

Guide to **Your Care**



Fred Hutch
Cancer Center

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Welcome to Fred Hutch Cancer Center

At Fred Hutch Cancer Center, we are committed to taking care of you. Your care is built around you, your goals of care and what you and your family need. We are devoted to giving you the best possible care, treatment options and support throughout your time here.

As part of that commitment, we created this guide to your care. The purpose of the guide is to help you understand your treatment experience. It is not meant to be read in one sitting; rather, it's meant for you to review and refer to throughout your care.

Feel free to share it with your caregiver, family and friends. They can also read it online at FredHutch.org/Guide-to-Your-Care (or scan the QR code at right). We hope this guide becomes a valuable resource during your time at Fred Hutch.

We bring together the leading research teams and cancer specialists of Fred Hutch and UW Medicine.

This approach truly sets us apart in how we care for you.

When you seek treatment at Fred Hutch, you access a network of providers whose sole mission is the pursuit of better, longer, richer lives for our patients.

Your health, safety and comfort are our highest priorities.

1354 Aloha Street, Seattle, WA 98109

(206) 606-7222

Toll-free: (855) 557-0555

FredHutch.org

Fred Hutch is an independent, nonprofit organization that also serves as the cancer program for UW Medicine. This unique relationship allows for enhanced care coordination with one of the world's leading integrated health systems.

UW Medicine





Interpreter services

Interpreters are offered free of charge for Fred Hutch patients.

If you speak Spanish, Mandarin, Russian, Korean or Vietnamese and need an interpreter on the phone when you call Fred Hutch, call toll-free (855) 670-9798 (TDD: 711).

If you speak any other language, call Fred Hutch toll-free at (855) 557-0555 or (206) 606-7222. Say “interpreter” and the name of the language you speak. Wait on the line until an interpreter joins your call.

Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al (855) 670-9798 o (TDD: 711).

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 (855) 670-9798 or (TDD: 711).

Если вы говорите по-русски, и вам нужен переводчик во время телефонного разговора с Fred Hutch, звоните по бесплатному номеру (855) 670-9798 (TDD: 711).

귀하가 한국어로 말하고 Fred Hutch에 전화하는 데 통역이 필요한 경우, 무료 전화 (855) 670-9798 (TDD: 711)번으로 전화하십시오.

Nếu quý vị nói tiếng Việt và cần thông dịch viên qua điện thoại khi gọi đến Fred Hutch, vui lòng gọi số điện thoại miễn phí (855) 670-9798 (TDD: 711).

Notice of non-discrimination

At Fred Hutch, we stand firmly against racism, intolerance and prejudice in any form. Respect for all identities and backgrounds is one of our core values. We remain dedicated to being a welcoming and safe space for all.

Fred Hutch does not discriminate on the basis of race, color, religion, creed, ancestry, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity or gender expression, political ideology, or other characteristic protected by applicable state, federal, or local laws.

Let's work together

Because we want all patients and staff to feel comfortable while they're here, we are:

- Fragrance-free (no perfumes, colognes or other scents)
- A non-smoking campus
- Weapon- and gun-free
- Plant- and flower-free



Service animals

We welcome service animals that fall under titles II and III of the Americans with Disabilities Act. If you bring a service animal, be sure to check in at the front desk on the first floor when you arrive. The front desk staff will ask you some screening questions; if your animal qualifies, they will give you a navy blue Fred Hutch bandana to tie around your service dog's neck or leash. This bandana is optional and helps our staff know that your service animal has been screened.



**Trained service animals welcome.
Sorry, no pets or therapy animals allowed.**

Your team

At Fred Hutch Cancer Center, you are at the center of everything we do.

We are proud to be on your team, and we value this approach to your care.



Stay connected

Our relationship with you matters. We will share the highs and lows of your experience, and we're here for you every step of the way. Your questions and concerns are important to us. Please reach out to us when you have them.

See the Resources section of the guide for a list of suggested questions to ask your care team.

Your care team

You are the most important person on your care team. We value, care about and respect your input throughout your journey. We want you to feel empowered to ask questions and communicate changes in your body, mood and symptoms, because sharing these important details can make a real difference in your medical care.

In addition to you, your care team is made up of a core group of professionals that includes a physician, nurses, medical assistants and patient care coordinators. Some teams also have advanced practice providers. Each person on your care team specializes in treating people with cancer and will know the details of your disease and treatment plan.

You may be on more than one care team. If you are, your teams will work together to support you. Your team will partner with other cancer specialists throughout Fred Hutch to give you the best care possible. This can include pharmacists, infusion nurses, dietitians, social workers, physical therapists, psychiatrists and others.

Here's how the members of your care team will help you.

Physician

Your physician (also called an “attending”) works with you to understand your disease, manage your symptoms and plan your treatment. Depending on your treatment plan, you may see one or more of these physicians: surgeon, medical oncologist or radiation oncologist.

Advanced practice provider (APP)

Your team may include an APP. If it does, you will see them often. An APP is either a licensed nurse practitioner (NP) or a physician assistant (PA, PAC). An APP partners with you and your physician to make decisions. They help manage your care and work with nurses on your care team.

Nurses (RNs and LPNs)

Your team includes nurses who work together to support your care. Nurses play a few different roles. They are navigators who help guide you through the health care process. They are triage specialists who answer your questions and concerns over phone and email. And they provide care when you come to the clinic.

Medical assistants (MAs)

Medical assistants bring you to your appointment room, take your vitals (blood pressure, pulse, temperature) and help prepare you for your visit with your physician or APP. They also do administrative work, such as filling out forms, requesting outside records and other behind-the-scenes care.

Patient care coordinator (PCC)

Your patient care coordinator schedules your appointments. You may also hear them called a scheduler.

Fred Hutch is a teaching facility. In addition to caring for you, we also teach and train current and future doctors, nurses and other health professionals. You may see one of these providers alongside your care team while at Fred Hutch.

Supportive Care Services

Your primary care team works closely with specialists throughout Fred Hutch. These specialists become part of your extended care team. Please see the supportive care services brochure or webpage (FredHutch.org/supportive-care-services) for more information on:

- Cancer Rehabilitation
- Child Life Services*
- Clinical Social Work
- Financial Assistance Resources
- Housing Options
- Integrative Medicine
- Interpreter Services
- Living Tobacco-Free Services
- Medical Nutrition Therapy
- Oncoreproduction and Fertility
- Oral Medicine
- Pain Clinic
- Patient and Family Resource Center
- Patient Navigation
- Physical Therapy
- Psychiatry
- Retail Stores: Shine and the Gift Shop
- Spiritual Health
- Supportive and Palliative Care Service
- Survivorship Clinic
- Volunteer Services

**Child Life Services are available to children of adult patients. Child Life specialists support children and families during illness and hospitalization, with the goal of reducing stress and fostering coping and resiliency.*

Wellness Center

The Wellness Center includes our prevention and survivorship clinics as well as our Clinical Genetics and Genetic Counseling program. Depending on your disease, your care team may recommend an appointment at the Wellness Center or with one of their specialists.

MyChart

Stay connected to your care



Through MyChart's online patient portal, you can:

- Complete eCheck-in
- Access medical records
- View test results
- View and request appointments
- View medication lists, provider notes, after visit summaries
- Message your provider
- Request prescription refills
- Pay bills online
- Opt in/out of SMS texts for appointment and billing reminders

Test results and messaging

Test results display in MyChart as soon as they are available, which means you are likely to see them before your provider has seen them. Providers' offices will contact you if test results require a change in care. Read the Cures Act handout for more information at FredHutch.org/MyChart.

MyChart is for non-urgent messages only. Call your care team to report symptoms or ask in-depth questions about care.



Scan this code or visit
FredHutch.org/MyChart
to learn more about MyChart.

Your treatment

You are unique, and your care team will design a treatment plan specifically for — and with — you.



Phases of care

This section will help you learn about the types of care and treatments you may receive. Keep in mind that each person's experience is different, and your physician and care team will go over all treatment options in more detail at your appointments.

Diagnosis

Diagnosis is the process of identifying cancer. We diagnose or confirm your diagnosis by looking at your signs and symptoms, your health history, a physical exam and tests (such as blood tests, imaging tests and biopsies).

Staging

Staging is the process of determining details about your cancer, such as tumor size and whether it has spread. During staging, you will be told whether your cancer is stage I, II, III or IV. Some cancers have classifications instead of stages. The stage or classification guides decisions about treatment.

Treatment

You and your care team will decide on the right treatment plan for you. While you may have only one of the following treatments, it is common to receive a combination of treatments.

Depending on your treatment or symptoms, you may need to stay in the hospital. If so, your care may be provided by Fred Hutch at UW Medical Center - Montlake, UW Medical Center - Montlake or UW Medical Center - Northwest.

Surgery

Many people with cancer are treated with surgery. Depending on the type of cancer you have and how advanced it is, surgery can be used to:

- Remove the entire tumor
- Remove part of a tumor
- Decrease cancer symptoms

Chemotherapy

Chemotherapy uses medication to kill cancer cells. It works by stopping or slowing the growth of cancer cells, which can grow and divide quickly. Chemotherapy is also used to treat and ease cancer symptoms.

Immunotherapy

Immunotherapy uses certain parts of your immune system to fight diseases such as cancer. This can be done by stimulating your immune system to work harder or smarter. It can also be done by giving your immune system special tools to fight cancer.

Transplant

A bone marrow or stem cell transplant restarts your body's ability to make healthy new blood cells. It can act as a reset for diseases such as leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, multiple myeloma and myelodysplastic syndrome.

Radiation

Radiation therapy (also called radiotherapy) uses high-energy particles or waves — such as X-rays, gamma rays, electron beams or protons — to destroy or damage cancer cells. Radiation is used to treat cancer or ease cancer symptoms.

Surveillance

Surveillance is another way of saying, “Watch, wait, and see.” During surveillance, you will receive tests and exams on a regular schedule without any treatment, unless there are changes in exams or test results. Surveillance may be used to find early signs that a disease has come back. It may also be used if you don't have cancer right now, but you have an increased risk of getting it.

Survivorship

Survivorship is the time from a person's diagnosis through their lifespan. At Fred Hutch, our Survivorship Clinic offers help to those transitioning from active treatment to day-to-day living as a cancer survivor. The clinic welcomes any survivor who has completed their treatment, either at Fred Hutch or somewhere else.

Clinical trials

As part of your care, you may be eligible to participate in a clinical trial. Fred Hutch has one of the most active clinical trial programs in the world. The goal of clinical trials is to increase our knowledge about diseases and to develop safer, more effective treatments in the fight against them. Clinical trials look at many aspects and stages of the disease — they are not just for patients in the final stages of illness. Trials can help us:

- Examine ways to prevent cancer in healthy people
- Better detect and diagnose cancer
- Treat patients who are starting their first round of treatment and patients whose disease has returned
- Assess the quality of life of cancer patients and survivors

Through clinical trials, you may be able to gain access to promising new treatments. Every advance in cancer treatment has resulted from clinical trials. For example, bone marrow transplantation, which is considered the most important advance in cancer treatment in the last 25 years, started at Fred Hutch and is a treatment currently offered at Fred Hutch.

For more information on clinical trials, talk to your care team or visit FredHutch.org/research/guide-clinical-trials.

Goals of care

We encourage you to speak with your care team about your goals for cancer treatment. Your primary goal may be to cure your cancer, and you may have other priorities as well — for example, avoiding side effects, such as hair loss, nausea and vomiting, or long-term complications, such as heart damage. You may also want to do everything you can to preserve your ability to do activities that are important to you, such as playing piano or running.

The more your care team understands what you want, the more they can use this information when making recommendations for your care. Consider filling out the Values Worksheet, available with the Fred Hutch Health Care Directive form (FredHutch.org/advance-care-planning), and sharing this information with your care team. This can help you clarify what is important to you, your family and your care team.

Goals of care, continued

It is also important that you understand the intent, or purpose, of your treatment. Talking to your care team about whether your treatment is intended to cure your cancer or control its growth is an essential part of your care. Your wishes may change over time if your cancer gets worse or spreads to other parts of your body.

Advance care planning

Advance care planning is the process of making plans now for care you may need later. It helps your doctors and family give you the medical care you want if you aren't physically able to speak for yourself. Advance care planning is for all adults, not just people who have an illness. If your cancer is more advanced, and you would like guidance on communicating with your medical team, please see "How to Talk to Your Doctor" by the Conversation Project. (bit.ly/HowToTalkToDr)

Once you figure out your medical care wants and desires, you can use them to create a legal document called an advance directive.

An advance directive is usually made up of two documents: a durable power of attorney for health care (DPOA-HC) and a health care directive.

- A durable power of attorney for health care is a form that lets you name a health care agent. A health care agent is someone who can make decisions about your care, including decisions about life support, if you can no longer speak for yourself. If you do not name your health care agent, Washington State has a system for assigning you a health care agent. You can learn more in the Questions and Answers section of our Fred Hutch DPOA-HC form.
- A health care directive is a form that expresses your wishes about your medical care in writing, including decisions about life support, if you cannot speak for yourself (for instance, if you are in a coma). Written instructions can help reduce confusion or disagreement among your family members or health care providers.

You can complete just the DPOA-HC or both the health care directive and DPOA-HC. Both are available from your provider or on Fred Hutch's Advance Care Planning webpage at FredHutch.org/advance-care-planning.

Advance care planning, continued

You can change these documents at any time. Please make sure you give a copy of your completed, signed forms to any member of your medical team so they can add it to your Fred Hutch/UW Medical Center electronic medical record. You should also give photocopies to your health care agent(s), physician(s), lawyer and anyone else who might become involved in your health care.

Questions about advance care planning

If you have questions or need help preparing your advance directive, several teams at Fred Hutch can help you.

- Social Work: (206) 606-1076
- Palliative Care: (206) 606-7474
- Spiritual Health: (206) 606-1099

You can find more information about advance care planning in the Patient and Family Resource Center on the third floor of the clinic. For your convenience, Patient and Family Resource Center staff can notarize your advance care planning documents free of charge, by appointment only. To make an appointment, call (206) 606-2081.

Caring for all of you

We believe state-of-the-art care includes support for healing your body, mind and spirit.



Guidelines for the use of integrative medicine at Fred Hutch

Integrative medicine is a patient-centered, evidence-informed field of cancer care that uses mind-body practices, acupuncture, natural products and lifestyle modifications, together with conventional cancer treatments.

While medical treatments focus on fighting the disease, integrative medicine, along with our other supportive care services, can help you cope with side effects from treatment and enhance your wellness and quality of life by helping to access the body's inner ability to heal. Integrative medicine providers at Fred Hutch will work closely with your care team to combine complementary therapies with conventional cancer treatment.

Definitions

- Traditional therapies: Culturally-based health practices
- Alternative therapies: Used **instead of** conventional medicine
- Complementary therapies: Used **with** conventional medicine
- Integrative medicine: Evidence-based use of complementary therapies **in addition to** conventional therapies

We offer the following evidence-based services:

- Integrative medicine consultations
- Naturopathic medicine
- Mind-body medicine
- Acupuncture

Integrative medicine therapies and practices can be empowering, therapeutic tools to help relieve your cancer symptoms and treatment-related side effects and improve your overall wellness and quality of life during any stage of treatment and survivorship.

Integrative Medicine offers:

- Education on dietary supplements and non-pharmacologic products.
- Training in mind-body medicine therapies to help with managing symptoms, improving mood, boosting energy and relieving stress. Therapies include progressive muscle relaxation, relaxation breath work, guided imagery, mindfulness-based stress reduction, mindful eating and self-hypnosis. A variety of mind-body exercises and techniques can be found online at FredHutch.org/patient-education-videos. Look for the Mind-Body Relaxation playlist.
- Counseling on lifestyle management, including diet, physical activity, sleep and weight.
- Acupuncture to help with pain, nausea, fatigue, hot flashes, neuropathy, constipation/diarrhea, mouth sores, dry mouth, insomnia and stress.

Integrative medicine is available to Fred Hutch patients who are undergoing or have completed treatment following a cancer diagnosis.

Using integrative, complementary or alternative medicine outside of Fred Hutch

Fred Hutch offers evidence-based services from integrative medicine providers who are part of your cancer care team. If you are receiving these services from a non-Fred Hutch provider, please talk to your care team to make sure that all aspects of your cancer care work together. This is important because treatments, dietary supplements or diets that seem safe may interfere with your cancer treatment.

The National Cancer Institute has information on how to decide if a therapy is safe and how to talk to your provider about it.

cancer.gov/publications/patient-education/367ncinewv2.pdf

cancer.gov/about-cancer/managing-care/using-trusted-resources

The Federal Trade Commission, the nation's consumer protection agency, recommends talking to the doctor who is treating your cancer about any treatments or products you'd like to try. It also provides tips for identifying products that have not been proven to be effective treatments for cancer.

consumer.ftc.gov/articles/0104-cancer-treatment-scams



Tracking your symptoms

The more we know, the better we
can care for you.



Symptom reporting

We encourage you to talk to your care team with any concerns you have about your treatment, its side effects or your quality of life. The more your clinicians know about what you are experiencing and what you are hoping for, the more they can take this information into account when making a treatment recommendation.

Symptom tracker

Tracking your symptoms can help you communicate what you are experiencing to your care team. You do not need to give this page to your care team, but try using the table below if you think it would be helpful. When you run out of space, you can continue tracking your symptoms in a notebook at home. Your care team will educate you on what symptoms you may expect based on your diagnosis and treatment.

Date	Symptoms	Notes

Cancer treatment tracker

This section can help you keep track of your health information. Feel free to use this if you think it would be helpful. You do not need to give these pages to your care team. Please note that your care may not involve everything in this section.

Cancer diagnosis			
Type	Stage	Date of diagnosis	Notes

Cancer-related surgeries			
Type	Surgeon	Date of surgery	Problems/other notes

Chemotherapy/immunotherapy			
Name of chemotherapy/immunotherapy	Dates received	Oral or IV	Side effects and medications to treat them

Radiation therapy

Area of body treated	Dates received	Amount/dose	Problems/other notes

Blood transfusions

Dates	Problems/concerns	Allergies to medications

Other health concerns:

--

Advance care directive

	If yes, who is my health care agent?	Who has signed copies?
Have I completed a <u>durable power of attorney for health care</u> ?		
Have I completed a <u>health care directive</u> ?		

Preventing infections

Patient safety is our top priority at Fred Hutch. As part of this commitment to you, we are dedicated to preventing infections.



The importance of preventing infections

Cancer is one of many conditions or diseases that weaken our immune system. This means that people with cancer are at a higher risk of getting infections and that their infections can become more severe. The medical term for this is immunocompromised.

At Fred Hutch, we are dedicated to preventing the spread of colds and other infections — including COVID-19, respiratory syncytial virus (RSV) and the flu — in our clinic. You can help us prevent infection before you come to the clinic, while you're at home and beyond.



Watch the video “Immunocompromised: What does it mean?” at FredHutch.org/patient-education-videos

Before you come to the clinic

If you have cold and flu symptoms, such as a runny nose, cough or sore throat, please:

- Wash your hands often.
- Wear a mask.
- Avoid crowded areas while you are in the clinic.
- Avoid Fred Hutch-operated shuttles.
- Call and notify your care team.
- If you have a caregiver or family member with cold or flu symptoms, please ask them to avoid coming to the Fred Hutch clinic until they feel better.
- When possible, limit the number of family members and caregivers who come with you to your appointment.
- Avoid bringing children under the age of 12 into the clinic.

During cold and flu season, you'll be asked to participate in a screening process when you arrive at the clinic. You'll receive information about the process when it goes into effect.

Tips to protect yourself from colds, the flu and other infections

- Wash your hands frequently and thoroughly with soap and water.
- Use hand sanitizer when soap and water are not available. Hand sanitizer is available throughout the Fred Hutch clinic.
- Get a yearly flu shot to protect yourself and others. Fred Hutch provides flu vaccines to patients, family members and caregivers each year.
- Avoid touching your eyes, nose and mouth. This is one of the most common ways to catch a cold or the flu.
- Cover your nose and mouth with your sleeve or a tissue when coughing or sneezing.
- Avoid others with cold and flu symptoms.
- Tell your care team if you develop new symptoms or if your symptoms worsen.



Wearing a mask at the clinic

Should I wear a mask at the Fred Hutch clinic?

According to CDC guidelines, when you cover your mouth and nose, it's thought you are less likely to spread viruses like COVID-19. This is important if you have a virus and are not showing symptoms (asymptomatic) or if you have early symptoms that aren't recognized.

Wearing a mask also helps make sure you don't touch your face during the day. It's important to recognize that masks are meant to protect other people from your germs; they may not protect you from other people's germs. This is why they are not a replacement for social distancing and hand hygiene.

We offer free surgical masks at clinic entrances if you would like one. Please know that mask requirements may change at any time.

What if I have symptoms such as coughing, sneezing or a runny nose?

Wear a mask if you are coughing, sneezing, have a cold or flu, or if you are a patient on respiratory isolation. When worn correctly, masks help decrease the spread of respiratory viruses and bacteria. If you have the cold or flu, you should also:

- Tell your care team you have symptoms **before** coming to your appointment.
- Sit in the designated respiratory isolation areas in the lobby. Ask a staff member if you have questions.
- Avoid high-traffic areas in the clinic, such as food service areas, crowded elevators, classes and Fred Hutch shuttles.
- Use hand gel and/or wash hands often.

Fresh flowers and plants

Fresh or dried flowers and plants are not allowed in the clinic because of the organisms that grow on them and in the dirt or water, which can cause infections. Balloons and silk flowers are welcome. Make sure there is no decorative moss around silk flowers; only artificial moss is allowed.



Your rights and responsibilities

We want to make sure you have the help you need so you can focus on your cancer treatment.



Patient rights and responsibilities

Fred Hutch respects the rights of all our patients, equally and individually

Fred Hutch was formed to provide state-of-the-art, patient-focused cancer care; support the conduct of cancer clinical research and education; enhance access to improved cancer interventions; and advance the standard of cancer care, regionally and beyond. Our staff is committed to working as a team that includes you as a patient and your family members. We respect the rights of all our patients equally and individually. Fred Hutch does not discriminate on the basis of race, color, religion, creed, ancestry, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity or gender expression, political ideology, or other characteristic protected by applicable state, federal, or local laws. If you feel you experienced discrimination as a patient at Fred Hutch, please contact Fred Hutch's civil rights coordinator at (206) 606-7154 or integrity@fredhutch.org.

Patient rights

As a patient at Fred Hutch, you have the right to:

1. Care that supports privacy, personal dignity, respect and your individual needs.
2. Reasonable access to care and treatment and/or accommodations that are available or medically advisable regardless of one's race, color, religion, creed, ancestry, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity or gender expression, political ideology, or other characteristic protected by applicable state, federal, or local law.
3. Medical care guided by the best medical practice.
4. Care that is respectful of your cultural, psychosocial and spiritual preferences.
5. Express your values and beliefs and to exercise spiritual and cultural beliefs that do not interfere with the delivery of patient care, the well-being of others or your planned course of treatment.
6. Reasonable access to interpreter services if you are non-English-speaking or have vision, speech, hearing or cognitive impairments.
7. Receive information in a manner that you can understand.
8. Security and protection of your physical person and rights.
9. Delivery of care that is free from mental, physical, sexual or verbal abuse, neglect or exploitation. Children or vulnerable adults who are unable to care for themselves have the right to protective intervention by the appropriate agencies to correct hazardous living conditions, abuse, neglect or exploitation.

10. Be free from restraint or seclusion, of any form, imposed as a means of coercion, discipline, convenience or retaliation. Restraint or seclusion may only be imposed to ensure the immediate physical safety of the patient, a staff member or others, and must be discontinued at the earliest possible time.
11. You, your family and/or your legally authorized surrogate decision-maker(s) have the right, in collaboration with your doctor, to be informed and involved in making decisions about your health care, including resolving problems with care decisions, the right to accept medical care or to refuse treatment to the extent of the law, and to be informed of the medical consequences of such refusal.
12. Be informed of unanticipated outcomes.
13. Formulate advance directives about end-of-life decisions and have the hospital respect and follow those directives to the extent allowable by hospital policy, state and federal law.
14. Appoint a surrogate to make health care decisions on your behalf to the extent of the law.
15. Access your own health information, request an amendment to it and receive an accounting of disclosures about it, as permitted under applicable law.
16. Have a family member or representative of your choice and your own doctor (if requested) notified promptly of your admission to the hospital or change in level of your care, at your request.
17. Be fully informed of your health care needs and the alternatives for care when a hospital cannot provide the care you request. If it is necessary and medically advisable, you will be discharged and transferred to an appropriate and acceptable facility.
18. Have your medical needs prioritized over the objectives of any research study.
19. Not participate in investigative studies and to be informed of alternative care options. Patients' access to care shall not be hindered should they decline to participate in investigative studies.
20. Have your pain assessed and managed as deemed medically appropriate.
21. Consideration for your personal privacy and the confidentiality of information and medical records.
22. Know the name of the doctor and other practitioners who have primary responsibility for your care, and to know the identity and professional status of individuals responsible for authorizing and performing procedures and care.
23. Have reasonable access to people outside Fred Hutch by means of visitors and by verbal and written communication. Such access is permitted so long as it does not interfere with the provision of patient care services and a reasonably safe and secure environment. Any restrictions on communication will be fully explained to you and/or your family.

24. Participate in ethical questions and care concerns including issues of conflict resolution, withholding resuscitative services, forgoing or withdrawing of life-sustaining treatment and participating in investigational studies or clinical trials.
25. Have access to spiritual care.
26. Have access to a written statement that articulates the rights and responsibilities of patients. The statement is available in several languages specific to the populations served. If you cannot read, if you have special communication needs, or if the statement is not available in your language, an interpreter will be available.
27. Make complaints about your care and receive a timely response according to established policy. Patients can freely voice complaints and recommend changes without being subject to coercion, retribution, discrimination or unreasonable interruption of care, treatment and services.
28. Request and receive an itemized, detailed explanation of your bill for services rendered.

Patient responsibilities

As a patient at Fred Hutch, you are an important part of your care team. You have the responsibility to:

1. Keep appointments or let us know if you cannot make them.
2. Provide accurate and complete information about your health, symptoms and medications.
3. Provide accurate and timely information about sources of payment and your ability to meet financial obligations.
4. Promptly meet any financial obligation agreed to with Fred Hutch.
5. Participate in discussion, ask questions and make decisions affecting your plan of care.
6. Ask your provider questions when you do not understand the planned treatment, care or what is expected of you.
7. Tell your health care providers when a cultural situation exists concerning the health care process.
8. Tell your health care providers if you have unique needs.
9. Follow the treatment plan to which you agreed. Patients and their families are responsible for the outcomes if they do not follow the care, treatment and service plan.
10. Notify your providers if you have concerns or complaints about any aspect of your care. Fred Hutch encourages patients to talk with their health care team first. Your nurse or social worker can be an advocate for you. If this course of action does not fully address your concerns, you may also contact Patient Relations at (206) 606-1056 or ptrelate@fredhutch.org.
11. Be considerate of the rights of other patients and personnel. Patients may not verbally or physically assault staff, faculty or providers. Verbal or physical threats, violence, disrespectful communication or harassment of other patients or of any staff member, for any reason — including because of an individual's

race, color, religion, creed, ancestry, national origin, sex, age, disability, marital or veteran status, sexual orientation, gender identity or gender expression, political ideology, or other characteristic protected by applicable state, federal, or local laws — will not be tolerated. This prohibition applies to patients as well as their family members, representatives and visitors. In addition, requests for changes of provider or other staff based on that individual's race, ethnicity, religion, sexual orientation, or gender identity will not be accommodated. Requests for provider or staff changes based on gender will be considered on a case-by-case basis and only based on extenuating circumstances.

12. Not disrupt or interfere with care provided to other patients and the operations of Fred Hutch.
13. Be respectful of the property of other persons and Fred Hutch.
14. Be responsible for your personal belongings. This includes, but is not limited to dentures, eyeglasses, crutches, wheelchairs and personal items such as jewelry. Fred Hutch is not responsible if these items are damaged or misplaced while here.
15. Not conduct any illegal activity on the premises.
16. Not bring weapons or illegal substances on Fred Hutch property.

Advance directives

If you are an adult (at least 18 years of age and have the capacity to make health care decisions), you have the right to make your wishes known about the extent of treatment you would desire if you became unable to communicate those wishes. This communication is called an advance directive. Two commonly used advance directives are:

- A health care directive (living will), in which you communicate orally or in writing the specific treatment desired if you cannot communicate these wishes later.
- A durable power of attorney for health care, in which you designate another person to make decisions about your health care if you become unable to do so.

Social work staff members are available to assist you with advance directives. Fred Hutch will respect the intent of your directives to the extent permitted by law and Fred Hutch policy.

Conflict resolution

Please notify your care team if you have concerns about your care, so Fred Hutch can:

- Investigate and address any wrongful actions against your rights.
- Address concerns about the quality of care Fred Hutch provides.

Fred Hutch encourages you, the patient, to talk with your health care team first. If this course of action does not meet your needs, we encourage you to contact Patient Relations at (206) 606-1056 or ptrelate@fredhutch.org.

You have the right to contact the following government agencies:

Washington State Department of Health

Phone: (360) 236-4700

Web: doh.wa.gov

The Joint Commission

Attn: Office of Quality and Patient Safety

The Joint Commission

One Renaissance Boulevard

Oakbrook Terrace, IL 60181

Web: jointcommission.org

Notice to Medicare beneficiaries only

You may also submit complaints to the Quality Improvement Organization (QIO) for Centers for Medicaid/Medicare Services (CMS):

Acentra Health

Call: (813) 280-8256 (local)

(888) 305-6759 (toll-free)

TTY: (855) 843-4776

(833) 868-4064 (toll-free)

Visit: acentraqio.com

Personal valuables

You are responsible for your personal belongings. This includes, but is not limited to dentures, eyeglasses, crutches, wheelchairs and personal items such as jewelry. Fred Hutch is not responsible if these items are damaged or misplaced while here.

Weapons and illegal substances

Weapons and illegal substances are not allowed on Fred Hutch property. To report or request assistance in handling a suspected case or actual observed violation, contact our 24/7 Security Control Room at (206) 606-1111. The existence of a concealed weapons permit does not exempt a person from this policy. Please secure weapons prior to entering the clinic.

Family Medical Leave Act (FMLA)

At some point during your treatment, you may need to take time off work. FMLA entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave. Eligible employees are entitled to 12 work weeks of leave in a 12-month period for:

- A serious health condition that makes the employee unable to perform the essential functions of his or her job; or
- To care for the employee's spouse, child or parent who has a serious health condition.

For more information and to get forms for FMLA, talk to your employer. You can also visit the U.S. Department of Labor's website at dol.gov/agencies/whd/fmla.

Paid Family and Medical Leave (PFML)

Some Washington residents may be eligible for Paid Family and Medical Leave. To be eligible, you need to have worked 820 hours (about 16 hours a week) for a participating employer in Washington, have experienced a qualifying event and be able to provide proof of identification. Certain workers are not automatically eligible for paid leave. For more information, talk to your employer or visit the Washington Paid Family and Medical Leave website at paidleave.wa.gov.

Release of medical information

If you would like us to share your Fred Hutch health information with someone or to get your health records from another facility, please contact our Health Information Management department at (206) 606-1114 for a Release of Information form. There is no charge for records released to you or your physician.

Financial and billing assistance

Health care can be challenging and complicated, especially insurance coverage. Our Patient Financial Services team helps you manage the financial side of your medical care. This includes helping you understand your bills, payment options — such as finding out if you qualify for financial assistance — and insurance coverage. If you are interested in learning more about financial services at Fred Hutch, please ask your scheduler for an appointment with a financial counselor. You can also contact one directly at (206) 606-6226 or fincounsel@fredhutch.org.

Financial and billing assistance, continued

Financial assistance documents are available at Patient Registration in the clinic. You can also download them at FredHutch.org/financial-assistance or ask to have a copy sent to you. If you need financial assistance for services provided at UW Medical Center, please contact them directly.

Resources

We know you're taking in a lot of information. We've gathered some resources you can refer to throughout your care.



Patient and Family Resource Center

Our Patient and Family Resource Center, on the third floor of the South Lake Union clinic, is a welcoming place where you can spend time learning about a specific diagnosis, treatment, support and survivorship. All materials and services are free of charge.

The Resource Center also has:

- Computer workstations
- Notary services
- An online library of e-books
- Information on lectures, classes and support groups around Seattle (not just at Fred Hutch locations)

Resource center staff are available during certain hours to provide support and guidance as you look for materials. Contact staff at patientresourcectr@fredhutch.org or (206) 606-2081, or visit FredHutch.org/resource-center.

Classes and events

Fred Hutch offers wellness classes and programs to support you and your caregiver. To learn more about in-person and virtual classes and events, please visit FredHutch.org/classes-and-events.

Patient Education

Your care team will provide education that is specific to your health situation. You can also find patient education videos, handouts and other useful information at FredHutch.org/patient-education.

Scan the codes for more information



Resource Center



Classes and Events



Patient Education

Patient and family advisors

Patient and family advisors are current and former Fred Hutch patients or caregivers who help us better understand the patient's and family's point of view. To help us improve the quality of care we provide, advisors share their feedback and stories in speaking panels, committees, short- and long-term projects and the Patient and Family Advisory Council.

For more information on being a patient and family advisor, including how to apply, visit FredHutch.org/patient-family-advisors.

Trusted cancer care organizations

After receiving a cancer diagnosis, you may be looking for more information. Below are websites and phone numbers for trusted cancer organizations.

	Website	Phone
American Cancer Society	cancer.org	(800) 227-2345
Fred Hutch Cancer Center	FredHutch.org	(855) 557-0555
National Cancer Institute	cancer.gov	(800) 422-6237
National Comprehensive Cancer Network	nccn.org	
National Center for Complementary and Integrative Health (NCCIH) — Cancer Prevention and Treatment	nccih.nih.gov/health/cancer	



Questions for your care team

We know you have a lot on your mind. We've put together this list of questions you might want to ask your care team. Our hope is that it helps organize your thoughts.

At diagnosis

What is the exact name of my diagnosis, disease or condition?

If my diagnosis has other names, what are they?

What is the stage of my cancer?

What are the ways to treat my type and stage of cancer?

Are the treatments meant to cure my cancer or just control the spread?

What are the benefits and risks of each of these treatments?

What treatment do you recommend? Why do you think it is best for me?

What is my chance of being cured with this treatment?

Would a clinical trial (research study) be right for me?

How do I find out about studies for my type and stage of cancer?

Do I need to tell my other doctors?

What do I tell my friends and family?

I'm struggling (emotionally). Is there someone who can help me?

I am worried about my (family, children, finances, transportation, etc.). Is there someone who can help me?

How do I make sure I get the treatment I want if, at some point, I am not able to speak for myself? How should I document the kind of care I would want to receive? Who can help me with this?

If I become too sick to make medical decisions for myself, can I choose someone to make decisions about my care?

Treatment

What are the risks or complications of these treatments or procedures?

Are there any long-term effects from this treatment?

How long does this treatment or procedure take? How many treatments will there be?

Will I need to be in the hospital for treatment? If so, for how long?

How will we know if the treatment is working? How often will I need to have this treatment?

Can I have a break in my treatment?

Will I need someone to drive me to and from the clinic or hospital when I have this treatment or procedure?

Will I need a family member or friend to be a caregiver (someone who can help with my care at the hospital or at home)?

Are there any activities that I need to avoid when undergoing this treatment?

Could my prescribed medications have interactions with any foods or over-the-counter medicines?

What happens if I do not take all of my medications?

What are the expected side effects? Who do I call to discuss managing my side effects?

When should I call for help?

How do I get help on the weekends and after hours?

After treatment

When should I have follow-up clinic visits and tests?

How long will it be before I feel like myself?

When do I make an appointment with the survivorship clinic?

Common tests

Tests are a normal part of cancer care. They help you and your care team develop and adjust your treatment plan. These are some common tests that Fred Hutch uses in caring for patients.

EKG (ECG or electrocardiogram)

This test shows changes in the electrical activity of your heart over time. It can show abnormal conditions, including blocked arteries and changes in electrolytes.

Labs

“Labs” is short for “laboratory tests.” Labs involve testing a sample of blood, urine or some other substance from your body. They can help determine a diagnosis, plan treatment, check to see if treatment is working or monitor the disease over time.

Imaging scans

You may have several types of imaging scans before, during and after your treatment. Your care team will tailor an imaging plan for you. After you are scheduled for an imaging scan, you will receive instructions on how to prepare for your scan from your patient care coordinator/scheduler.

- **A computed tomography (CT)**, also called a CAT scan, takes cross-sectional images of your internal organs, bones and blood vessels. This is a painless diagnostic imaging scan that typically takes 5–15 minutes. CT scans are used to help find and stage cancer.
- **Magnetic resonance imaging (MRI)** uses a powerful magnetic field, radio waves and a computer to take detailed pictures of the inside of your body. It can be used to help diagnose or monitor treatment for a variety of conditions in your chest, abdomen and pelvis.
- **Ultrasound** uses sound waves to show the structure and movement of your internal organs and blood flow. The machine is made up of a handheld scanner (also called a transducer), a computer and a video display screen.

Nuclear medicine scans

Nuclear medicine scans use a substance called a radiotracer (or tracer). A tracer contains radioactive molecules that help identify cancer. A tracer is injected into your bloodstream for these types of imaging scans.

- A **bone scan** helps detect bone cancer and shows whether cancer has spread from one part of your body to your bones.
- **Dual-energy X-ray absorptiometry (DEXA)**, also known as bone density scanning or bone densitometry, helps detect bone loss, which can happen because of chemotherapy treatment.
- A **multigated acquisition (MUGA)** shows how your heart ventricles are pumping blood to the rest of your body.
- A **positron emission tomography (PET) and computed tomography (CT) or PET/CT scan** shows the organs, tissues and bones inside your body. It helps detect cancer and shows whether your treatment plan is working.
- A **renogram** shows how your kidneys are working.

Words you may hear

You are going to hear new words and learn new things as you receive care. Here are some common terms and explanations of what they mean. We will do our best to make sure we are communicating clearly, but please let us know if you don't understand something during the course of your treatment.

Absolute neutrophil count (ANC): A measure of the number of neutrophils, a type of white blood cell that plays a major role in your body's immune system by preventing infection.

Adenocarcinoma: A type of cancer that begins in the cells that are mucus-producing glands.

Adjuvant therapy: A treatment added to the main therapy after it is complete (for example, chemotherapy given after surgery).

Adverse reaction: An unwanted effect that is caused by taking a drug.

Alopecia: Hair loss.

Anemia: Low red blood cell count.

Antibiotic: Medication that fights the germs or bacteria that cause infection.

Antiemetic: Medicine to prevent or treat nausea and/or vomiting.

Benign tumor: A tumor that is not cancerous.

Biologic therapy: Treatment that uses your immune system to fight infection and/or disease; also called immunotherapy or immune therapy.

Biopsy: The removal of a sample of tissue or fluid that is examined to see whether cancer is present. This may be done with a large needle or through surgical removal of tissue or fluids.

Bone marrow: The soft, spongy material in the center of your bones that produces all your blood cells, such as white blood cells, red blood cells and platelets.

Bone marrow aspiration: The removal of bone marrow using a needle and syringe. This is done to take a sample for laboratory study.

Bone marrow transplant: The process of treating disease with high doses of chemotherapy, radiation therapy or both. This treatment destroys the bone marrow's ability to produce blood cells. Bone marrow or peripheral blood stem cells are given after treatment to help the body make more blood cells.

Cancer: A general term used for over a hundred different diseases characterized by abnormal, uncontrolled cell growth.

Carcinoma: A type of cancer that begins in the cells that make up the skin or in the tissue that lines your organs.

Carcinoma in situ: A cancer that has not spread to other parts of the body or invaded nearby tissue. "In situ" is Latin for "on site."

Caregiver: A responsible family member or friend who is able to provide physical care, observation and emotional support for a patient. They may help make arrangements, attend appointments, maintain the home environment, provide assistance and support to other family members and act as a patient advocate.

Central venous catheter: A small, flexible tube inserted into a large vein near the heart. This serves as a route for medications, intravenous nutrition and to take blood samples. These catheters are also known as a Hickman line, central line, tunneled catheter or Port-a-Cath.®

Clinical trials: New and experimental ways to treat, manage or assess a disease. Patients may volunteer to participate in a clinical trial if they meet the participation criteria.

Complete blood count (CBC): A laboratory test that measures the number of red blood cells, white blood cells and platelets in a sample of blood.

Contrast: A substance injected into your vein or taken by mouth that helps make magnetic resonance imaging (MRI), X-rays and CT images clearer and easier to evaluate.

Counts: This usually refers to monitoring the absolute neutrophil count (ANC) and other blood cells when monitoring your CBC.

Drug resistance: The result of cancer cells' ability to resist the effects of a specific drug. Drug resistance may also happen when treating infections.

Edema: Swelling caused by fluid building up in tissue.

Evidence-based: A systematic approach to medicine in which doctors and other health care professionals use the best available scientific evidence from clinical research to help make decisions about the care of individual patients.

Growth factors: Substances naturally found in the body that control the production and function of blood cells. These substances may be given after chemotherapy and/or transplant to boost blood cell production.

Hormone: A substance produced by certain organs of the body that stimulates and regulates the body's function.

HPV (human papilloma virus): A general term for more than 80 similar viruses that cause warts to grow, such as the fairly common warts that grow on hands and feet or papillomas (non-cancerous tumors). Some HPVs are transmitted sexually. HPV is a major cause of some cancers.

Immunosuppression: A decrease in the ability of the immune system to fight infection, which can be caused by chemotherapy and/or radiation therapy or from taking medications that suppress your/the immune system.

Informed consent: The process in which a patient learns about and understands the purpose, potential risks and benefits of a protocol and/or procedure and then agrees to participate. A patient can also decide not to participate.

Infusion: An injection of medications or fluids into a vein over a period of time.

Intervention: An action taken to improve your health status.

Intramuscular (IM): A way to give medications by injecting them into the muscle.

Intravenous (IV): An injection of fluids or medications through a catheter that goes into a vein.

Leukocyte: A type of white blood cell that plays a major role in the body's immune system by preventing infection.

Lymph nodes: Tissue in the lymphatic system that filters lymph fluid and helps your immune system fight disease.

Malignant: Another word for cancerous.

Metastasis: The spread of cancer cells to other areas of the body by way of the lymph system or bloodstream.

Mucosa: The lining of the mouth and gastrointestinal tract.

Mucositis: Reddening and soreness of the tongue, lips, mouth, throat and gastrointestinal tract from chemotherapy and/or radiation therapy.

Neoadjuvant therapy: A treatment given before the main therapy (for example, chemotherapy given before surgery).

Neoplasm: An abnormal growth of tissue from a single cell. A neoplasm can be cancerous or noncancerous.

Neuropathy: Nerve damage causing abnormal sensations and/or impaired muscle movements.

Neutropenia: A low count of neutrophils, a type of white blood cell. A person with neutropenia is at high risk of developing an infection.

Neutrophil: A type of white blood cell that plays a major role in the body's immune system by preventing infection.

Non-steroidal anti-inflammatory drugs (NSAID): A group of pain medications, often sold over the counter, that includes ibuprofen and similar painkillers.

Nutritionist/dietitian: A care provider who is trained to evaluate your nutritional status and make recommendations on food management.

Oncology: An area of medical science that studies tumors and cancer.

Palliative care: Treatment intended to relieve symptoms caused by cancer.

Pathology: The study of the causes and characteristics of disease.

Petechiae: Small red or brown spots on the skin, which are tiny hemorrhages. These spots are caused by a low blood count and decreased clotting. They may be a result of chemotherapy, leukemia and other disorders.

Platelets: A type of blood cell that helps prevent bleeding and helps the blood to clot.

Polyp: A growth of tissue that sticks out into a body cavity, such as the nose or rectum. They may be benign or malignant.

Primary tumor: The original cancer site, even if it has spread through the body (for example, breast cancer that has spread to the bone is still called breast cancer).

Prognosis: A statement about the likely outcome of a disease in a patient.

Protocol: The outline or specific plan for treatment; it may be research or standard treatment.

Radiology: A branch of medicine that focuses on the use and study of radioactive substances to treat and diagnose conditions through imaging.

Red blood cell (RBC): A type of blood cell that carries oxygen in the body.

Referral: Your team may place a referral for you to see another specialist if you need specialized medical services. A referral may also be called a consult.

Relapse: The recurrence of disease after an apparent recovery.

Sarcoma: A type of cancer that begins in the cells of bones, connective tissue or muscle.

Side effect: An additional and usually unwanted effect or symptom from a drug or other treatment.

Standard treatment: A treatment or other intervention currently being used and considered to be of proven effectiveness based on past studies.

Subcutaneous injection (SubQ): A way to give medications by injection into the fatty tissue under the skin.

Total parenteral nutrition (TPN): A form of nutritional support given intravenously (IV).

Tumor: An abnormal lump or mass of tissue. Tumors are either benign or malignant.

Upper respiratory infection (URI): An infection in the respiratory system caused by a virus. It can affect your nose, throat, sinuses and ears. Symptoms may include sore throat, sneezing, runny nose, nasal congestion cough, watery eyes and headache.

Urinary tract infection (UTI): An infection in the urinary tract. Symptoms may include pain or burning when you use the bathroom, fever, tiredness or shakiness, an urge to use the bathroom often, pressure in your lower belly, urine that smells bad or looks cloudy or reddish, and sometimes nausea or back pain.

White blood cell (WBC): A type of blood cell that plays a major role in the body's immune system by preventing infection.

References include the National Cancer Institute and the American Cancer Society.

Useful phone numbers

For emergencies, call 911.

Service	Phone	What they can help you with
Information Desk	(206) 606-1000	<ul style="list-style-type: none"> • General information; they can transfer you to anyone or any department in the clinic
Patient Financial Services	(206) 606-6226	<ul style="list-style-type: none"> • Understanding your bills, payment options and insurance coverage
Medical Records	(206) 606-1114	<ul style="list-style-type: none"> • Getting a copy of your medical records
Patient and Family Resource Center	(206) 606-2081	<ul style="list-style-type: none"> • Finding information about: <ul style="list-style-type: none"> ◦ Your diagnosis, treatment, support and survivorship ◦ Fred Hutch and other local events and support groups for patients and families
Patient Relations	(206) 606-1056	<ul style="list-style-type: none"> • If you have concerns about quality of care that cannot be resolved by your care team
Pharmacy	(206) 606-6500	<ul style="list-style-type: none"> • Getting a prescription refilled or transferred to another pharmacy
The Gift Shop	(206) 606-8270	<ul style="list-style-type: none"> • Cards, gifts, snacks and other items
Shine	(206) 606-7560	<ul style="list-style-type: none"> • Cards, gifts, clothing, and specialty oncology products, service and guidance, including: <ul style="list-style-type: none"> ◦ Compression garments ◦ Fittings for post-surgical and mastectomy garments and prosthetics ◦ Canes ◦ Wig fittings, trims and head shaves
Security (lost and found, after-hours valet parking)	(206) 606-1111	<ul style="list-style-type: none"> • To find something you lost • To retrieve your car after hours

In the event of an Fred Hutch phone outage, please call (206) 467-4950 or (206) 467-4951.



Your notes

This image shows a full page of blank, lined paper. It features approximately 20 horizontal blue lines spaced evenly across the page, typical of notebook paper. The lines are thin and light blue, set against a plain white background. There is no handwriting or other markings on the page.

[illegible]

1354 Aloha Street, Seattle, WA 98109
(206) 606-7222
Toll-free: (855) 557-0555
FredHutch.org



Fred Hutch
Cancer Center