (Dana-Farber) or 617-732-6636 (Brigham and Women's).

More questions? Visit the Concierge Desk in the Shapiro Center for Patients and Families (on the first floor of the Yawkey Center) or call **617-632-3750**.

We are Tobacco-Free

To promote a healthy environment for patients, visitors, and staff, **the use of tobacco products is prohibited** throughout the campuses of Dana-Farber and Brigham and Women's Hospital – including outdoor areas.



The AstraZeneca Hope Lodge Center is located at 125 South Huntington Ave., just a mile from DF/BWCC, in Boston's Jamaica Plain neighborhood. It offers temporary housing to eligible cancer patients and family members who travel far from home. Learn more online at www.cancer.org/hopelodge.



How to Help

Many patients and families ask us how they can support Dana-Farber/Brigham and Women's Cancer Center and ease the experience of others. Here are some ways you may be able to help.

Donate Blood or Platelets

Cancer patients may need to replace blood and platelets lost during chemotherapy. You can donate whole blood and red cells at the Brigham and Women's Hospital Blood Donor Center in a process that takes about

45 minutes. The Kraft Family Blood Donor Center at Dana-Farber collects platelets in a process that takes about 90 minutes. To schedule an appointment or learn more, call 888-LETS-GIV (888-538-7448) or visit www.dana-farber.org/blooddonation.

Join our Patient and Family Advisory Council (PFAC)

The DF/BWCC Adult Patient and Family Advisory Council consists of patients, family members, and staff who work together to improve and strengthen patient care at the cancer center. The council serves as a resource to staff about patient-related issues, participating in the design of patient-care areas and helping improve a wide range of processes. New members are welcome. To learn more, call 617-632-4319 or visit www.dana-farber.org/pfac.

Participate in the Legislative Action Network

Dana-Farber's Legislative Action Network brings people and organizations together to support public policies that affect cancer care and research. With the help of people like you, the network supports key cancer-related issues, such as strengthening federal funding for cancer research. Learn more at www.dana-farber.org/legislative-action-network.

Register to be a Stem Cell Donor

Only 30 percent of patients who need a stem cell transplant will find a matching donor within their own family. The remaining 70 percent search a worldwide database of unrelated donors, looking for their “miracle match” – someone who is willing to donate lifesaving cells.

Joining the National Marrow Donor Program's Be the Match® registry involves swabbing the inside of your mouth to get a small cell sample, but it also means that you'd be willing to donate your stem cells to a person in need, if called upon as a match.

To learn more about becoming a donor, or about hosting a donor registration drive, visit www.dana-farber.org/nmdp or call our marrow donor recruitment office at 617-632-2561 or toll-free 866-875-3324.

Volunteer

Volunteering at Dana-Farber Cancer Institute or Brigham and Women's Hospital can be a rewarding experience. Many volunteers are cancer survivors, family members, or friends of someone with cancer. There are a variety of opportunities, such as greeting visitors, visiting inpatients, or working in a resource center.

To learn about volunteering at Dana-Farber, call 617-632-3307 or visit www.dana-farber.org/volunteer. At Brigham and Women's, call 617-732-5998 or visit www.brighamand-womens.org/about_bwh/volunteer.

 To learn more about supporting DF/BWCC programs and services, visit www.dana-farber.org/how.

Become an Ambassador

Volunteer ambassadors at Dana-Farber serve as friendly hosts in blue vests who help patients and their families find their way around and learn more about DF/BWCC. To inquire about becoming an ambassador, please call Volunteer Services at 617-632-3307 or e-mail volunteerservices@dfci.harvard.edu.

Phone Numbers

Main Numbers

Brigham and Women's Hospital
617-732-5500

Dana-Farber Cancer Institute
617-632-3000

Dana-Farber/Brigham and Women's
Cancer Center (DF/BWCC)
877-332-4294

Adult Palliative Care

617-632-6464

Billing Inquiries (Accounting)

617-632-3930

Blum Resource Center

617-632-5570

Clinical Trials

866-790-4500

Concierge Services

617-632-3750

Disability Services/ ADA Coordinator

617-582-7100 (Dana-Farber)
800-439-0183 (Massachusetts TDD/
TTY relay line)

Directions

617-632-3400 (Dana-Farber)
617-732-5500 (Brigham and Women's)

Ethics Consult Service

617-632-5713

Family Connections (Support Program)

617-632-4020

Financial Services/ Insurance Questions

617-632-3455 (Dana-Farber)
617-732-8001 (Brigham and Women's)

Friends Place

866-860-6053

Interpreters

617-632-3673 (Dana-Farber)
617-732-6639 (Brigham and Women's)

Medical Records

617-632-3225 (Dana-Farber)
617-732-4939 (Brigham and Women's)

Mental Health (Psychosocial Oncology)

617-632-6181

Nutrition

617-632-3006

One-to-One (Support Program)

617-632-4020

Parking

617-632-3134 (Dana-Farber)
617-732-5877 (Brigham and Women's)

Patient/Family Relations

617-632-3417 (Dana-Farber)
617-732-6636 (Brigham and Women's)

**Patient and Family
Advisory Council (PFAC)**

617-632-4319

Patient Privacy

617-632-2235 (Dana-Farber)

Patient Safety

617-632-4935 (Dana-Farber)

617-732-7543 (Brigham and Women's)

Pharmacy

617-632-3338 (Dana-Farber
outpatients)

**Shapiro Center for Patients
and Families (including
Concierge Services)**

617-632-3750

Spiritual Care (Chaplains)

617-632-3908 (Dana-Farber)

617-732-7480 (Brigham and Women's)

Support Groups

617-632-4235

**Zakim Center for
Integrative Therapies**

617-632-3322

Reminder

If you have a medical emergency, dial 911. For non-emergency situations, ask your care team what number you should call during regular business hours, and keep this phone number handy.

After hours or on weekends, you can page your doctor or an on-call doctor by dialing **617-632-3352** (Dana-Farber) or **617-732-5500** (Brigham and Women's).

For a more complete list of phone numbers, go to **www.dana-farber.org/directories** or visit **www.brighamandwomens.org** and click on "Contact Us."



To request copies of this handbook, call 617-632-4090.

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About Dana-Farber/Brigham and Women's Cancer Center

Dana-Farber/Brigham and Women's Cancer Center (DF/BWCC) is a collaboration between Dana-Farber Cancer Institute and Brigham and Women's Hospital to provide the best possible care to adults with cancer or certain blood diseases. Dana-Farber provides most outpatient services, while inpatient care is provided by Brigham and Women's Hospital. Although your care is coordinated through DF/BWCC, you may receive separate bills from separate institutions, such as Dana-Farber Cancer Institute, Brigham and Women's Hospital, or one of our satellite centers.

DF/BWCC's satellite centers allow patients to benefit from our expertise and resources in the convenience of their own communities:

- **DF/BWCC at Faulkner Hospital**, in Jamaica Plain, Mass.
- **DF/BWCC at Milford Regional Medical Center**, in Milford, Mass.
- **DF/BWCC in clinical affiliation with South Shore Hospital**, in South Weymouth, Mass.

Dana-Farber also has a satellite center in Londonderry, NH, at **Dana-Farber/ New Hampshire Oncology-Hematology**.

DANA-FARBER/BRIGHAM AND WOMEN'S



C A N C E R C E N T E R

